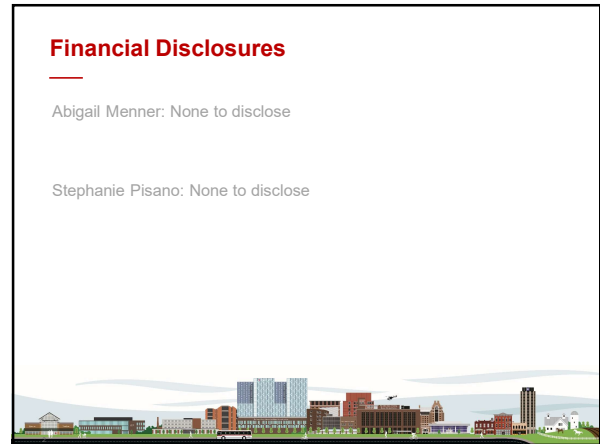
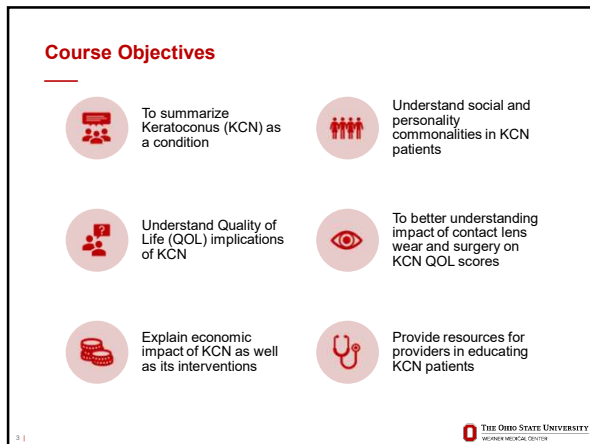




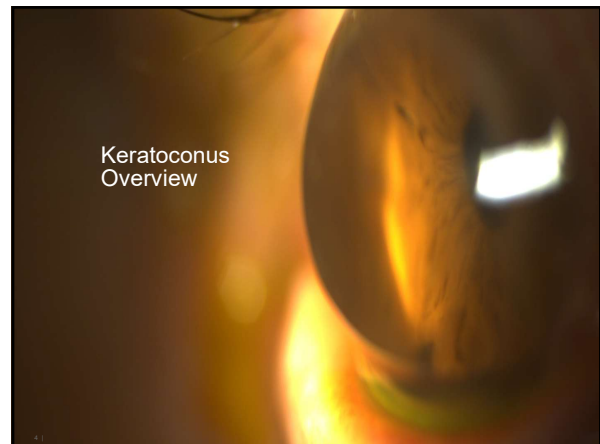
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4

Keratoconus Overview

- Non-inflammatory localized **thinning** of the cornea
- Can present **bilaterally**, often **asymmetric**
- **Progressive** in nature, associated with age of diagnosis
- High keratometry values
- High amounts of irregular astigmatism (often ATR/oblique)
 - Resulting in reduced spectacle acuity
 - Often requires rigid contact lenses for improved VA/visual rehabilitation

5

Keratoconus Overview

Non-Surgical Intervention:

- Patient education, avoiding rubbing eyes
- Anti-allergy treatment (topical, orals)
- Preservative-free topical lubricants to reduce ocular irritation
- Spectacle Rx or Soft CL Rx
- Gas-permeable CL (for visual rehabilitation)

Surgical Intervention:

- Corneal Crosslinking (in an effort to halt disease progression)
- INTACS (Intracorneal ring segments)
- Anterior Lamellar Keratoplasty
- Penetrating Keratoplasty

6

Keratoconus Overview

Prevalence: 1.38 per 1000 in world population (Highest found: 23 per 1000 in Jews living in Jerusalem)

**Variability exists due to genetics and ethnicity of population studied*

As the prevalence of keratoconus is low, many public health policy makers view the disease as a minor concern when contrasted with eye diseases such as glaucoma and age-related macular degeneration

Gender: Correlations contradictory, odds of developing KCN were only 1% higher in men compared with women

Age of onset: differs based on population studied

Onset around puberty

KCN onset in childhood is more aggressive than onset in adulthood

7

Keratoconus Associations

Systemic:

Obstructive Sleep Apnea (OSA): KCN patients are 1.8 times more likely to have OSA

- OSA patient have increased serum levels of MMP-9 compared with obese controls

Down Syndrome: Rates in the range of 10.6%–71.3% in studies that included corneal topography

Diabetes: Odds of developing KCN were 1.4 times higher in diabetic versus healthy subjects

- Odds of developing KCN were 23% lower in Type II diabetic patients

8

Keratoconus Associations

Environmental:

Atopy: Increased IgE serum levels may promote inflammatory collagen/keratocyte changes, evidence to manage IgE levels even in absence of allergic symptoms

Allergy: did not increase risk of disease, causal pathway of keratoconus and can be considered an indirect cause of keratoconus

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Keratoconus Associations

Mechanical:

Eye-rubbing: Odds ratio 3 times higher (some studies range as high as 10) in patients with abnormal eye rubbing on a daily basis

*Differing definition/criteria of eye rubbing

*Majority of KCN patients unaware of association

- Dominant hand theory: the more advanced keratoconus may be on the same side as the dominant hand
- Concomitant allergy may increase KCN progression, especially in severe untreated eye rubbers

Preferential Side Sleeping: patient sleeps on side with worse KCN

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Keratoconus Associations

Biochemical:

Oxidative Stress (OS): Oxidative stress markers increased and antioxidants decreased in several samples of KCN compared to healthy subjects.

