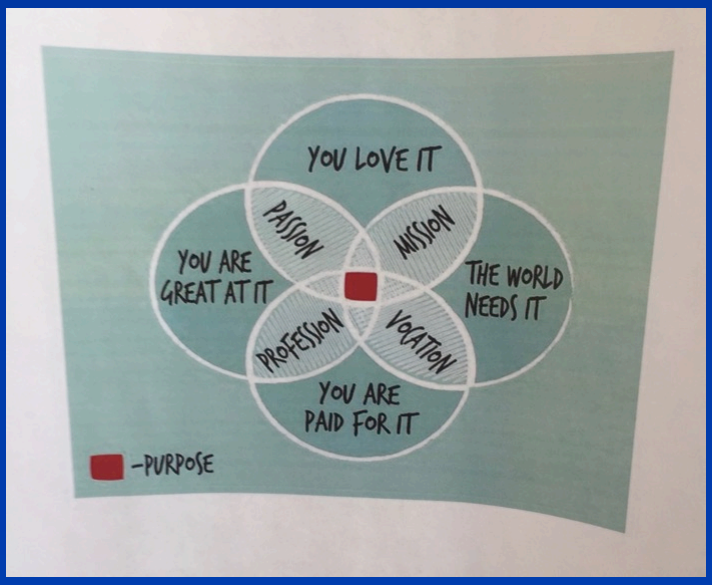
PURPOSE



Ten Years and Counting: Lessons From a Decade of Successful Eye Surgery For People With Intellectual Disability

12th Annual "Focus" on Vision Impairment and Blindness Conference
March 8, 2017

Susannah Rowe, M.D. MPH

Director, Exceptional Vision Service
Vice Chair for Patient Safety and Quality
Department of Ophthalmology
Boston University School of Medicine
Boston Medical Center

Acknowledgments

- Lisa DiBonaventura
- Barry Kran
- Jean Ramsey
- FOCUS Team
- BMC EVS Team
- BMC Ophthalmology Residents
- George Hicks and wbur

Case

- "LL" is a 50-year old man with Down's syndrome and moderately severe intellectual disability who has lived with his mother since birth
- His mother developed worsening Alzheimer's and was placed in a nursing home about a year ago
- LL was moved to a group home, and is living without his mother for the first time in his life

Case, cont.

- Caregivers in the group home have noticed that LL seems to be getting increasingly confused and disoriented over the last year
- He has stopped walking and uses a wheelchair
- Will no longer feed himself
- Has more emotional outbursts
- Does not acknowledge his mother during visits

Case, cont

- His primary physician wonders if LL is developing early Alzheimer's or is becoming depressed
- He refers LL for an eye exam but the surgeon says LL isn't a candidate for surgery therefore an eye exam isn't necessary
- Eventually LL is referred to BMC's Exceptional Vision Service

Case, cont

- LL has a hard time in my office- scared, unable to let me touch him
- Tracks a bright light with his eyes but does not seem to see a book when shown to him
- On very limited exam, it looks like his lenses may be cloudy

Case, cont

- Long discussion about whether dementia makes the cataract a moot point
- Together with caregivers and guardian, decision is made to do an examination under anesthesia ("EUA")
- Plan is to do cataract surgery on one eye at the same time if needed

Case, cont

- Anesthesia Service is consulted:
  - **Anesthesia for someone with Down's requires C-spine films to assess stability of neck bones (potential for atlanto-occipital instability)**
- General anesthesia will be OK with special intubation techniques
- EUA with potential cataract surgery is scheduled

Case, cont

- EUA is performed. He has a dense cataract in each eye. Everything else looks healthy
- Cataract surgery is performed in one eye using scleral tunnel technique, many sutures, no supplemental local anesthetic block

Case, cont

- The next day LL comes to see me for his first post-op visit. He walks off the elevator and into the office, sits down, looks around at everyone in the room, and smiles

Case, cont

- He did well and the second eye was done shortly after
- Now he recognizes his mother, walks, and feeds himself
- His doctor does not think he has Alzheimer's or depression

Boston Medical Center's Exceptional Vision Service

- Formally established 10 years ago
- Focus: surgical eye care for people who cannot tolerate usual care
- 12-15 cases/year
- > 100 procedures to date

Exceptional Vision Service

- Currently funded through clinical revenues and in-kind support from BMC
- Capacity 2-3 new patients per month
- Wait list for surgery 4-6 months
- Growth primarily limited by availability of OR time

EVS: A Team-Based Model

- Susannah Rowe MD MPH Director
- Jean Ramsey, Pediatric Ophthalmologist
- Jenna Titelbaum, Optometrist
- Marissa Bailey, Surgical scheduler
- Estefany Peralta, Administrative Assistant
- Mark Houston, Lead Ophthalmic Technician
- BMC Peri-Operative Surgical Team
- BUMC Ophthalmology Residents

EVS Educational Mission

- To inspire more surgeons to care for people who have special needs
- To train more surgeons to be technically capable of handling these high-risk, complex surgeries
- To demonstrate how careful planning and teamwork can mitigate challenges
- To teach and model understanding and respect for people with special needs and their caregivers

