COVID-19 Webinar Series:
A Unified Voice for the Ageing Community

Panelists:
Dr. Keith Gordon
Chairperson, Retina Action

Dr. Heather Snyder
Alzheimers Association

Karen Denton
AMD Ambassador, Retina SA

Donna Walsh
European Federation of Neurological Associations

Kindly supported by NOVARTIS
THE IMPACT OF THE COVID-19 PANDEMIC ON CANADIANS WHO ARE BLIND, DEAF-BLIND, AND PARTIALLY-SIGHTED

Keith D Gordon Ph.D.
Senior Research Officer
Canadian Council of the Blind
COVID-19 Impact Survey

Objective

• To determine the impact that the COVID-19 pandemic was having on Canadians who are blind, deaf-blind or partially sighted.

• The objective of the survey was to provide recommendations to the federal, provincial and municipal governments in order to assist them in creating policies to support those living with disabilities during this time of COVID-19.
COVID-19 Impact Survey

Background

- Survey conducted April 7 – April 14, 2020
- Conducted via Survey Monkey
- Email to:
  - CCB Email List (2X),
  - Balance E-newsletter,
  - AEBC Email List and
  - Fighting Blindness Canada Email Patient List
COVID-19 Impact Survey - Results

- 572 Respondents
- All Provinces - 53.6% from Ontario
- Respondents:
  - 42% ≥ 65
  - 37% Blind
  - 60% Partially Sighted
  - 3% Deaf-blind
  - 28% One or more additional disabilities
  - 28% of respondents live alone
  - Only 1% live in retirement homes
COVID-19 Impact Survey
Access to Information

- Main sources of information:
  - TV, Radio, Internet, variety of social media

- 69% had accessed government information
  - 54% of these said government websites fully accessible
  - 32% of these said government websites only accessible sometimes

- Half of Deaf-blind community didn’t have access to deaf-blind interpreter
COVID-19 Impact Survey
Access to COVID-19 Testing Sites

- 58% unaware of local COVID-19 testing site
- 25% knew where testing site was, but didn’t know if it was accessible

- How would you get to testing site if you needed to?
  - Unaware 19%
  - Public transport 22%
COVID-19 Impact Survey
Leaving Home

- Almost everyone has left home
  - 25% continue to leave home for essential work
  - 75% for a walk
  - 57% for grocery shopping
  - 37% to buy prescriptions/medications
  - 14% to visit a doctor

- 47% need a sighted guide when they leave home

- 46% felt unsafe when they leave home
COVID-19 Impact Survey
Shopping for Groceries and Essentials

- 34% shop in-store themselves
- 36% of those shopping in-store not comfortable interacting with staff
- 35% shop online - 38% for first time
  - 16% of online shopping websites accessible
  - 61% of online shopping websites partially accessible
COVID-19 Impact Survey
Healthcare Issues

• 86% aware of online provision of healthcare

• Healthcare worries:
  • 74% Ability to see a doctor if they got sick
  • 33% Arranging a telehealth appointment should the need arise
  • 25% Ability to get prescriptions
  • 42% Having someone accompany to doctor/hospital
  • 49% Ability to get transportation to doctor/hospital
COVID-19 Impact Survey
Personal Care Workers

- 51% had PCW come into home

- Of those who had PCW come into home, 40% said the PCW wasn’t using the proper PPE (masks, gloves, gowns if necessary)
COVID-19 Impact Survey
Stress, Fear and Apprehension

- 90% more apprehensive over wellbeing of their family

- 53% concerned that additional stress of pandemic on their mental health may cause them to be overwhelmed

- 40% of respondents said they were experiencing more than moderate stress, with 29% rating their stress level at 7 or higher.
COVID-19 Impact Survey
Special Concerns

• Large number of fears:
  • Social distancing
  • Accessing healthcare
  • Fear that they may get virus
  • Fear of developing mental health conditions
  • Feelings of being alone and isolated
  • Concerns about their eye condition and fear they may lose more vision
  • On-line learning sites not all accessible
  • Fear of what might happen to guide dog if they become sick
COVID-19 Impact Survey
Implications for the Future

Healthcare in the future needs to take into account:
• A patient population under stress
• Access to health care
• Access to information
• Accessibility of websites, online learning
• Loneliness
• Mental health issues
• Missed eye doctor appointments
COVID-19
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THE EYE IS A WINDOW TO THE BRAIN
IMPACT OF COVID-19 ON COGNITION IN PEOPLE LIVING WITH DEMENTIA

Most people with dementia are 65 or older, which puts them at increased risk of COVID-19.

Many people with dementia are likely to have underlying health problems. This can increase their risk for COVID-19 complications.