- OS: Induces activation of tissue proteinases and degradation of proteinase inhibitors that lead to progressive corneal thinning

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Corneal Hysteresis and Biomechanics

Cornea exhibits viscoelastic properties:

- Elasticity, Creep, Stress Relaxation, and Hysteresis
- Strength of cornea arises from collagen

Collagen Lamellae are significantly different in keratoconus patient versus normals

- Significant decrease in number
- Altered orientation of fibrils
- Reduced number of crosslinks between
 - = altered integrity

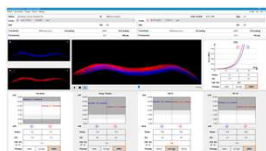
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Corneal Hysteresis and Biomechanics

Roberts Model for Progression

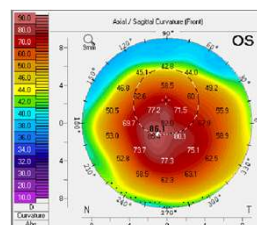
- Localized reduction in elasticity within cone area
 - Results in protrusion of the weakened area due to IOP induced stress
 - Subsequent redistribution of stress to cone
- Not overall bulging of cornea
- Testing corneal hysteresis
 - CorVis ST
 - ORA



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Keratoconus and Genetics

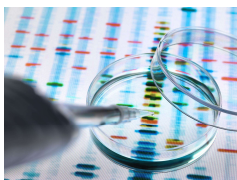


- Multifactorial
- Genetic predisposition may be triggered by environmental factors
- ~10% of patients have genetic component
- 1st degree relative is most significant risk factor
- >20 genes associated with genetic susceptibility

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Keratoconus and Genetics



Genes with most keratoconus association

- VSX-1** (visual system homeobox)
- DOCK9** (cytokinesis 9)
- TGFB2** (transforming growth factor beta)

Prevalence and incidence is variable

Genetic Testing

- Patient options
- Availability
- Cost

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15

Social And
Personality
Implications

16

Social and Personality Implications of KCN

"...It can be said that keratoconus patients are more **pessimistic, intuitive, withdrawn and insecure** than the studied emmetropes....Several authors found different data observing more **passive-aggressive, paranoid and hypomanic people**, associating keratoconus with **type A personality** behavior described as being **articulate, systematic and authoritarian** ..." Moreira et al (2007)

17

Keratoconic Personality

"....less **conforming**, less **emotionally stable**, and **lack trust** with regard to interpersonal relationships.." Mannis et al. (1987)

"...[exhibit] **pain avoidance, general anxiety** or deficiencies associated with imagination, **withdrawal**..." Moreira et al. (2007)

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Keratoconic Personality

Maladaptive Coping Style:

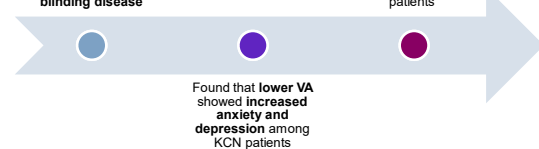
As this disease onset is during immature years of adolescence, this negative impact on quality of life causes a **dissonance between patient and physician perceptions of disease burden.**

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Mental Health and Social Burden of KCN: CLEK Study

The average mental health score of KCN patients with normal VA was comparable with that of people with advanced potentially blinding disease

There was also an **increased prevalence of anxiety-related disorders** among KCN patients



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Keratoconus and Mental Health

- 37% of KCN patients have a diagnosis of mental health disorders
- Men with KCN can exhibit schizophrenia. Women can exhibit depression.
- Patients usually do not discuss mental health with eye care providers
- Perception of disability that extends beyond visual impairment

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Keratoconus and Mental Health

KCN significantly impacts:

Emotional well-being

Effects on activities of daily living (ADLs)

KCN patients exhibit anxiety concerning:

Worsening vision

Possible future surgery

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Mental Health and Social Burden of KCN

Shout out to all of us fighting a battle that most people don't understand.

18 comments

Like Comment

2

Dec 30, 2021

First thoughts and feelings when diagnosed with keratoconus? I felt like I have a rare disease and that will slowly go blind.

22 comments

Like Comment

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Disconnected Practitioner/Patient Relationship:

KCN patients often dissatisfied with information provided by their doctors.

+

Uncertainty and ambiguity concerning condition may provide anxiety and worsen concerns about KCN.

→

Patient education about KCN may alleviate patient anxiety

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25

Quality of Life (QOL) Implications of KCN

Quality of life is defined by a number of domains including:

- Cognitive status
- Social environment
- Physical function
- Overall Health
- Symptoms

26 | <https://essencanceralliance.nhs.uk/national-quality-of-life-survey-launched-for-cancer-patients/>

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Types of Quality of Life (QOL)

Quality of life can be separated into specific categories:

- Health-related quality of life : HR-QOL
 - Measures functioning and well-being in physical, mental, and social realms of life
- Vision-related quality of life: VR-QOL
 - Specific to visual tasks and visual ability of patient

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Quality of Life (QOL) Questionnaires

National Eye Institute Vision Function Questionnaire (NEI-VFQ): a tool sensitive to changes in visual function

25-item version developed in 2001

51-item version developed in 1998

The Keratoconus Outcome Research Questionnaire (KORQ): measures 2 domains of VR-QoL in patients with keratoconus

Activity limitation scale (18 items)

Symptom scale (11 items)

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Quality of Life (QOL) Questionnaires

Keratoconus End-Points Assessment Questionnaire (KEPAQ):
Consists of two sections:
Functional Compromise (KEPAQ-F): very similar approach to the KORQ
Emotional Compromise (KEPAQ-E): newest aspect of the scale

The Impact of Vision Impairment (IVI) Questionnaire: Composed of three subscales:

Reading and Accessing information (9 items)

Mobility and Independence (11 items)

Emotional well-being (8 items)

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Why does KCN impact QOL?

