### Psychological Effects of LASIK Complications Presented by Roger D. Davis, PhD

### My credentials:

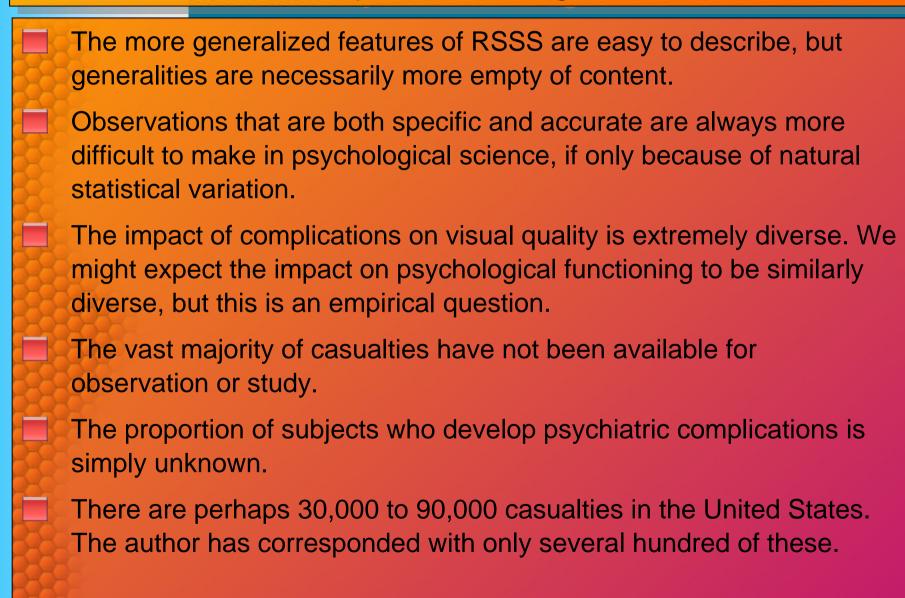
- Coauthor of most widely used theoretically based inventory used to assess personality disorders and classic psychiatric disorders for adults and adolescents in United States.
- Coauthor of "Disorders of Personality: DSM-IV and Beyond", considered the classic text in the field of clinical psychology, for both professionals and graduate students.
- Coauthor of first undergraduate text to introduce personality disorders to college students, "Personality Disorders in Modern Life."
- Co-editor of the "Oxford Textbook of Psychopathology," a graduate-level text that has been used at Harvard University, among others.
- Dry eye, fluctuating quality of vision, double vision, and symptoms of Depression and PTSD following LASIK in 1998, lasting to the present day.

## **VERSION 1.6: 3-17-04**

### **NOTICE:** Limitations of this Presentation

-5	The contents of this presentation are not the result of published empirical research.
Ì	Instead, the contents are based upon
3	My own correspondence with 200-300 LASIK casualties across the United States.
3	An intensive review of the short "Lasik biographies" of over 40 refractive surgery patients, culminating in enough text to fill a novel.
3	Periodic review of postings made by patients at the Surgical Eyes bulletin board at www.SurgicalEyes.org.
3	My expertise as a psychological researcher, therapist, and designer of psychological tests now in use everyday across the United States.
3	My own experience as a Lasik casualty.
ESS	Because the contents of this presentation are not based upon empirical research, they should be viewed not as fact, but as provisional hypotheses to be sustained, or not, by the scientific method.
	As such, these contents are subject to revision, amplification, or even retraction. Science is never static.
LETT	These limitations do not constitute a "fine print legal disclaimer," but should be taken seriously.
3	

