Aging & Vision Loss: There’s More Than Meets the Eye

American Foundation for the Blind
Rebecca Sheffield, Ph.D.
NCOA Center for Healthy Aging Annual Meeting, May 24, 2018
Aging and Vision Loss by the Numbers:
- National Health Interview Survey
- American Community Survey,
- & more!

In their own words:
Concerns expressed by older people with vision loss and their families
National Health Interview Survey (NHIS)

• Annual survey of civilian, non-institutionalized population
• “Do you have trouble seeing, even when wearing glasses?”
• “Are you totally blind or unable to see at all?”
25.5 million adults 18+ (10.4%) with Vision Trouble, 2016 National Health Interview Survey

IPUMS-NHIS, University of Minnesota, www.NHIS.IPUMS.org
9.7 million older people 60+ (14.3%) with Vision Trouble, 2016 National Health Interview Survey

IPUMS-NHIS, University of Minnesota, www.NHIS.IPUMS.org
2016 NHIS Demographics: Age (adults with vision trouble)
Prevalence of Vision Trouble Among People with Health Conditions (NHIS, 2013-2016), ages 65+

- Hypertension: 17% with vision trouble
- Coronary Heart Disease: 20% with vision trouble
- Stroke: 25% with vision trouble
- Arthritis: 18% with vision trouble
- Cancer: 16% with vision trouble
- Diabetes: 20% with vision trouble

Vision trouble in general population 65+ (15%)
American Community Survey (ACS)

- Annual survey of civilian, non-institutionalized population
- “Is this person blind or does he/she have serious difficulty seeing, even when wearing glasses?”
7.55 million Adults 18+ (3.0%) with Vision Difficulty, 2016 American Community Survey

IPUMS-USA, University of Minnesota, www.IPUMS.org
4.20 million Older People 60+ (6.1%) with Vision Difficulty, 2016 American Community Survey

IPUMS-USA, University of Minnesota, www.IPUMS.org
<table>
<thead>
<tr>
<th>Age Bracket</th>
<th>Vision Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-64</td>
<td>3.7%</td>
</tr>
<tr>
<td>65-69</td>
<td>4.1%</td>
</tr>
<tr>
<td>70-74</td>
<td>4.9%</td>
</tr>
<tr>
<td>75-79</td>
<td>6.6%</td>
</tr>
<tr>
<td>80-84</td>
<td>9.2%</td>
</tr>
<tr>
<td>85-89</td>
<td>13.8%</td>
</tr>
<tr>
<td>90-94</td>
<td>21.9%</td>
</tr>
<tr>
<td>95+</td>
<td>24.1%</td>
</tr>
</tbody>
</table>

Vision Difficulty by Age (ages 60+)

2012-2016
5-year ACS dataset
American Community Survey (ACS), other disability questions

• **Hearing difficulty**  Is this person deaf or does he/she have serious difficulty hearing?

• **Cognitive difficulty**  Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

• **Ambulatory difficulty**  Does this person have serious difficulty walking or climbing stairs?

• **Self-care difficulty**  Does this person have difficulty dressing or bathing?

• **Independent living difficulty**  Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor’s office or shopping?
Prevalence of Vision Difficulty Among People with Other Disabilities (ACS, 2016), ages 65+

- Hearing: 22% with vision difficulty, 78% without
- Cognitive: 25% with vision difficulty, 75% without
- Ambulatory: 18% with vision difficulty, 82% without
- Self-care: 24% with vision difficulty, 76% without
- Independent Living: 23% with vision difficulty, 77% without

Vision difficulty in general population 65+ (7%)
Vision, Hearing, & Age

2012-16 5-yr ACS dataset

% Experiencing Difficulty Hearing

- men, vision difficulty
- men, no vision difficulty
- women, vision difficulty
- women, no vision difficulty

55-69: 37% vs. 23%
70-84: 49% vs. 33%
85-99: 64% vs. 54%
Vision Difficulty & Ethnicity

2012-16 5-yr ACS dataset

- Vision loss (60+): 11.4%
  - Spanish/Hispanic/Latino: 20%
  - not Spanish/Hispanic/Latino: 84%

