

The Patient Experience with Diabetic Retinopathy: Qualitative Analysis of Patients with Proliferative Diabetic Retinopathy

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Supplementary Materials

Supplementary Methods

Screener Form Eligibility Criteria

Inclusion Criteria

- ≥ 18 years of age
- Confirmed diagnosis of type 1 or type 2 diabetes mellitus
- Proliferative diabetic retinopathy (Diabetic Retinopathy Severity Scale [DRSS] levels 61, 65, 71, or 75) in the affected eye
- Treatment with aflibercept (e.g., Zaltrap[®] or Eylea[®]), panretinal photocoagulation (PRP), or any combination of the aforementioned treatments in the past 6 months
- Willingness and ability to participate in one or two audio-recorded telephone interviews, each lasting up to 1 hour
- Ability to speak, read, write, and understand English

Exclusion Criteria

- Diabetic macular edema (central subfield thickness ≥ 305 μm and ≥ 320 μm for females and males, respectively) in the affected eye* that occurred before PRP
- Any intra- or periocular corticosteroid treatment in the affected eye*
- Any intraocular sustained-release treatment, implantable device, or gene therapy in the affected eye
- History of vitreoretinal surgery or intraocular pressure ≥ 25 mmHg in the affected eye,* or evidence of active infectious blepharitis, keratitis, scleritis, or conjunctivitis in either eye

- Substantial visual impairment that would interfere with reading questionnaire items on paper or a screen with or without the use of visual aids

*If both eyes were eligible, the eye with the worse DRSS score was considered the affected eye. If both eyes had the same DRSS score, the recruiting clinician selected the affected eye.

Supplementary Tables

Table S1. Search strategy for concepts related to symptoms and impact

Search	Terms	Results
1	Qualitative OR interview OR focus group OR survey OR framework	2,114,197
2	Quality of life OR QOL OR wellbeing OR well-being OR disease burden OR symptom OR activities of daily living OR self-care OR function* OR independence	17,009,813
3	Diabetic retinopathy [MeSH Terms] OR peripheral vision OR nyctalopia OR night vision	29,197
4	1 AND 2 AND 3	2832
5	Filters: Published in the last 10 years, Humans, English	1294

MeSH, Medical Subject Headings.

Table S2. Search strategy for concepts relating to treatment experience

Search	Terms	Results
1	Treatment experience OR treatment burden OR treatment preference OR outcome OR adverse event OR complication OR side effect	5,126,193
2	Eylea OR Zaltrap OR aflibercept OR panretinal photocoagulation OR anti-vascular endothelial growth factor OR field sparing laser	6440
3	Diabetic retinopathy [MeSH Terms] Field: Title/Abstract	24,369
4	1 AND 2 AND 3	787
5	Filters: Published in the last 10 years, Humans, English	460

MeSH, Medical Subject Headings.

Table S3. Coding tree for concepts identified from patient interview transcripts

Code	Subdomain	Overarching domain	Domain
Aggravating	Aggravation	Impacts	Emotions
Anxiety: Vision worsening	Concern for future/worsening symptoms	Impacts	Emotions
Blurry vision	Blurred vision*	Symptoms	Vision problems
Blurry vision: Close up: Probed	Blurred vision*	Symptoms	Vision problems
Blurry vision: Far away: Probed	Blurred vision*	Symptoms	Vision problems
Most bothersome: Going blind in the future	Concern for future/worsening symptoms	Impacts	Daily activities
Blurry vision: Worse when dark	Blurred vision*	Symptoms	Vision problems
Most bothersome: Worry of getting worse	Concern for future/worsening symptoms	Impacts	Daily activities
Fuzzy vision	Blurred vision*	Symptoms	Vision problems
Most bothersome: Blurry vision: Probed	Blurred vision*	Symptoms	Vision problems
Cloudy vision	Cloudy/hazy/foggy vision	Symptoms	Vision problems
Foggy vision	Cloudy/hazy/foggy vision	Symptoms	Vision problems
Hazy vision	Cloudy/hazy/foggy vision	Symptoms	Vision problems
Most bothersome: Foggy vision: Probed	Cloudy/hazy/foggy vision	Symptoms	Vision problems
Bleeding: Depth perception impact	Depth perception issues	Symptoms	Vision problems
Depth perception	Depth perception issues	Symptoms	Vision problems
Depth perception: Worse at night	Depth perception issues	Symptoms	Vision problems
Worry got treatment too late	Concern for future/worsening symptoms	Impacts	Daily activities
Most bothersome: Feeling sorry for yourself	Decreased self-perception	Impacts	Daily activities
Fear of going blind	Fear and anxiety	Impacts	Daily activities
Fear of losing independence	Fear and anxiety	Impacts	Daily activities
Fear of losing sight	Fear and anxiety	Impacts	Daily activities
Frustration	Frustration and anger	Impacts	Daily activities
Depth perception: Worse during the day	Depth perception issues	Symptoms	Vision problems
Most bothersome: Loss of independence	Loss of independence	Impacts	Daily activities

