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Letter from the editor

It's hard to believe that we are already half way between the 12th and 13th ISLRR international conference! I am very excited that this issue contains the first call of the Dublin meeting in July 2020. The organisers challenge us to "Imagine the impossible" – a bold and thought-provoking theme.

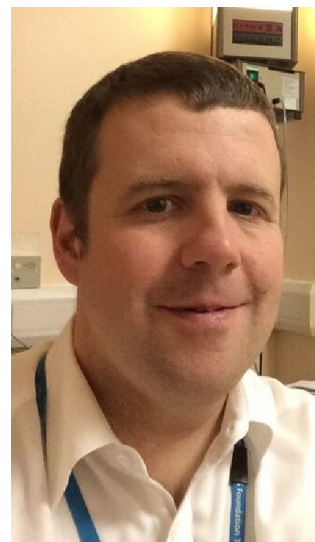
This issue also contains an announcement for the next European Society for Low Vision Research and Rehabilitation, in Manchester, UK. In the future it would be great to have similar organisations on every continent, to provide continent-wide collaboration and to have more local meetings in between our international conferences.

Might the first African Society for Low Vision Research and Rehabilitation meeting be in Accra? Michael Ntodie introduces us to Ghanaian low vision in our regular "postcard from..." feature.

Maybe one day our international conferences will be hosted in virtual reality. Youtube has already broken international barriers for communication. In this issue we introduce some Youtube channels which provide peer support, entertainment and education for people with low vision.

I hope you enjoy this issue of ISLRRVIEW. Please keep your submissions coming to islrview@gmail.com.

Michael Crossland
London, UK





The impact of fatigue in adults with visual impairment

Wouter Shakel, Amsterdam UMC– VUmc, The Netherlands w.schakel@vumc.nl

In a recent study at the VU University Medical Centre in Amsterdam, we found that fatigue is much more prevalent in adults with visual impairment compared to normally sighted peers. Severe symptoms of fatigue were present in 57% of participants with vision loss (n=247), compared to only 22% in those with normal sight (n=233). Fatigue is often described as an overwhelming sense of tiredness associated with impaired cognitive and/or physical functioning. In a qualitative study, we found that people with visual impairment experience fatigue as an indirect result of vision loss through a high cognitive load, high effort that is necessary for visual perception, difficulties with light intensity and negative cognitions related to negative thoughts. In addition, we found that 40% of the people with vision loss experience a high negative impact of fatigue on their daily lives, compared to only 11% of the people with normal sight. Therefore, especially in people with visual impairment fatigue may have a significant impact on peoples' daily life.



The impact of fatigue in adults with visual impairment (cont.)

Because fatigue is prevalent in people with visual impairment and it has a major impact on their daily life, it may also have a substantial economic impact on society. Research in other chronic patient populations suggest that fatigue may increase direct costs due to increased healthcare utilization and indirect costs due to negative implications for work. Studies in patients with cancer and multiple sclerosis for example, have identified fatigue as the key symptom influencing work capacity and preventing return to work. In our most recent study, we investigated the burden of visual impairment and comorbid fatigue in terms of impact on daily life, by estimating societal costs (i.e. direct medical costs and indirect costs) accrued by these conditions. This cost-of-illness study was performed from a societal perspective. Cross-sectional data of visually impaired adults and normally sighted adults were collected through online surveys and structured telephone interviews. Cost differences between participants with and without visual impairment, and between participants with and without fatigue were examined. A significant interaction was found between visual impairment and high fatigue impact for total societal costs (€449; 95% CI [33, 1017]). The presence of high fatigue impact in addition to visual impairment was significantly associated with a double fold increase of the societal costs (mean difference €461; 95%CI [126, 797]), but this effect was not observed for participants with normal sight (€12; 95%CI [-527, 550]). Therefore, we can conclude that visual impairment is associated with an increased prevalence of disabling fatigue, that in addition to the experienced burden of patients, also determines a large amount of the economic burden of visual impairment. The societal costs seem substantial and emphasize the need for evidence-based interventions aimed at coping with the consequences of vision-related fatigue.

Wouter Shakel, Amsterdam UMC—VUmc, The Netherlands

w.schakel@vumc.nl





Opportunities in teaching and learning Low Vision: Sharing my experiences

Moyra McClure, Optometry, Ulster University

me.mcclure@ulster.ac.uk

In the United Kingdom, undergraduate optometry students are taught low vision so that, when qualified, they can:

- Undertake a low vision assessment
- Prescribe optical low vision aids
- Understand the epidemiology of sight loss
- Appreciate the benefit of multi-disciplinary holistic low vision care for emotional and practical support.