- Without vision loss (60+): 8.4%
  - Spanish/Hispanic/Latino: 0%
  - not Spanish/Hispanic/Latino: 100%
### Vision Difficulty, Marital Status, & Age

#### 2012-16 5-yr ACS dataset

<table>
<thead>
<tr>
<th>Category</th>
<th>Married</th>
<th>Widowed/Divorced/Separated</th>
<th>Never Married</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision difficulty (60+)</td>
<td>39%</td>
<td>53%</td>
<td>8%</td>
</tr>
<tr>
<td>No vision difficulty (60+)</td>
<td>59%</td>
<td>35%</td>
<td>6%</td>
</tr>
<tr>
<td>Vision difficulty (80+)</td>
<td>27%</td>
<td>68%</td>
<td>5%</td>
</tr>
<tr>
<td>No vision difficulty (80+)</td>
<td>39%</td>
<td>57%</td>
<td>4%</td>
</tr>
<tr>
<td>Women, vision difficulty (80+)</td>
<td>15%</td>
<td>81%</td>
<td>5%</td>
</tr>
<tr>
<td>Women, no vision difficulty (80+)</td>
<td>24%</td>
<td>72%</td>
<td>4%</td>
</tr>
</tbody>
</table>
From 2015 to 2050, the number of adults ages 40+ who are blind is expected to double (Varma, et al., 2016).
Projected Increase in Vision Loss, 2015-2050

(Varma et al., 2016)

Adults 40+

- Blindness: 1.02 million in 2015, 2.01 million in 2050
- Visual impairment: 3.22 million in 2015, 6.95 million in 2050

Adults 80+

- Blindness: 0.43 million in 2015, 1.18 million in 2050
- Visual impairment: 1.61 million in 2015, 4.44 million in 2050
Vision Impairment & Falls
(Crews, Chou, Stevens & Saaddine, 2014)

• 2014 Behavioral Risk Factor Surveillance Survey:
  • Are you blind or do you have serious difficulty seeing, even when wearing glasses?
  • In the past 12 months, how many times have you fallen? (fallen = when a person unintentionally comes to rest on the ground or another lower level)
  • 47% of adults aged 65+ with severe vision impairment fell vs. 28% of those without severe vision impairment.
Where to Get More Numbers?
From the Census Bureau (and friends)

- **American Fact Finder**: [factfinder.census.gov](https://factfinder.census.gov)
  - American Community Survey

- **DataFerrett**: [dataferrett.census.gov](https://dataferrett.census.gov)
  - American Community Survey

- **National Health Interview Survey** (National Center for Health Statistics, Center for Disease Control and Prevention): [https://www.cdc.gov/nchs/nhis/index.htm](https://www.cdc.gov/nchs/nhis/index.htm)

- **Integrated Public Use Microdata Series**: [https://www.ipums.org/](https://www.ipums.org/)
  - American Community Survey (IPUMS-USA)
  - National Health Interview Survey (IPUMS-IHIS)
AFB.org/stats
  - Easy to access stats, includes separate datasets for adults and children with vision loss

AFB.org/navigator
  - AFB's Research Navigator quarterly supplement to the AFB DirectConnect newsletter
  - Coming soon! More state level data

rsheffield@afb.net  progers@afb.net
  - Email us if you cannot find what you’re looking for!
What are the concerns of older people with vision loss and their families?
Feedback on the Experiences of Older Americans with Vision Loss: Topical Areas Identified in the 2015 White House Conference on Aging