Difficulty reaching for a doorknob: Depth perception	Depth perception issues	Symptoms	Vision problems
Never travel alone	Loss of independence	Impacts	Daily activities
Difficulty reaching for a handrail: Depth perception	Depth perception issues	Symptoms	Vision problems
Most bothersome: Not being able to get sight back	Concern for future/worsening symptoms	Impacts	Daily activities
Can't see ground: Stumbling	Problems navigating obstacles	Impacts	Daily activities
Most bothersome: Navigating crowds and traffic	Problems navigating obstacles	Impacts	Daily activities
Difficulty with depth perception	Depth perception issues	Symptoms	Vision problems
Most bothersome: Depth perception	Depth perception issues	Symptoms	Vision problems
Cold in eye	Feeling of coldness	Symptoms	Eye problems
Difficulty adapting to lighting changes	Difficulty adapting to lighting changes*	Symptoms	Vision problems
Difficulty adapting to lighting changes: Probed	Difficulty adapting to lighting changes*	Symptoms	Vision problems
Difficulty adjusting to lighting changes	Difficulty adapting to lighting changes*	Symptoms	Vision problems
Day-to-day pain	Pain	Symptoms	Eye problems
Difficulty recognizing faces	Problems recognizing people*	Impacts	Daily activities
Difficulty recognizing faces: Probed	Problems recognizing people*	Impacts	Daily activities
Bleeding: Can't see phone/computer	Problems using phone/computer	Impacts	Daily activities
Difficulty playing games on phone: Probed	Problems using phone/computer	Impacts	Daily activities
Transition: Outside to inside	Difficulty adapting to lighting changes*	Symptoms	Vision problems
Can't differentiate colors: Red and green	Difficulty distinguishing colors or colorless vision	Symptoms	Vision problems
Color perception: Probed	Difficulty distinguishing colors or colorless vision	Symptoms	Vision problems
Difficulty differentiating colors	Difficulty distinguishing colors or colorless vision	Symptoms	Vision problems
Difficulty with color vision	Difficulty distinguishing colors or colorless vision	Symptoms	Vision problems

Difficulty focusing	Difficulty focusing	Symptoms	Vision problems
Difficulty reading phone: One continuous line	Problems using phone/computer	Impacts	Daily activities
Difficulty seeing scroll bar	Problems using phone/computer	Impacts	Daily activities
Difficulty seeing: Phone	Problems using phone/computer	Impacts	Daily activities
Bright light: Aching	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Difficulty using computer: Probed	Problems using phone/computer	Impacts	Daily activities
Difficulty with computer use	Problems using phone/computer	Impacts	Daily activities
Fatigue: Computer use	Problems using phone/computer	Impacts	Daily activities
Stinging: Staring at computer	Problems using phone/computer	Impacts	Daily activities
Difficulty walking: Balance	Problems walking	Impacts	Daily activities
Difficulty walking: Glare from sun	Problems walking	Impacts	Daily activities
Can't drive	Problems with driving	Impacts	Daily activities
Can't drive at night	Problems with driving	Impacts	Daily activities
Can't drive at night: Limits places can go	Problems with driving	Impacts	Daily activities
Decreased confidence driving	Problems with driving	Impacts	Daily activities
Difficulty driving	Problems with driving	Impacts	Daily activities
Difficulty driving: Can't see past hood of car	Problems with driving	Impacts	Daily activities
Difficulty driving: Blurred vision	Problems with driving	Impacts	Daily activities
Difficulty driving: Bright lights	Problems with driving	Impacts	Daily activities
Difficulty driving: Bright lights: Probed	Problems with driving	Impacts	Daily activities
Difficulty driving: Can't see unless close	Problems with driving	Impacts	Daily activities
Difficulty driving: Can't tell where headlights are coming from	Problems with driving	Impacts	Daily activities
Difficulty driving: Daytime	Problems with driving	Impacts	Daily activities
Difficulty driving: Glare from sun	Problems with driving	Impacts	Daily activities
Difficulty driving: In dim light	Problems with driving	Impacts	Daily activities
Difficulty driving: Night	Problems with driving	Impacts	Daily activities
Difficulty driving: Night: Glare	Problems with driving	Impacts	Daily activities
Difficulty driving: Night: Pain	Problems with driving	Impacts	Daily activities