My Low Vision teaching includes the causes of sight loss so that students appreciate different eye and brain conditions and how central vision can be slightly, moderately or severely blurred while peripheral eyesight (visual fields) may or may not be affected. Certification and registration processes are explained to enable students to learn of the benefits and importance of this step for the person with low vision.

Students need to learn how to measure sight loss on specialist charts, such as a logMAR chart. The challenge of simulating sight loss has been overcome by using:

1. Cambridge simulation glasses (University of Cambridge: <http://www.inclusivedesign toolkit.com/csg/csg.html>). This resource provides reduced vision on the distance chart or for near, small print is not clear for reading. Contrast sensitivity, measured with a Pelli-Robson chart where grey letters are viewed on a white background, is reduced with the Cambridge spectacles; students can measure reduced contrast sensitivity and understand its effect on ability to see faces and poorly contrasting print like newspaper.
2. VINE (Visual Impairment North East: <https://vinesimspecs.com/index.php>) simulation package. These aid students grasp more complex sight loss such as hemianopia or light perception.
3. My own tool of painted and taped trial lenses (the lenses in the optometrists' box to test eyes). These help students test eyesight and assess for spectacles

Students provide positive feedback about the practical sessions:

- Students measure their reading ability with a range of hand, stand, spectacle and electronic magnifiers to realise the benefits and drawbacks of devices.
- Students appraise telescope use by viewing through a range of monocular and binocular telescopes.
- Fictional cases assist students in evaluating magnification requirements and identifying the possible magnification or sensory substitution options that can be provided for tasks; real life examples such as food packets, newspapers, large print and audio products (talking clock) are vital.



Opportunities in teaching and learning Low Vision: Sharing my experiences (cont.)

Educators can utilise “A compendium of low vision learning activities from around the world” by Junghans and Dalton (2011) (<http://www.olt.gov.au/project-delivering-optometric-graduates-ready-unsw-2007>).

One highly beneficial method of learning about sight loss is the opportunity for students to interact with people who have low vision. Students shadow optometrists and sensory support in low vision services and reflect on this experience, often commenting about the availability of emotional and practical support.

Learning low vision is an ongoing and motivating process: optometrists can acquire new skills by studying for the College of Optometrists’ accredited Professional Certificates in Low Vision.

The ISLRR conference is beneficial in my enjoyable role of explaining to students and optometrists how the wealth of low vision research offers evidence for the clinical care and how new products continue to be developed: looking forward to 2020 in Dublin!

Moyra McClure
Professional Higher Certificate in Low Vision
Lecturer (Optometry, Ulster University)/
Specialist Optometrist (Belfast Trust)

Contact: me.mcclure@ulster.ac.uk



What can YouTube teach us about low vision?

For years it was “a pop star,” then it was “to be on TV,” but more recently the number one aspiration of children in my low vision clinic is to be a YouTuber.



YouTubers – broadcasters who make video blogs on YouTube – can be huge celebrities: British beauty blogger Zoella has more than 12 million subscribers, and Spanish language German YouTuber **HolaSoyGerman** is subscribed to by 33 million viewers. I’ve never managed to watch more than 20 seconds of any videos by PewDiePie, yet more than 41 million people don’t agree with me and subscribe for updates to these zany and baffling videos, making him currently the most viewed YouTuber (despite the fact that he has been tainted by accusations of racism).

YouTubers work from home, on computers, expressing themselves with speech and drama. These are all skills which many of our low vision clients have. Although I have yet to meet a parent who agrees, I think YouTubing is a great activity choice for a dynamic and eloquent young person with low vision.

So which blind and partially sighted YouTubers already exist? And should we be recommending their channels to our patients?

Tommy Edison is probably the best known blind YouTuber. Blind since birth, his channel **TommyEdisonXP** covers a very broad range of subjects related to blindness. He answers a variation of Molyneux’s problem by seeing if he can identify models of real world objects by touch. He answers questions I’ve never thought of such as “How do blind people discover their sexual orientation?” which got 217,000 views and he talks movingly about how his parents told him that he was blind (this video alone got 2.2 million views). Tommy is a likable, entertaining broadcaster with a relaxed manner and I recommend watching his videos. His “blind film critic” movie reviews are great too.