- Managing medications, monitoring diabetes
- Accessing medical care
- Accessibility of information
- Patient advocacy
- Preventative care, exercise, healthy eating
- Mental health, depression, and isolation
- Participating in and receiving effective long-term services and supports
- Limitations in saving for retirement
- Extra expenses related to vision loss
- Financial management and financial literacy
- Accessibility of text-based financial and legal information
- Abuse, scams, discrimination, and theft
“I know I will have to stop driving very soon and am concerned about accessing my doctors' appointment. Senior transportation is very sparse where I live, taxis are expensive, and you have to be judicious in asking friends for transportation.”
“...in clinical documentation, often the information is not in a state easily read by older eyes. Fonts too small, unclear on paper forms. No electronic standards that would allow me to keep the information myself and to make going from doctor to doctor to pharmacy and test results easy to access.”
“Medical services are readily available but **socially supported rehabilitation** almost impossible to obtain. While I live in one of those ‘best places to retire,’ services like SAAVI in Tucson and Phoenix do not extend to so-called ‘rural’ Arizona. We have almost no **certified vision rehab specialists**, which includes essential **orientation and mobility therapy**, for safety and independence.”
“Cooking/shopping is more difficult; healthy foods, such as fruits and vegetables, are expensive for those on fixed incomes. Without proper training and devices, microwave and canned/processed foods are all some can manage to prepare for themselves in addition to fast food.”
“My husband was blind, and I am blind ... We had developed a system that worked for both of us, but the caregiver decided we weren't doing things correctly and reorganized our system. This meant my husband wasn't getting the right meds at the right time... Healthcare workers need to realize people may have developed their own techniques and work with them rather than change them...”
“My vision loss has had a huge impact on my financial situation. I was a full-time employed RN deemed disabled and am now collecting Social Security. I am only 57 years old. All of my retirement dreams have been squashed.”
“I could not read the papers for selling my house last week. Fortunately, I trusted my husband to tell me where to sign.”
Join us in the 21st Century Agenda on Aging and Vision Loss

www.afb.org/aging
Thank You!

References:


Group Exercise for Blind and Vision Impaired Older Adults

Andrew DeMott - University of Illinois at Chicago
Laurine O’Donnell - The Chicago Lighthouse
Conflict of Interest

- We have no financial conflict of interests to disclose
Introductions

- Andrew DeMott, MPH
  - Coordinates Center for Research on Health and Aging at University of Illinois at Chicago (UIC)
  - Fit & Strong!™ Project Manager

- Laurine O’Donnell
  - Director of Seniors Program at The Chicago Lighthouse

- Susan Hughes, PhD
  - Professor, School of Public Health, UIC
  - Director, Center for Research on Health and Aging, UIC

- Janet Szlyk, PhD
  - President and CEO, The Chicago Lighthouse
Goals of Presentation

1. Review prevalence and significance of osteoarthritis (OA)
2. Briefly review aging and vision loss literature
3. Discuss how The Chicago Lighthouse and University of Illinois at Chicago adapted the Fit & Strong!™ program for vision impaired seniors
4. Discuss results of 4 pilot Fit & Strong!™ classes implemented at The Chicago Lighthouse
Osteoarthritis

- Most common cause of chronic joint disability
- Associated with increased mortality (Nuesch et al. 2011)
- $42.2 BILLION spent on joint replacements in 2009 (Murphy & Helmick 2012)
- Estimated 30.8 million people have OA in US (Arthritis Foundation, 2017)
- Persons with OA have decreased functioning and muscle strength compared to age-matched controls (Minor et al., 1989; Semble et al., 1990)
- Pain in weight bearing joints leads to sedentary behavior, de-conditioning, increased stiffness and pain
  - A vicious cycle!
Aging and Vision Loss

- Aging and vision loss both independently associated with:
  - Mobility decline
  - Falls risk
  - Impairment performing ADLs

- Older adults with vision loss are an acute public health risk and their numbers will only continue to grow

- This group has very limited support in the way of evidence-based programs

- (Kempen et al, 2012; Crews, Jones, & Kim, 2006; Dhital, Pey, & Stanford, 2010)
Background

- To address these concerns The Chicago Lighthouse (CLH) partnered with the University of Illinois at Chicago (UIC) implement Fit & Strong!™ with vision impaired seniors
- CLH submitted a grant proposal to the Retirement Research Foundation to adapt and test Fit & Strong!™
The Chicago Lighthouse

- Founded in 1906, The Chicago Lighthouse is a non-profit agency committed to providing high-quality educational, clinical, rehabilitation, employment and independent living services for people of all ages who are blind or visually impaired, including those who are deaf and blind, multi-disabled, and Veterans.