Difficulty driving: Night: Probed	Problems with driving	Impacts	Daily activities
Difficulty driving: Night: Run into curbs	Problems with driving	Impacts	Daily activities
Bright light: Burning feeling	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Difficulty driving: Nighttime: Signs blurry	Problems with driving	Impacts	Daily activities
Difficulty driving: On highway	Problems with driving	Impacts	Daily activities
Difficulty driving: Parallel lines distorted	Problems with driving	Impacts	Daily activities
Difficulty driving: Seeing lines on road	Problems with driving	Impacts	Daily activities
Difficulty driving: Seeing signs	Problems with driving	Impacts	Daily activities
Can't sit outside: Glare: Hurts	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Darker rooms: More comfortable	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Difficulty driving: Without glasses	Problems with driving	Impacts	Daily activities
Difficulty parking: Depth perception	Problems with driving	Impacts	Daily activities
Difficulty reading signs: Driving	Problems with driving	Impacts	Daily activities
Driving at night: Wears glasses	Problems with driving	Impacts	Daily activities
Most bothersome: Not being able to drive at night	Problems with driving	Impacts	Daily activities
Most bothersome: Potential of not driving: Probed	Problems with driving	Impacts	Daily activities
No longer drive: At dusk and dawn	Problems with driving	Impacts	Daily activities
Spots: Cause to not drive	Problems with driving	Impacts	Daily activities
Difficulty finding items at grocery store	Problems with grocery shopping	Impacts	Daily activities
Can't do crafts	Problems with hobbies	Impacts	Daily activities
Can't see shooting target clearly	Problems with hobbies	Impacts	Daily activities
Decreased activities: Fishing	Problems with hobbies	Impacts	Daily activities
Decreased activities: Hunting	Problems with hobbies	Impacts	Daily activities
Difficulty playing golf	Problems with hobbies	Impacts	Daily activities
Difficulty riding bike: Glare from sun	Problems with hobbies	Impacts	Daily activities
Difficulty sewing	Problems with hobbies	Impacts	Daily activities
Difficulty shooting gun accurately	Problems with hobbies	Impacts	Daily activities

Difficulty threading needle	Problems with hobbies	Impacts	Daily activities
Difficulty watching TV	Problems with hobbies	Impacts	Daily activities
Difficulty watching TV: Eye fatigue	Problems with hobbies	Impacts	Daily activities
Difficulty watching TV: Streaks	Problems with hobbies	Impacts	Daily activities
Decreased activities: Cutting grass	Problems with household activities	Impacts	Daily activities
Difficulty changing temp on thermostat	Problems with household activities	Impacts	Daily activities
Difficulty cooking	Problems with household activities	Impacts	Daily activities
Difficulty cutting grass	Problems with household activities	Impacts	Daily activities
Difficulty doing laundry: Missing stains	Problems with household activities	Impacts	Daily activities
Difficulty dusting: Missing spots	Problems with household activities	Impacts	Social activities
Difficulty sweeping: Missing objects	Problems with household activities	Impacts	Social activities
Tripping on furniture: Night	Problems with navigating obstacles	Impacts	Daily activities
Day vs night: Day worse	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Difficulty seeing in bright light	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Difficulty seeing in bright light: Probed	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Difficulty seeing in sun: Probed	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Difficulty seeing: Glare from sun	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Difficulty finding kid in crowd	Problems with caretaking	Impacts	Daily activities
Light sensitivity	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Nighttime vision: Easier: Probed	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Sensitive to sunlight	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Sensitivity to glare	Difficulty seeing in bright light/glare*	Symptoms	Vision problems
Difficulty seeing objects on table			
Bleeding: Difficulty reading	Problems with reading	Impacts	Daily activities
Difficulty seeing far away	Difficulty with distance vision	Symptoms	Vision problems
Difficulty seeing far away: Probed	Difficulty with distance vision	Symptoms	Vision problems
Can't read own writing without glasses	Problems with reading	Impacts	Daily activities
Difficulty looking up addresses	Problems with reading	Impacts	Daily activities
Difficulty reading	Problems with reading	Impacts	Daily activities