### RSSS: Barely Scratching the Surface

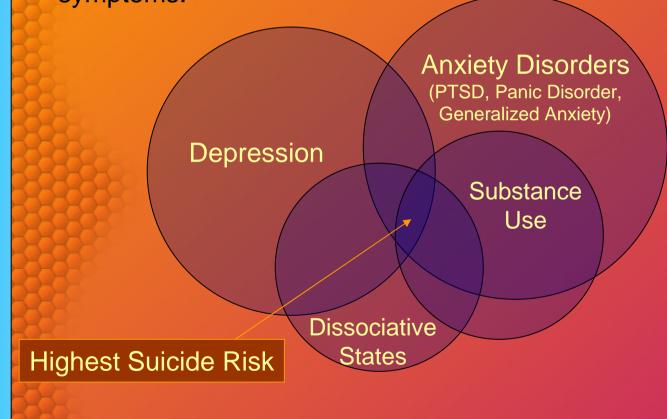


# Refractive Surgery Shock Syndrome:

Formal Diagnostic Properties

### Refractive Surgery Shock Syndrome (RSSS)\*

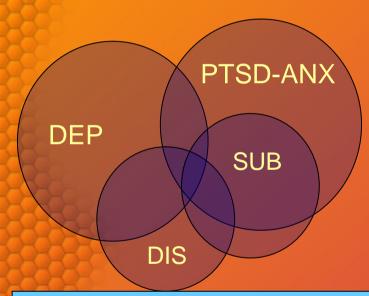
• At the level of diagnoses, RSSS is probably a highly heterogeneous syndrome which can combine depression, PTSD, other anxiety disorders, substance abuse, and occasionally, certain Dissociative symptoms.



\* The name
"Refractive Surgery
Shock Syndrome"
was coined by Gary
Vatter in a letter to Ron
Link in February, 1999.

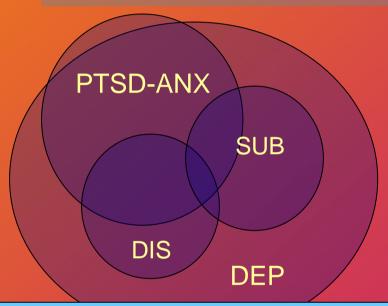
# Formal Properties of RSSS: A "Tight" or "Loose" Diagnostic Syndrome?

"Loose" Syndrome



As a loose syndrome, RSSS patients with similar degrees of damage would develop depression, PTSD, and substance use either in combination or isolation, determined by premorbid characteristics of the patient and contextual factors (i.e., family, work, doctor-patient relationship).

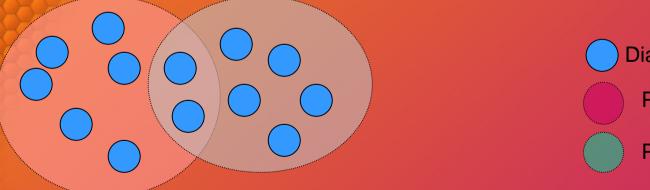
"Tight" Syndrome



As a tight syndrome, RSSS patients with similar degrees of damage might develop depression first, then develop symptoms of PTSD and other disorders as level of visual damage increases. Symptom development would have its own intrinsic order. Here, the nature of the disorder determines its manifestation.

#### Prototypal Model of DSM is Appropriate for RSSS

- Prototypal model adopted in DSM-III in 1980 by the American Psychiatric Association.
- Intended to recognize and accommodate the heterogeneity of patients sharing a diagnosis.
  - Patients with the same diagnosis may share few diagnostic symptoms.
  - And therefore, differ greatly in their clinical presentation, sharing a diagnosis, but having few symptoms in common.



Diagnostic Criterion

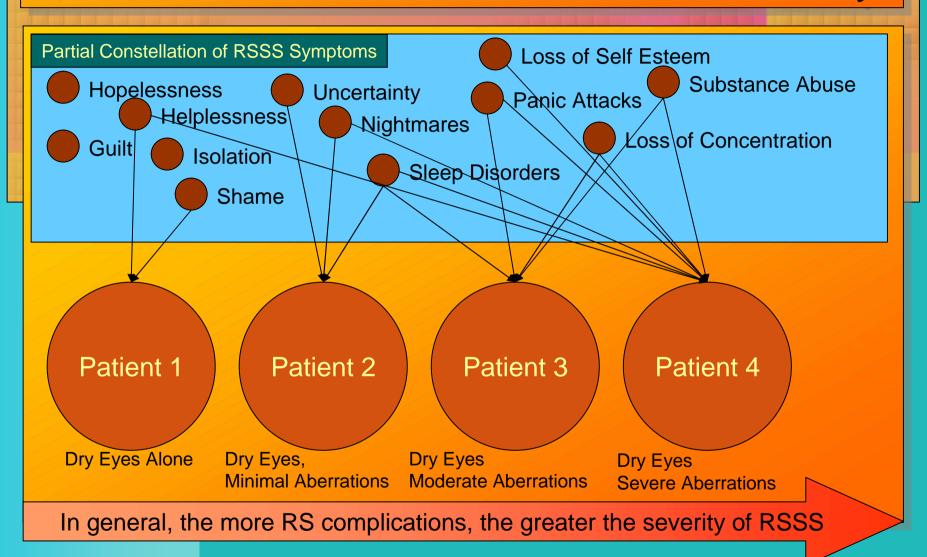
Patient 1

Patient 2

# Formal Properties of RSSS as a Diagnostic Syndrome

- Hierarchical structure: RSSS includes and subsumes depression, suicidal ideation, PTSD, other anxiety disorders, and some Dissociative symptoms.
- Because RSSS is probably a highly heterogeneous "loose syndrome"...
  - Few patients will exhibit the full symptom picture.
  - Some patients will exhibit only a single DSM diagnosis (e.g. Depression)
  - And most patients will probably combine symptoms from various DSM diagnoses.
  - Some patients may exhibit diverse symptoms that would not qualify them for any single DSM diagnosis, but nevertheless be "diagnosed" as RSSS.