- Keratoconus has negative impact on QOL due younger age of onset/diagnosis
 - Chronic
 - Progressive
 - Frequent changes in condition
- Perceived vision loss is **disproportionate to acuity**
- Lower visual function and disability are associated
 - Visual impairment is strong predictor of severe ADL limitations



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QOL and Vision Related-QOL



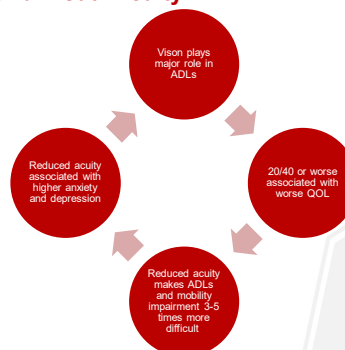
- Good visual acuity does not equal good **quality** of vision
- Subtle vision changes can have large impact
 - Irregular astigmatism
 - Higher order aberrations
 - Ghosting/shadowing



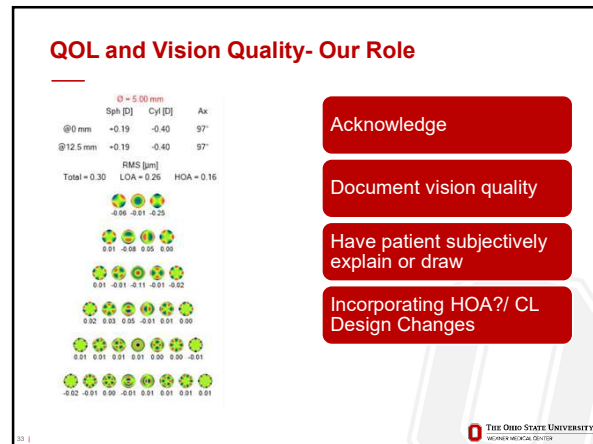
• QOL is significantly impacted **before** onset of visual impairment and functional disability

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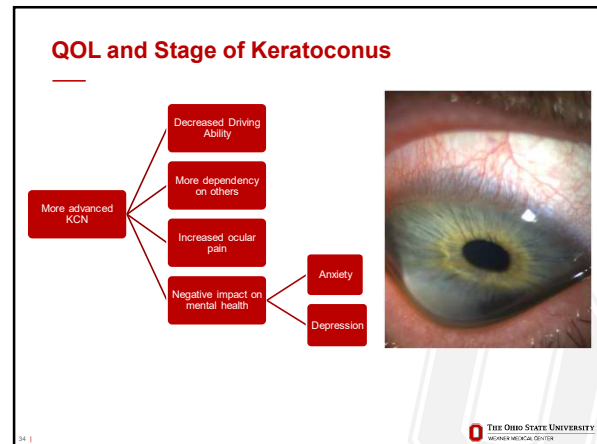
QOL and Visual Acuity



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CLEK Study: QOL Highlights

KCN patients scored low QOL measurements on all scales

Strongest association with lower V-QOL at baseline:

- visual acuity worse than 20/40
- corneal curvature of 52 D or more

A 3.00-D increase or more in curvature was associated with a decline in all scales

Because of KCN:

- 1.4% changed jobs
- 2.1% retired
- 11.5% were dismissed
- 35.6% noted KCN **greatly affected their ability to work.**

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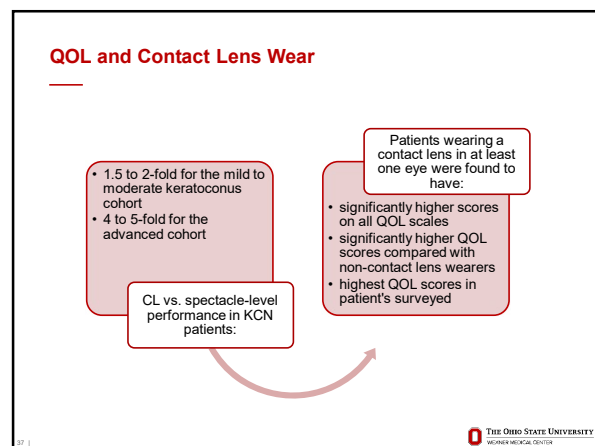
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QOL and Contact Lens Wear

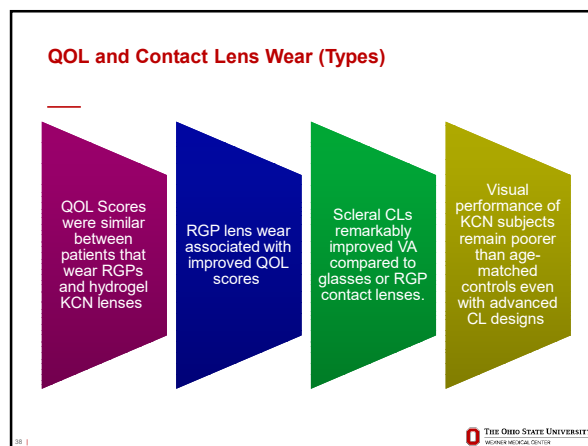
"Patients with keratoconus who are able to wear contact lenses are more **optimistic, extroverted and communicative** than those who cannot wear them, suggesting the **relationship between personality and satisfaction with optical correction...**" Morerira et al (2007)