COVID-19 may negatively impact the brain and affect thinking, learning and cognitive skills in people with dementia.
IMPACT OF COVID-19 ON PROVIDING CARE FOR SOMEONE LIVING WITH DEMENTIA

Need to educate individuals with dementia of the importance of hygiene

- Signs to wash hands with soap for 20 seconds
- Demonstrate thorough hand-washing
- Hand sanitizer as alternative

- Make alternative plans for adult day care, respite, etc.
- Request prescriptions for more days
- Make alternative plans if primary caregiver becomes ill

If rapid increase in confusion occurs, contact health care provider.
IMPACT OF COVID-19 ON RESEARCH

Many basic science experiments and clinical trials have been impacted due to concerns about safety and adequate social distancing for researchers, trial volunteers and staff.

The dementia research community is committed to advancing current studies, despite the challenges of COVID-19.

OPPORTUNITIES

Amplifying publications in A&D, analyzing data and preparing manuscripts.

Generating new ideas, using big data platforms like GAAIN.

Scientific meetings like AAIC are going virtual. Opens doors for more participation around the globe.
Coronavirus (COVID-19): Tips for Dementia Caregivers

Most likely, dementia does not increase risk for COVID-19, the respiratory illness caused by the new coronavirus, just like dementia does not increase risk for the flu. However, dementia-related behaviors, increased age and common health conditions that often accompany dementia may increase risk.

For example, people with Alzheimer’s disease and all other dementia may forget to wash their hands or take other recommended precautions to prevent illness. In addition, diseases like COVID-19 and the flu may worsen cognitive impairment due to dementia.

Tips for dementia caregivers at home
Caregivers of individuals living with Alzheimer’s and all other dementia should follow guidelines from the Centers for Disease Control and Prevention (CDC), and consider the following tips:

- For people living with dementia, increased confusion is often the first symptom of any illness. If a person living with dementia shows rapidly increased confusion, contact your health care provider for advice. Unless the person is having difficulty breathing or a very high fever, it is recommended that you call your health care provider instead of going directly to an emergency room. Your doctor may be able to treat the person without a visit to the hospital.

- People living with dementia may need extra and/or written reminders and support to remember important hygiene practices from one day to the next.
  - Consider placing signs in the bathroom and elsewhere to remind people with dementia to wash their hands with soap for 20 seconds.
  - Demonstrate thorough hand-washing.
  - Alcohol-based hand sanitizer with at least 60% alcohol can be a quick alternative to hand-washing if the person with dementia cannot get to a sink or wash their hands easily.

- Ask your pharmacist or doctor about filling prescriptions for a greater number of days to reduce trips to the pharmacy.

- Think ahead and make alternative plans for the person with dementia should adult day care, respite, etc. be modified or cancelled in response to COVID-19.
COVID-19
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COVID 19 AND RETINAL DISEASE

A South African Perspective
A GLIMPSE OF SOUTH AFRICA
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- 16% Population

Private Funding:

84%: State -

Diabetes ++++++++
A GLIMPSE OF SOUTH AFRICA

- **Access to Treatment:**
  - COVID 19 exaggerated disparities
  - Escalation of Expenses incurred from the virus:
    - Fewer people able to afford ongoing private medical funding -
RETINA SA UTILIZED LOCKDOWN TIME

- Called people with Retinal disease on our data base:

... ISSUES Voiced:

- Loneliness isolation – chats up to 1 hour +
  - Fear of C19, for self and families
  - Financial Impact

- AND

- Fear of dr visits for antiVEGF
RETINA SA UTILIZED LOCKDOWN TIME …

- **Access to Treatment (Private):**
  - Major Private Medical Funders … reluctant to provide 2\textsuperscript{nd} line antiVEGF
  - Relentless Advocacy campaign
    - Marked success
ADDITIONAL PROBLEM:

- Methanol damages optic nerve
- Multiple Dangers with Isopropyl Alcohol
RETINA SA DESCRIBED POSITIVES...

- Cyber Connections
- Work productivity
- Shopping (impulse buying, petrol, parking)
- Access to info, learning, conferences
  (no longer only 1-2 conferences annually)
THANK YOU
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Where’s Neurology?

Influencing Covid Recovery Planning, Programmes and Policies
1. Not access to medicines – but access to services and supports
2. An Info-demic!
3. Increased demand for services of patient organisations vs. decreased resources
4. Slowing of research and development
5. Social impact
6. Carers
7. Mental wellbeing
8. Lack of patient involvement
1. Increased focus on public health and more resources

2. Acceleration of digital transformation

3. More innovation, collaboration and flexibility in research, regulation and reimbursement?

4. New models for care delivery and patient pathways

5. Opportunities for increased patient and public involvement in recovery planning

6. We know it can be done! … but we need neurology to be positioned centrally and seen as a priority first!
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