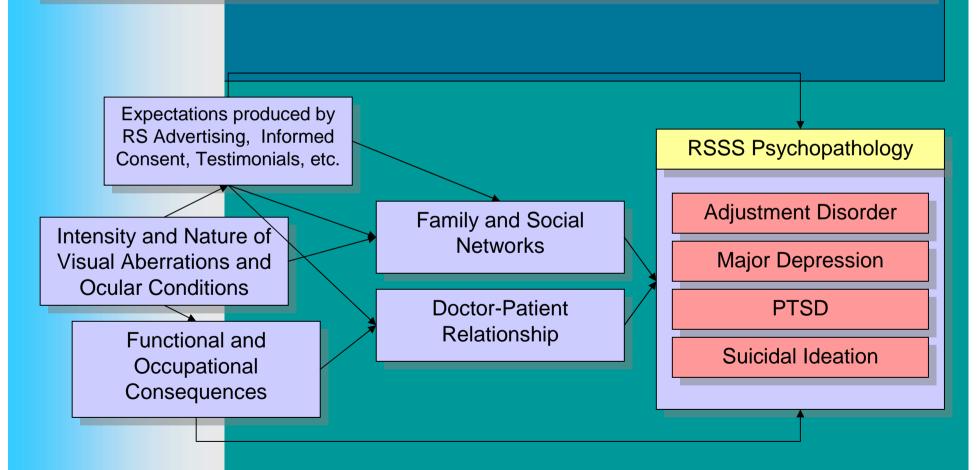
### RSSS exists on a Continuum with Normality



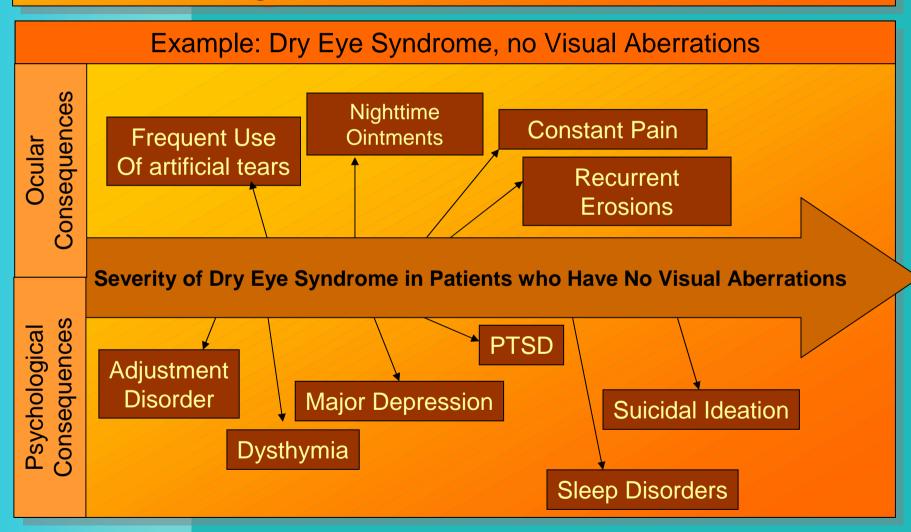
# Refractive Surgery Shock Syndrome:

Mapping Visual Aberrations and Ocular Conditions to Psychopathology

RSSS: Because Complications of RS Affect the Total Person, the Causal Picture is a Complex Mapping of Visual Aberrations, Ocular Conditions, and Personality and Social Factors to Psychopathology



## If Severe, a Single Complication is Enough to Induce Severe RSSS



# Example: Interaction of Dry Eye Severity and Quality of Vision in Producing RSSS symptoms

Research Hypothesis: As dry eye syndromes grows more severe, quality of vision, daytime pain, induced sleep disorders, and their collective functional consequences begin to make independent contributions to the severity of RSSS

**Quality of Vision Issues** (as tear volume decreases, visual aberrations that might be masked at normal tear volume increase in severity)