Popular channel Cut has a series of videos featuring blind people, such as “Kids describe colour to a blind person” (11 million views) and “Blind people tell us what questions annoy them the most” (5.5 million views). Spoiler alert about this video: questions such as “how did you lose your sight?” and “can I pray for you?” are not great, as are actions such as randomly being grabbed or touched is a big no-no.



What can YouTube teach us about low vision? (cont.)

Molly Burke is a motivational speaker and activist but has a variety of relevant videos on her YouTube channel, including blind baking, mirrorless makeup, and “My five blind girl must-haves.”

More makeup, fashion, and emotional advice can also be found on Lucy Edward’s channel. Lucy is a 22-year-old British youtuber with incontinentia pigmenti who clearly has no problem doing elaborate makeup with poor sight.

“Low on vision, high on tech” is a great video title that comes from “Circle of the Blind Mice”, a low vision tech channel. In these quite long videos, presenter Tammy describes accessibility functions and reviews mainstream and visual impairment technology, from iPhones and MacBook to CCTVs and smartcanes.

The Blind Life is another low vision tech site. I’m less keen on this one, mostly because of the power rock backing track in some of the videos, but there are interesting perspectives on products here.

I fully recommend spending a morning browsing low vision related YouTube videos. I learnt a lot about daily life with poor vision and discovered answers to questions and problems I’d never thought of. In particular, teenagers and young adults are likely to find support and entertainment in some of these channels.

Let us know about videos you particularly like and we’ll share them in future issues of ISLRRview, ISLRRview@gmail.com

Michael Crossland
London, UK

mcrossland@nhs.net





... ANNOUNCEMENT!

MANCHESTER
1824

The University of Manchester



ESLRR 2019

10th-12th September 2019

The biennial international multi-disciplinary low vision conference - "From Innovation to Implementation" - organised for the European Society for Low-vision Research and Rehabilitation

will run in conjunction with

BCOVS 2019

British Congress of Optometry and Visual Science

11th and 12th September 2019



The conferences will be held in the Renold Building of the University of Manchester, which is a few minutes walk from Manchester Piccadilly station. Accommodation will be available in a wide range of city centre hotels, from budget to luxury. The joint Conference Dinner will be held in the Living Worlds Gallery of the Manchester Museum.



To receive updates on the meetings contact:

chris.dickinson@manchester.ac.uk

or

laura.gordon@manchester.ac.uk





... ANNOUNCEMENT!



VISION 2020
Dublin, Ireland

IMAGINING THE IMPOSSIBLE

**13th International Low Vision Conference
by the International Society for Low Vision
Research and Rehabilitation**

Sunday 12th - Wednesday 15th July 2020
The Convention Centre Dublin - Ireland



Hosted by: VISPA (Vision impaired service provider's alliance)

VISPA Organisation members are: NCBI, ChildVision, Irish Guide Dogs, Fighting Blindness

IMPORTANT DATES



Call for abstracts:
15th July 2019



Opening of Registration:
14th October 2019



Abstract submission ends:
14th November 2019



Abstract Acceptance:
13th February 2020



End of Early Registration:
13th April 2020



End of Regular Registration:
26th June 2020

For further information on the conference
and to add yourself to our mailing list, visit
www.vision2020dublin.com



ISLRR View: Postcard from...

Postcard from Ghana: Low Vision care in my country

Michael Ntodie, Optometrist, University of Cape Coast, Ghana

Where are most low vision patients assessed in your country?

Hospital (Korle Bu Teaching Hospital, Koforidua Regional Hospital)

Who pays for magnifiers and optical low vision aids?

Patient/service user

How about larger low vision aids such as video magnifiers?

Mostly non- existent

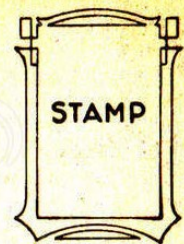
What are the most common causes of low vision in your setting?

Congenital disorders (RoP), glaucoma, corneal opacification from various causes

What particular challenges do you face in low vision care in your country?

- **Limited outlets to source low vision aids for patients**
- **Financing for low vision aids (currently not covered by the National Health Insurance Scheme)**
- **Absence of refresher courses for low vision practitioners (mostly Optoms)**

Post
Card
ADDRESS



Let the world know about low vision care in your country! Do the services offered meet international standards or are there challenges with access to clinics, or funding of devices?

Email islrview@gmail.com to participate in the next "Postcard from..."