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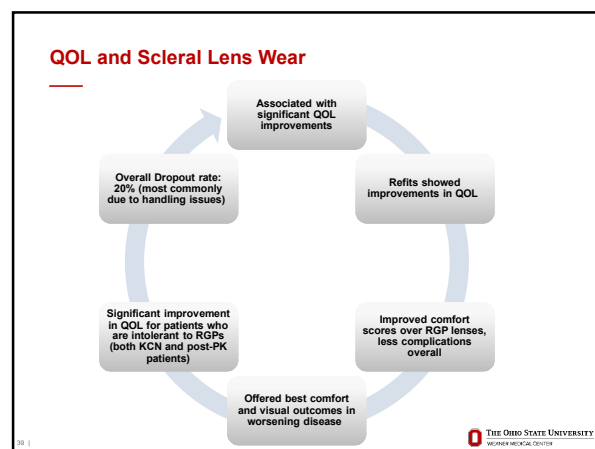
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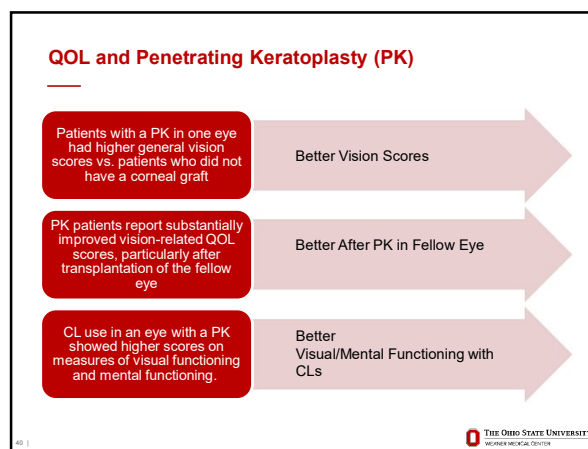
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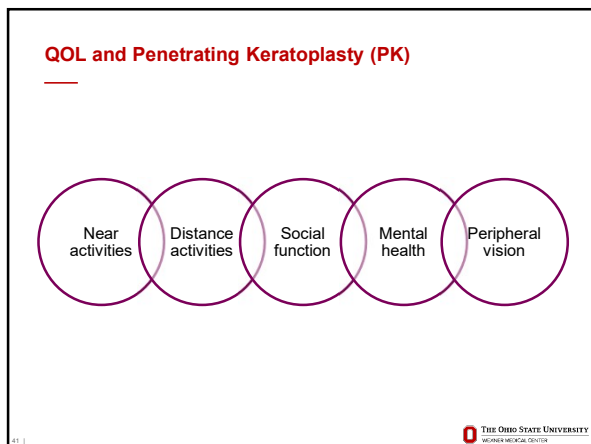
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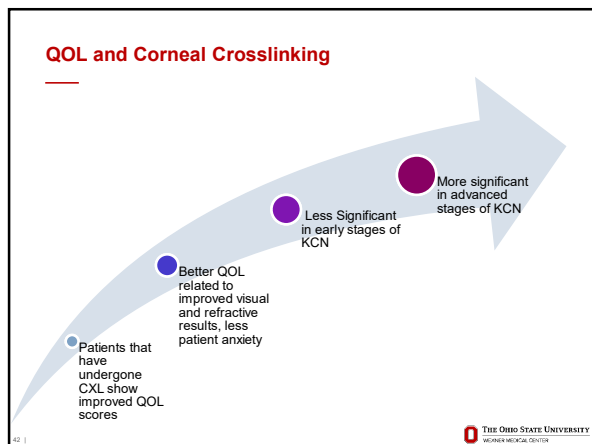
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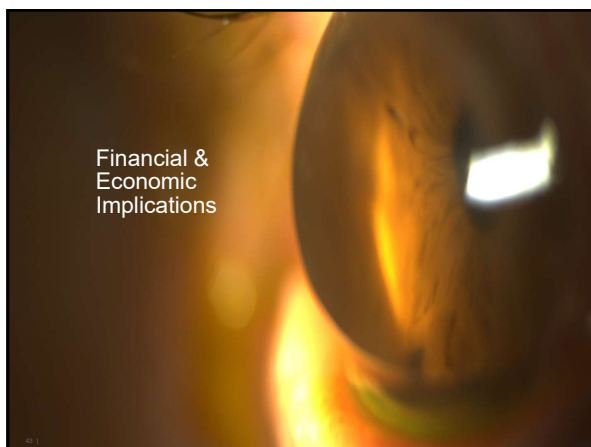
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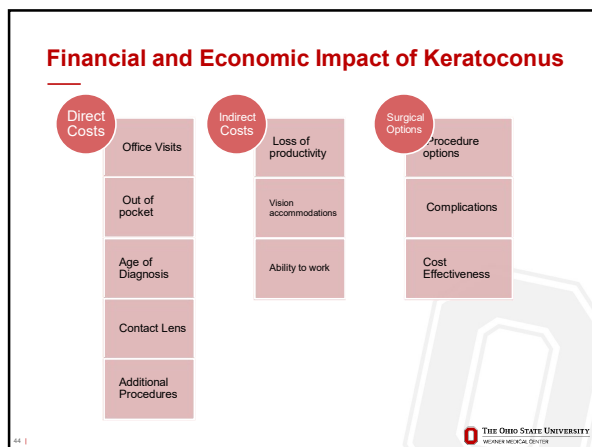
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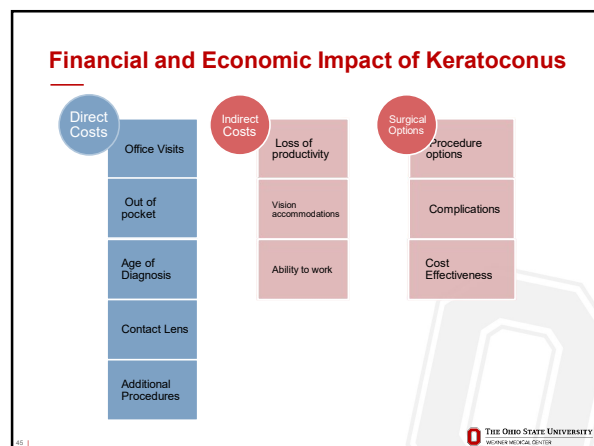
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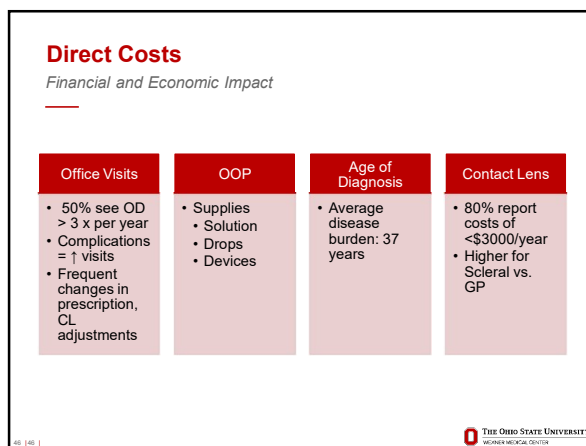