Second-Year Ophthalmology Residents

- 3 months on EVS service:
  - Multidisciplinary, collaborative care
  - Vision-related quality of life for people with intellectual disabilities
  - Refractive and intra-ocular lens considerations
  - Principles of patient-centered care
  - Creative problem-solving to address special needs

Senior Ophthalmology Residents

- 3 months on EVS service
  - Risk/benefit analysis and surgical decision-making
  - Techniques for complex high-risk cataract surgery (prior trauma, congenital conditions, advanced cataract)
  - Secure wound construction
  - Post-operative management
  - Collaboration with other surgical specialties

Exceptional Vision Service Intake Process

- 45-minute structured appointments during quiet time in clinic (empty waiting room)
- Extensive telephone and electronic communication with family, caregivers
- Detailed discussion of post-operative care plan

EVS Areas of Focus

- Primarily cataract surgery
- Also Yag Laser Capsulotomy after cataract surgery
- Subspecialty surgical eye care as needed
- Coordination with other services to address other preventive health issues where possible

Modifications

- Surgery can be more challenging, but some simple modifications make all the difference

Simple Pre-Op Modifications

- Decision based on history alone
- Exam deferred to the operating room (special equipment for lens measurement)
- Prepare in advance for whatever one might find

Simple Surgical Modifications

- Scleral tunnel and sutures (sturdy wound)
- No local anesthetic block
- No patch

Simple Post-Op Modifications

- Ointment twice a day (vs drops 4x/day)
- Fewer post-op visits, but
- Direct contact between surgeon and caregivers (cell phone)

EVS Outcomes To Date

1) Most Important: Nobody Got Sick or Died

- Over 70 surgeries in 10 years
- Zero systemic complications
- Zero significant anesthesia complications

EVS Outcomes To Date:
2) There Were No Surgical Complications

- Zero intraoperative surgical complications (compared to 1.8% surgical complications in neurotypical patients for same surgeon in same time frame)
- Zero post-operative complications or infections (vs <1% in neurotypical patients)

EVS Outcomes To Date:
3) We Couldn't Help Everyone

- 3 people had EUA but no surgery (retinal detachment)
- 1 person could not have EUA due to severe systemic health issues unrelated to intellectual disability
- About 10% of people who had surgery reported no real improvement

EVS Outcomes:
4) Most Patients Had Big Improvements

- Close to 90% of caregivers reported significant improvements in visual function
- About 10% of caregivers reported life-changing improvements in quality of life and independence
- No patients had worsened visual function after surgery per caregivers

More Complex Surgical Challenges Requiring Specialized Care

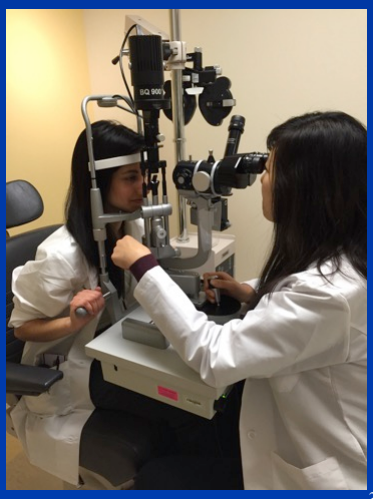
- Intraoperative lasers
- Complex ophthalmic testing
- Limited range of motion, positioning challenges
- Extremely dense cataract

Special Challenges: Intraoperative Lasers for Posterior Capsular Opacity

- Reported in the literature (mostly kids)
- Challenges include
  - Transport of expensive laser to different building
  - Patient positioning
  - Navigating E/T tube
  - Cervical stability (Down's)

Typical YAG Laser Protocol

- Precise positioning
- Bulky contact lens placed on surface of eye to prevent blinking
- No movement of eye or head for 3-5 minutes



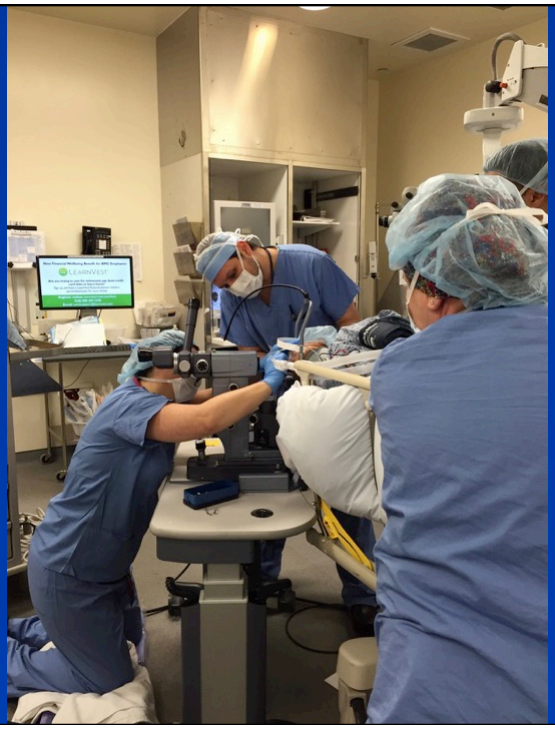
EVS Alternative: YAG Laser Capsulotomy in OR