Difficulty reading fine print	Problems with reading	Impacts	Daily activities
Difficulty reading from far away: Probed	Problems with reading	Impacts	Daily activities
Difficulty reading signs	Problems with reading	Impacts	Daily activities
Difficulty reading signs: Probed	Problems with reading	Impacts	Daily activities
Difficulty reading street signs	Problems with reading	Impacts	Daily activities
Difficulty reading: Blurry	Problems with reading	Impacts	Daily activities
Difficulty reading: Books	Problems with reading	Impacts	Daily activities
Difficulty reading: Bring book closer	Problems with reading	Impacts	Daily activities
Difficulty seeing: Things far away: Distance	Difficulty with distance vision	Symptoms	Vision problems
Difficulty reading: Bring screen closer	Problems with reading	Impacts	Daily activities
Double vision	Double vision*	Symptoms	Vision problems
Difficulty with eye exam			
Difficulty reading: Computer	Problems with reading	Impacts	Daily activities
Difficulty reading: Coping: Place magnifier over phone	Problems with reading	Impacts	Daily activities
Double vision: Probed	Double vision*	Symptoms	Vision problems
Discomfort: At night	Strain/discomfort	Symptoms	Eye problems
Dizzy	Dizziness	Symptoms	Headaches and dizziness
Dizzy: Sit down	Dizziness	Symptoms	Headaches and dizziness
Flashes of light	Flashes of light	Symptoms	Vision problems
Flashes of light: Driving	Flashes of light	Symptoms	Vision problems
Difficulty reading: Coping: Screenshot and zoom	Problems with reading	Impacts	Daily activities
Dry eye	Dry eye	Symptoms	Eye problems
Eye ache	Pain	Symptoms	Eye problems
Eye pain	Pain	Symptoms	Eye problems
Eye pressure	Eye pressure	Symptoms	Eye problems
Eye pulsate	Eyes vibrating/pulsing	Symptoms	Eye problems

Eyes burn	Burning and itching*	Symptoms	Eye problems
Eyes vibrating	Eyes vibrating/pulsing	Symptoms	Eye problems
Eyestrain	Strain/discomfort	Symptoms	Eye problems
Black spot: Shape change	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Fatigue/tired eyes: Probed	Eye fatigue	Symptoms	Eye problems
Fatigue around eye: Probed	Eye fatigue	Symptoms	Eye problems
Difficulty reading: Eye fatigue	Problems with reading	Impacts	Daily activities
Difficulty reading: Farsighted	Problems with reading	Impacts	Emotions
Fear of light: Probed	Feariness		
Difficulty reading: Focus	Problems with reading	Impacts	Emotions
Difficulty reading: Glare from iPad	Problems with reading	Impacts	Emotions
Film covering eyes	Filminess		
Film covering eyes: Morning	Filminess		
Film covering eyes: Reading	Filminess		
Black spots	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Bleeding: Black spot	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Bleeding: Spiderweb vision	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Floaters	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Floaters: Better in morning	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Floaters: Block vision	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Floaters: Comes and goes	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Floaters: Moves around	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Floaters: Worse in day	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Difficulty reading: In dim light	Problems with reading	Impacts	Emotions
Lines across eyes	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Most bothersome: Floaters	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Headache: From blurriness	Headaches	Symptoms	Headaches and dizziness