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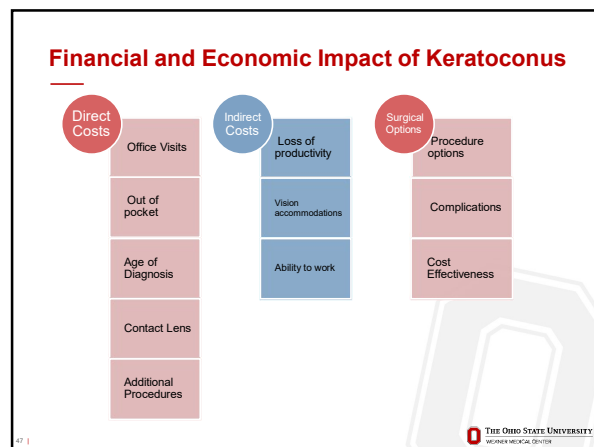
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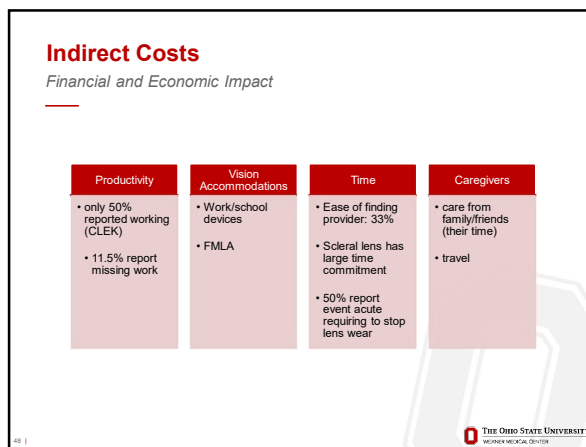
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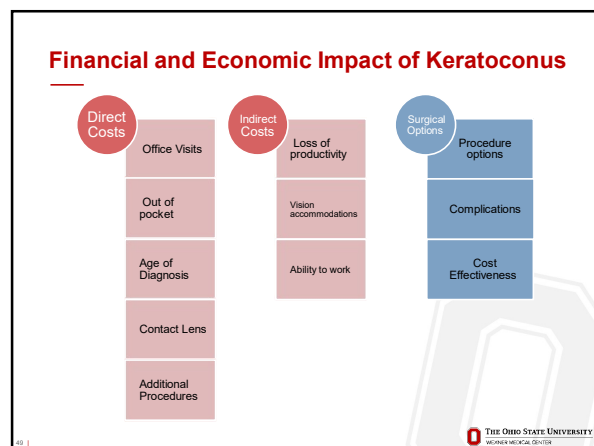
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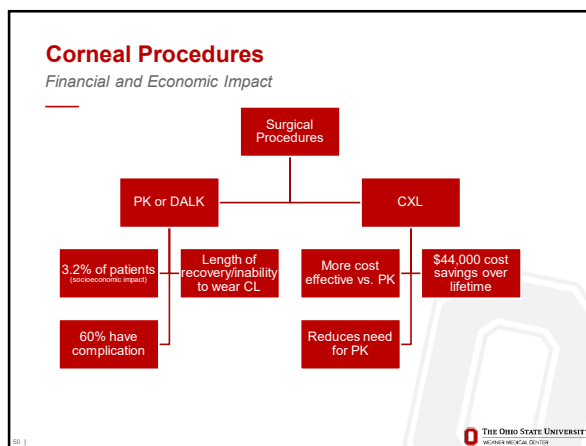
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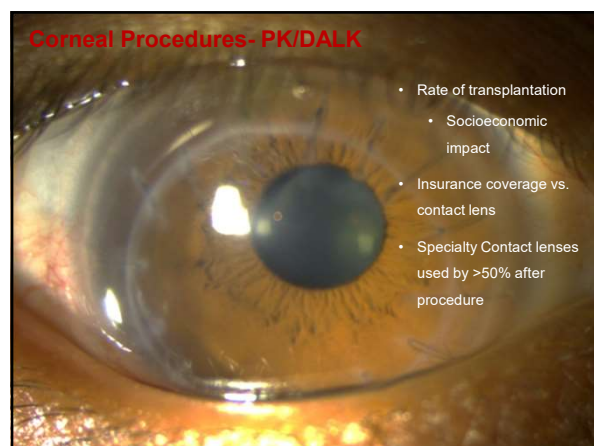
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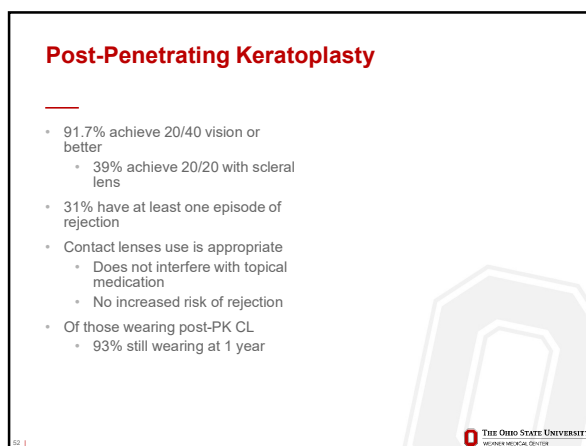
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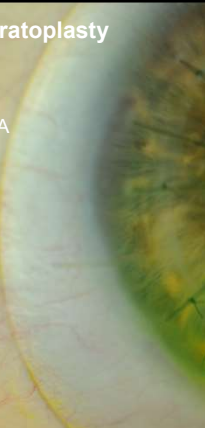
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Post-Penetrating Keratoplasty