- General anesthesia
- Team approach
- 30-40 minutes
- Can combine with other procedures

35

36

37



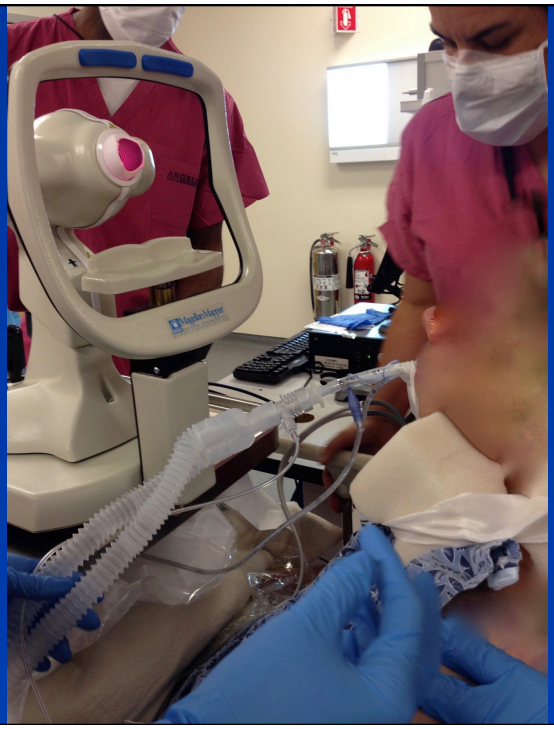
38

39

40

Special Challenges:
Complex Ophthalmic Testing

- Many complex ophthalmic tests are not designed for patients lying down asleep



Special Challenges:
Extremely Dense Cataract

- May require larger incision
- More demanding of surgical skill

Conclusion

- In our experience, when performed properly, cataract surgery for patients with intellectual disability is safe and highly effective

What Are Some of the Myths that We Can Debunk About Cataract Surgery for People With Intellectual Disabilities?

Myth # 1

- Cataract surgery isn't worthwhile for someone with severe intellectual disabilities because they will never be able to read/drive/work/etc

FACT

- As a group, our EVS patients enjoy far greater gains in quality of life and independence than our typically-abled patients

FACT

- American Academy of Ophthalmology:
  "*cataract surgery is indicated when visual function no longer meets the patient's needs and cataract surgery provides a reasonable likelihood of improved vision*"
- Cataract surgery should be considered for ANYONE whose cataract is affecting their quality of life

Myth # 2

- Cataract surgery won't help if a person is severely demented or has profound intellectual disabilities

FACT

- Cataract surgery, when needed, reduces functional declines in all people, and especially in people who have reduced intellectual capacity
- For people with dementia, cataract surgery has been shown to significantly improve cognition and quality of life

Myth # 3

- Cataract surgery in someone with intellectual disability is so high risk that it should be deferred until the cataract is really causing a lot of problems

FACT

- Cataract surgery is extremely low risk. Intellectual disability does not increase the risks of cataract surgery

Myth # 4

- By the time people with intellectual disability see a surgeon, the cataract is often too advanced to take out safely

FACT

- With modern surgical techniques, almost any cataract can be removed safely

Myth # 5

- A complete eye exam is necessary before deciding to take a person to the OR

Fact

- Every single part of the exam can be deferred until the person is comfortably asleep

Myth # 6

- The person will have to use an eye shield and not touch their eye after surgery or they will go blind

FACT

- A sutured scleral tunnel can withstand more than 10 pounds of pressure/square inch. No patch is needed if local anesthetic is avoided

Myth # 7

- The patient will need to have eyedrops 4-6 times per day

FACT

- There is actually no evidence that post-operative antibiotics reduce the risk of infection
- Steroid ointment can help limit inflammation. We can use steroid/ antibiotic ointment once or twice per day instead of drops

Myth # 8

- There are very few eye surgeons who can take care of people with intellectual disabilities

Fact

- BMC is graduating four EVS surgeons per year!
- Eye surgeons want to help people and will try to do what is right for the patient. With a few minor modifications and some thoughtful strategizing, many eye surgeons can take excellent care of people with intellectual disabilities

What We Have Learned

- Start small, stay focused on key service
- Build team of like-minded caregivers
- Don’t forget administrative staff in your team
- Leverage intangible benefits for team members
- Get buy-in of Chair and other leaders early/often
- Leverage intangible benefits to the Department and institution besides revenues

Next Steps

- Does this care model work well for an ACO model?
- Can we find a way to make the process more financially sustainable?
- Is this scalable to other specialties?

Summary

- Cataracts are more common in people with intellectual impairments
- Cataracts can significantly impair quality of life
- Cataract surgery is safe and highly effective
- Appropriate surgery can help people enjoy their eyesight to the fullest
- Minimally invasive surgery and a team approach is best