Headaches	Headaches	Symptoms	Headaches and dizziness
Impact homeschooling	Problems with caretaking	Impacts	Daily activities
Irritation	Scratchy/irritated	Symptoms	Eye problems
Itchiness	Burning and itching*	Symptoms	Eye problems
Itchiness: Probed	Burning and itching*	Symptoms	Eye problems
Itchy: Dry eye	Burning and itching*	Symptoms	Eye problems
Most bothersome: Floaters: Probed	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Spiderweb: Worse in morning	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Migraines	Headaches	Symptoms	Headaches and dizziness
Difficulty reading: On phone	Problems with reading	Impacts	Daily activities
Spots	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Streaks in vision	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Most bothersome: Cold in eye	Eye coldness	Symptoms	Eye problems
Spiderweb: Worse in morning	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Can't see in dark	Night blindness (difficulty seeing in dark or seeing in dim light)*	Symptoms	Vision problems
Difficulty reading: On TV: Probed	Problems with reading	Impacts	Daily activities
Difficulty seeing dark scenes	Night blindness (difficulty seeing in dark or seeing in dim light)*	Symptoms	Vision problems
Difficulty reading: Probed	Problems with reading	Impacts	Emotions
Difficulty seeing in dark: Probed	Night blindness (difficulty seeing in dark or seeing in dim light)*	Symptoms	Vision problems
Difficulty seeing in dim light	Night blindness (difficulty seeing in dark or seeing in dim light)*	Symptoms	Vision problems
Difficulty seeing in dim light: Probed	Night blindness (difficulty seeing in dark or seeing in dim light)*	Symptoms	Vision problems
Difficulty reading: Small fonts	Problems with reading	Impacts	Emotions
Most bothersome: Itch and burning feeling in eyes	Burning and itching*	Symptoms	Eye problems

Difficulty reading: Use phone as magnifying glass	Problems with reading	Impacts	Daily activities
Difficulty reading: Zoom in on computer	Problems with reading	Impacts	Emotions
Mixing up letters/numbers	Problems with reading	Impacts	Daily activities
Most bothersome: Difficulty reading	Problems with reading	Impacts	Daily activities
Most bothersome: Limited ability to read small print	Problems with reading	Impacts	Emotions
Can't see without reading glasses	Problems with reading	Impacts	Daily activities
Can't wear makeup	Problems with self-care	Impacts	Emotions
Difficulty organizing pills	Problems with self-care	Impacts	Emotions
Can't see things on side unless close	Peripheral vision issues*	Symptoms	Vision problems
Can't see head of a screw	Problems with work	Impacts	Daily activities
Outdoors at night: Easier: Probed			
Pain in eyes	Pain	Symptoms	Pain
Pain: At night	Pain	Symptoms	Pain
Pain: Dry eye pain	Pain	Symptoms	Pain
Pain: Headache over eye	Headaches	Symptoms	Headaches and dizziness
Pain: Sharp bursts	Pain	Symptoms	Pain
Discomfort when can't see side	Peripheral vision issues*	Symptoms	Vision problems
Peripheral vision: Less accurate	Peripheral vision issues*	Symptoms	Vision problems
Peripheral vision: Probed	Peripheral vision issues*	Symptoms	Vision problems
Can't work	Problems with work	Impacts	Daily activities
Side vision out of focus	Peripheral vision issues*	Symptoms	Vision problems
Difficulty doing mechanic work	Problems with work	Impacts	Emotions
Scratchy eye	Scratchy/irritated	Symptoms	Eye problems
Clear circle at center of redness	Red vision	Symptoms	Vision problems
Red vision	Red vision	Symptoms	Vision problems
Most bothersome: Constant shadow: Probed	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems

Shadows	Floaters (black spots, spiderwebs, or streaks)	Symptoms	Vision problems
Blind in one eye	Vision loss	Symptoms	Vision problems
Fading vision: Probed	Vision loss	Symptoms	Vision problems
Difficulty working	Problems with work	Impacts	Daily activities
Retired due to vision	Problems with work	Impacts	Daily activities
Most bothersome: Active bleed vision loss: Probed	Vision loss	Symptoms	Vision problems
Most bothersome: Fading vision	Vision loss	Symptoms	Vision problems
Unable to work	Problems with work	Impacts	Daily activities
Work: Can't see	Problems with work	Impacts	Daily activities
Uncomfortable feeling: Feels like someone is pushing on eyeball	Eye pressure	Symptoms	Eye problems
Uncomfortable feeling: Probed	Strain/discomfort		
Blurred vision: Difficulty writing	Problems with writing	Impacts	Emotions
Right eye: Minimal vision	Vision loss	Symptoms	Vision problems
Vision loss: Rapid	Vision loss	Symptoms	Vision problems
Watery eyes	Watery eyes	Symptoms	Eye problems
Sadness	Sadness	Impacts	Daily activities
Upset: Living with function of one eye	Other negative emotions	Impacts	Emotions
Vision worse	Vision loss	Symptoms	Vision problems

*Probed and spontaneous.