- Post- PK patients note VR-QOL remains impaired despite good VA
- QOL impact on inconvenience of being out of CL, complications
- 10% of patients regret procedure
- Having PK is associated with QOL decrease




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DALK vs. PK



Outcomes comparable in:

- Best corrected vision
- Refraction
- Higher order aberrations
- Contrast sensitivity



DALK

- Less endothelial cell loss
- Less risk of graft rejection
- Less IOP issues post-op


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Assessing Cost-Effectiveness

Quality adjusted life years gained = QALYs

- Enables policy maker to compare efficiency of all measures that affect human health regardless of medical condition targeted by a given treatment
 - Increases morbidity, mortality and health years gained
- The number of years gained is adjusted by applying 'weight factor' to the number of life-years lived with a certain diagnosis
 - Weight factor of 0 = death
 - Weight factor of 1 = perfect health
 - Estimates the patient's QOL in their health state
- Difficult with ocular conditions
 - VA can be variable between eyes
 - Subjective quality of vision



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Cost Effectiveness

PK vs DALK

DALK	PK
<ul style="list-style-type: none"> Twice as long procedure time Lower insurance reimbursement/RVU Lower Eye Bank fee Less complications post-op Less office visits More cost effective 	<ul style="list-style-type: none"> Shorter procedure time Higher Eye Bank fee More complications post-op \$1700 More likely to repeat

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Financial and Economic Impact- PK/DALK

How can we help?

Pre-PK/DALK

- New CL patient
- Contact lens trial before PK eval
- Expectations for patient
- Communicate with corneal specialist
- Existing CL patient
- Risk/Benefit
- Plan for refit following procedure /Insurance

Post-PK/DALK

- Goals with refit
- Explain to patient importance of follow up
- Communication with corneal specialist
- Anterior segment monitoring

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Is CXL Cost- Effective?

- CXL studies show:
 - Safe
 - Reduces need for PK
 - Insurance can be limiting factor
- Effective?
 - Yes – but studies unable to quantify duration of effectiveness
 - Must make assumptions for QALY calculations
 - Vision stability
 - Progression would have happened if CXL not performed
 - Normal KCN stabilization age
 - Patient perspective : vision is more relevant to outcome versus duration

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Financial and Economic Impact

CXL

- \$44,000 savings over lifetime
- \$4,200 reduction in cost to patient
- \$150 million in savings for US prevalence
- Patients self report improvements:
 - VR-QOL
 - Driving
 - Role limitations
 - Mental health
 - Dependency on others
- Reduces need for PK

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Financial and Economic Impact- CXL

How can we help?