- Seniors’ Program helps individuals, age 55 or over, maintain their independence by focusing on wellness.
  - Hosts social, physical exercise, emotional, educational, and technology programs.
Evidence-based group exercise/behavior change program for adults with lower-extremity pain and stiffness due to osteoarthritis

Program was tested through an efficacy study (randomized no-treatment controlled trial) and an effectiveness study

Fit & Strong!™ improves:
- Lower extremity pain, stiffness, and function
- Lower extremity strength
- Mobility
- Frequency of exercise
- Anxiety and depression

Many improvements maintained out to 18 months!

Each class is 90 minutes and led by a certified instructor.

Each class has 60 minutes of multiple component physical activity, incorporating:

- Flexibility/stretching
- Low-impact aerobics
- Progressive strength training focusing on lower body
- Balance exercises

Each class has 30 minutes of structured health education to promote self-efficacy for exercise and arthritis symptom management.

- All topics are taught from a Participant Manual

During each class iteration all participants meet with the class instructor 1-on-1 to develop a negotiated adherence contract.

- An individualized plan for staying active after the class is over.
Adapting Fit & Strong!: Focus Groups

- We conducted 2 focus groups with 14 participants of the seniors program at The Chicago Lighthouse
- Asked them about their:
  - Experience exercising
  - Barriers to exercise
  - Thoughts on group exercise
  - Input on the Fit & Strong!™ program
  - How to adapt Fit & Strong!™ to those with vision impairments
Adapting Fit & Strong!: Focus Groups

- Key findings
  - Participants overwhelmingly wanted to exercise, but faced substantial barriers
    - Many had bad experiences using exercise facilities, like parks and senior centers, because the exercise rooms and equipment were difficult to navigate and staff were not readily available to assist them
    - Felt unsafe walking outside of their home. They felt physically unsafe or were afraid of uneven sidewalks and unpredictable terrain
    - Felt they needed assistance exercising, but either did not have friends/family to help or did not want to burden them
Adapting Fit & Strong!: Focus Groups

- Key findings

- Participants were receptive to group exercise and were positive towards the social aspect of it, but felt the following adaptations would be needed:
  - Instructor would need to verbally describe exercises in detail, instead of relying on visual modelling
  - An assistant needed to work with participants 1-on-1 and perform functions like helping participants use exercise equipment
  - Participants stated they feel it is disrespectful for people to physically touch them without permission, which often happens to people with vision impairments. So instructors and assistants should ask permission before physically correcting a participant’s form
Adapting Fit & Strong!™: Focus Groups

- Key findings
  - Participants did not think the Participant Manual, which contains the 24 health education lessons, would be usable in its current form
    - Recommended modifying it for those who have some vision by making it large text, removing images, and making it black and white
    - Many participants did not use braille, so did not feel a braille version would be helpful
    - Many participants felt an audio version they could take home would be helpful
Adapting Fit & Strong!™: Instructor Training

- We trained a Chicago Lighthouse exercise instructor, who was also vision impaired, in Fit & Strong!™
- We made the following changes to our usual 8-hour instructor training:
  - Emphasized the need for detailed verbal descriptions of all exercises and to ask permission before physically correcting any participant’s form
  - Trained instructor to make sure the exercise room always remained clear of obstacles and potential trip hazards
  - Trained instructor to set up exercise space in a semi-circle, so low-impact aerobics could be performed by participants near their chair and they wouldn’t drift around the room
  - Required that the instructor or a class assistant read the health education topic to the class and then go into the discussion
Fit & Strong!™ Classes

- We recruited participants from The Chicago Lighthouse senior program to enroll in the Fit & Strong!™ classes
- Our inclusion criteria included:
  - Age 55 and over
  - Symptoms of lower extremity OA, including chronic pain or stiffness in one of the lower body joints
  - No medical diagnosis that would preclude exercise
  - No recent lower joint surgery
- Four classes were offered at The Chicago Lighthouse
  - Offered between October 2016 and November 2017
  - Classes offered 2 days/week for 12 weeks
  - Conducted in-person interviews before/after the classes to collect outcomes data
Findings: Baseline Demographics (n=44)