Pre- CXL

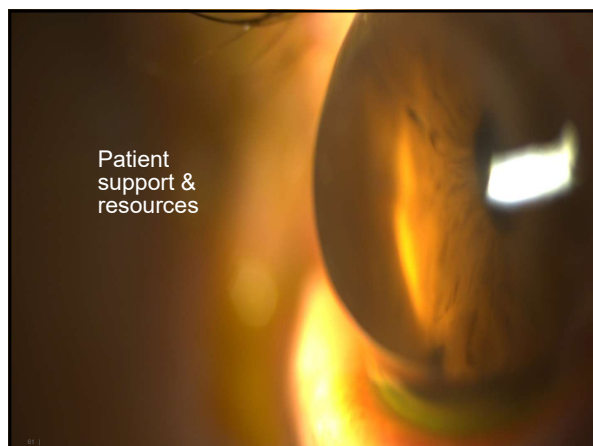
- Consistently monitoring topography + pach
- Communication with corneal specialist
- Patient expectations

Post- CXL

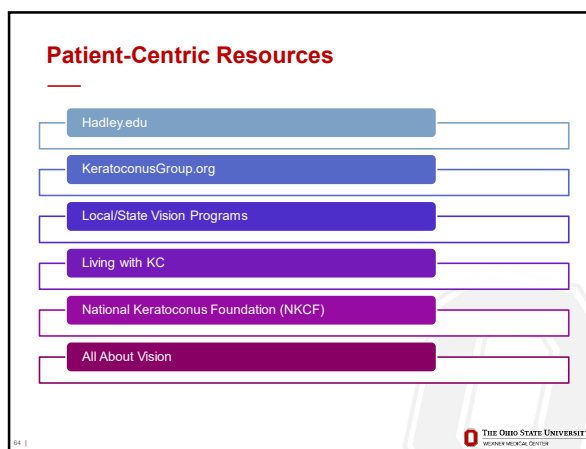
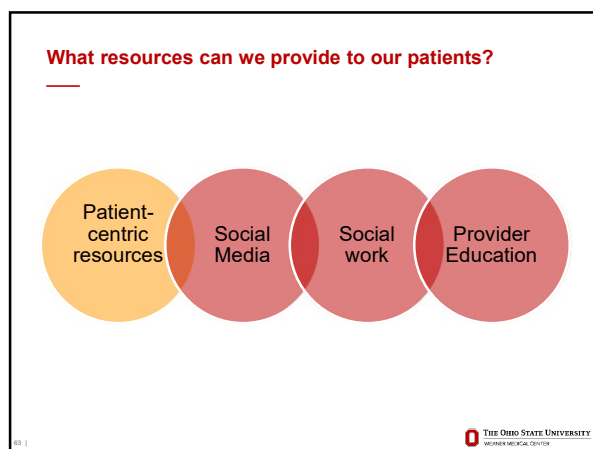
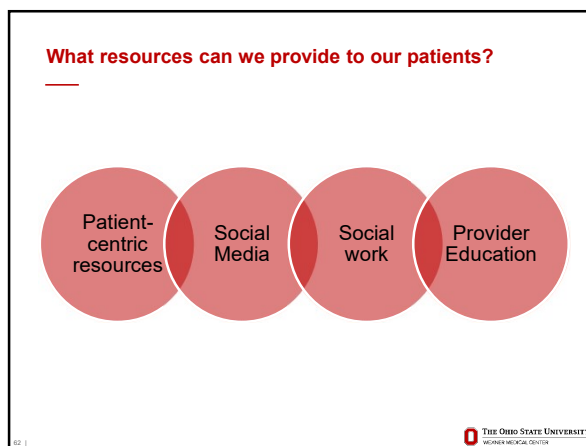
- Need for refit
- Expectations

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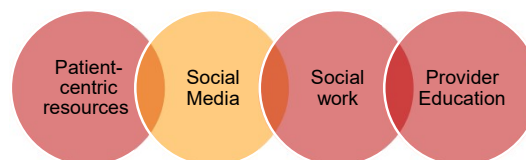
Patient Print resources



- Patient handouts in office
- List of links/websites
 - QR codes
- Be mindful of acuity

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What resources can we provide to our patients?



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Social Media Resources



- Connection with other KCN patients
- Provider search
- Troubleshooting
- Sharing their story
- Patient education/webinars
- Treatment options

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Health Related Information & Internet

- 80% of internet users search for health information online
- Allows for unrestricted sharing and distribution of knowledge

Sumayyia et al

- 73% of patients said information would influence their health status
- 54% searched on behalf of family member
- 27% used social media to save time contacting their provider
- 38% would rely on person from social media's experience



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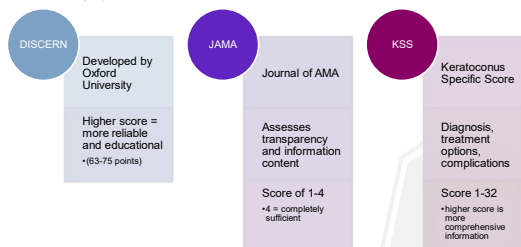
Who is uploading the Keratoconus content?

Content Creator	Content Types
<ul style="list-style-type: none"> • Optometrist/Ophthalmologist • 40-50% • KCN patient • 18-25% • Health Channel/institution • 20-30% 	<ul style="list-style-type: none"> • Informational • Patient experience/Testimonial • Educational Purpose

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Is the content reliable and accurate?

- Content can be objectively evaluated for reliability and accuracy
- 3 scoring systems



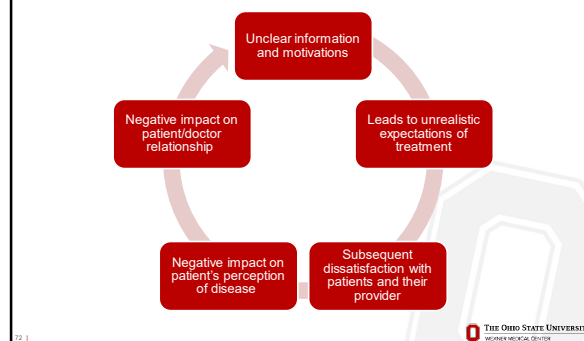
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Reliability of Social Media Health Information

Ozdemir et al	Çetinkaya et al	Bozali et al
<ul style="list-style-type: none"> • 9/2020 • DISCERN: lowest • JAMA: lowest • KSS: 6.4 • 13% Misleading • "curative" treatment • mostly regarding CXL • 48% was uploaded by providers • 29% testimonials/patients • 19% promoting unproven treatment 	<ul style="list-style-type: none"> • 1/2021 • DISCERN: 2nd lowest • JAMA: 2nd lowest • Scores are higher when uploaded by institution or doctor • 33% did not mention any treatment • 8% mentioned CL 	<ul style="list-style-type: none"> • 2021 • DISCERN: 2nd lowest • JAMA: lowest • minimal useful information • no significant benefit to patients

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How misleading content impacts patients



72

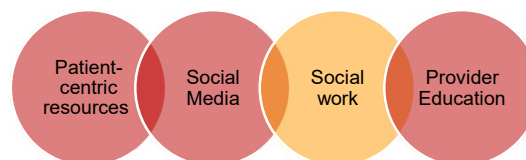
How can we improve social media content?

- Clearly label if patient was paid or compensated for testimonial
- Create content in segments
- Label "for patients" or "for HCP"
- Beware of misleading content
- Increase educational and unbiased content



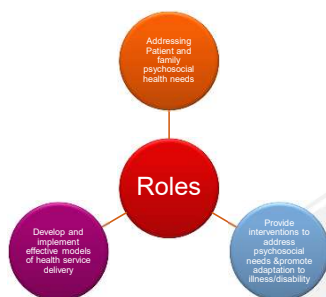
73

What resources can we provide to our patients?



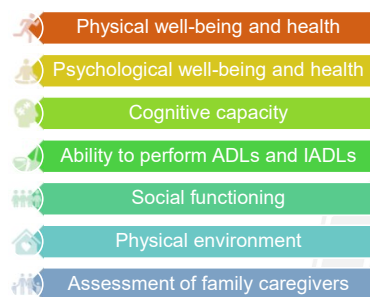
74

Role of Social Workers



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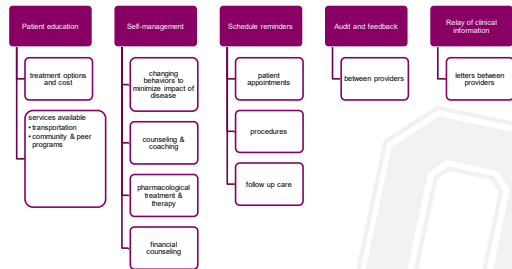
Social Work Approach for Chronic Conditions



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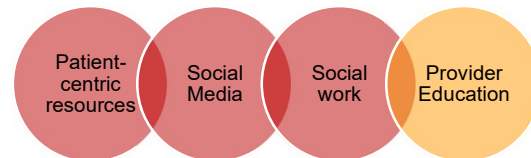
Care Collaboration – ECP + Social Workers

Definition: deliberate organization of patient care activities between 2 or more participants and the patient, to facilitate appropriate delivery of health care services



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What resources can we provide to our patients?



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Patient education- Patient perspective

- Purpose:
 - Increases patient knowledge, decreases anxiety, increases patient satisfaction, increases clinical outcomes
- if patient is not directly asked, they are reluctant to raise questions
 - Patient assumes we will have told them anything relevant
- Patients worry they will appear foolish for asking more questions
 - Do not want to take up more time
- Culturally specific information is preferred and increases retention of knowledge

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Keratoconus Patient issues with education

Most patients are aware of their condition but note explanation was unsatisfactory

Patients usually are dissatisfied with education from doctor

Patient's biggest concern is "if" they will go blind

Patients prefer **patient centered** education

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Patient centered education style

- AKA: Understanding & positive
 - Convey the information according to patient needs & cues
 - Check that patient is understanding the information
 - Show empathy
- Patients that view their provider as emotional and partnership oriented had higher satisfaction, suffered less anxiety and depression
 - Schmid et al 'Recipients' perspective on breaking bad news: how you put it really makes a difference."

81 |



81

Patient Education



82 |



82

Improving patient satisfaction & education

- Be interested, empathetic, attentive, supportive
- Non-dominant/not intimidating
- Provide supportive information
- Do not rush, leave room for questions
- Convey hope
- Explain how you and the patient are a team
- Lay out plan and direction for future
- Regularly check on information needs of longstanding patients

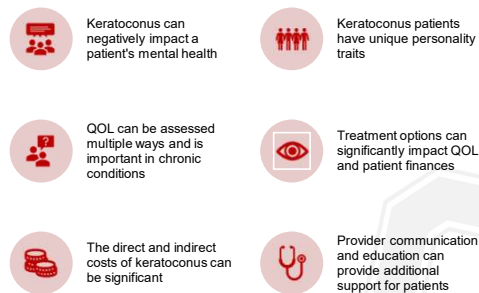


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Conclusion



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References

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