<table>
<thead>
<tr>
<th></th>
<th>Mean or %</th>
<th>SD or N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, y</strong></td>
<td>68.5</td>
<td>9.1</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>79.5%</td>
<td>35</td>
</tr>
<tr>
<td>Male</td>
<td>20.5%</td>
<td>9</td>
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<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
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<tr>
<td>Black, non-Hispanic</td>
<td>68.2%</td>
<td>30</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>22.7%</td>
<td>10</td>
</tr>
<tr>
<td>White, Hispanic</td>
<td>4.5%</td>
<td>2</td>
</tr>
<tr>
<td>Asian, Pacific Islander</td>
<td>4.5%</td>
<td>2</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>9.1%</td>
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<tr>
<td>High School Graduate</td>
<td>18.2%</td>
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<tr>
<td>Some College</td>
<td>52.3%</td>
<td>23</td>
</tr>
<tr>
<td>College Graduate</td>
<td>20.5%</td>
<td>9</td>
</tr>
<tr>
<td><strong>Chronic Conditions, of 17</strong></td>
<td></td>
<td></td>
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<tr>
<td>Vision Problems</td>
<td>100%</td>
<td>44</td>
</tr>
<tr>
<td>High Blood Pressure</td>
<td>86%</td>
<td>38</td>
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<tr>
<td>Arthritis</td>
<td>80%</td>
<td>35</td>
</tr>
<tr>
<td>Diabetes</td>
<td>48%</td>
<td>21</td>
</tr>
<tr>
<td>Measure</td>
<td>Baseline</td>
<td>12 Weeks</td>
</tr>
<tr>
<td>-------------------------------------</td>
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<tr>
<td>WOMAC</td>
<td>20.94</td>
<td>20.55</td>
</tr>
<tr>
<td>Timed Up and Go</td>
<td>19.12</td>
<td>17.39</td>
</tr>
<tr>
<td>30-Second Chair Stand</td>
<td>9.29</td>
<td>9.91</td>
</tr>
<tr>
<td>2-Minute Step Test</td>
<td>60.00</td>
<td>71.06</td>
</tr>
<tr>
<td>Weight (kg)</td>
<td>94.57</td>
<td>91.59</td>
</tr>
<tr>
<td>BMI</td>
<td>34.79</td>
<td>34.74</td>
</tr>
<tr>
<td>Self-Efficacy for Exercise</td>
<td>32.30</td>
<td>33.06</td>
</tr>
</tbody>
</table>

- WOMAC - measure of lower extremity pain, stiffness, function. High score = greater impairment
- Timed up and go - timed performance measure of balance
- 30-second chair stand - timed performance measure of lower extremity strength
- 2-minute step test - timed performance measure of aerobic capacity
Attendance (n=44)

- 10 participants (22.7%) attended 90% of the class sessions
- 19 participants (43.2%) attended 80% of the class sessions
- Mean attendance for all participants was 16 sessions (66.7%)
- Reasons for non-attendance included unrelated medical conditions and transportation issues
  - Many seniors rely on a paratransit service to get to/from The Chicago Lighthouse
Next Steps

- The Chicago Lighthouse plans to offer this low vision version of Fit & Strong! on an ongoing basis
  - Looking into securing additional grant funding
- Perform further analyses of outcomes and submit findings for publication
- Champion what we have learned to other service organizations that serve older adults with low vision
Thank You!

- We would like to give special thanks to:
  - UIC team members
    - Melissa Martinez
    - Siobhan Midgley
    - Deniz Evangelista
    - Kim Silva
    - Saja Frouhk
  - The Chicago Lighthouse team members
    - Meesa Maeng
    - Megan Frankenbach
Thank You!

- For information on the Fit & Strong!™ program, please contact
  - Andrew DeMott - ademot1@uic.edu

- For information on The Chicago Lighthouse, please contact
  - Laurine O’Donnell - Laurine.ODonnell@chicagolighthouse.org