**Daytime Pain** (all pain caused by dry eye, including scratchiness, feeling of dried mucus stuck in the corners of eyes, painful blinking, pain when opening eyes in the morning, recurrent erosions)

**Induced Sleep Disorders** (broken sleep leads to REM deprivation, daytime tiredness, loss of attention and concentration, irritability, lack of "psychological resiliency" facing normal hassles)

**Functional Consequences** (all the functional consequences of the above, that is, their impact on daily functioning, particularly in occupational settings and intimate relationships)

# Refractive Surgery Shock Syndrome:

# Observations Relevant to Specific DSM Disorders

# Premorbid Psychological Conditions Predispose to the Development of RSSS

- Premorbid psychological conditions predispose to the development of RSSS, but are not necessary for the development of RSSS.
- Surgeons should disqualify individuals with any history of depressive disorders or adjustment disorders of any kind, or any individual taking psychiatric medications.
- Individuals with existing psychological conditions more likely to develop full-blown symptom picture of RSSS, featuring multiple comorbid DSM-IV-TR diagnoses.
- Individuals taking SSRI antidepressant medications may not be able to take these medications after refractive surgery, because of dry eye.
- Individuals taking SSRI antidepressant medications may find their vision is worse if the dosage is increased, due to pupillary dilation.

#### Development of PTSD

- Who is likely to develop PTSD?
- According to the National Center for PTSD:
  - "Those who experience greater stressor magnitude and intensity unpredictability, uncontrollability, sexual (as opposed to nonsexual) victimization, real or perceived responsibility, and betrayal."
  - Unpredictability: Informed consent does not communicate the reality of complications. Pictures are not shown to patients, nor is the comorbidity of complications made real to candidates.
  - Uncontrollability: Following surgery, patients have little sense of control over their rehabilitation. Many patients become nomads going from doctor to doctor, looking for solutions that never arrive.
  - Responsibility: Patients are blamed by others who do not understand their situation, and eventually many blame themselves, if only for trusting their doctor in a "caveat emptor society."
  - **Betrayal:** Advertising and marketing provide a baseline for the development of expectations. The reality of visual aberrations and the inadequacy of informed consent create feelings of betrayal and deception.

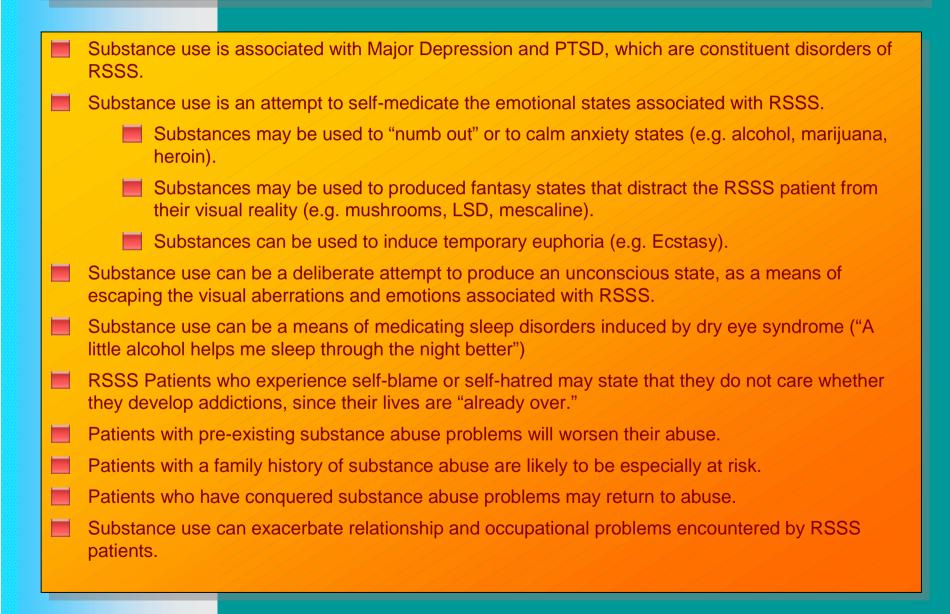
### RSSS PTSD: Dissociative Symptoms

Why? Dissociative symptoms occur because the patient cannot cope emotionally with the reality of what has happened. Simply put, the mind finds it necessary to distort reality, since accepting it would lead to psychological collapse. Decrease in Emotional Responsiveness: RSSS PTSD patients are "unable to process" what has happened to them, and yet, unable to "get away from their eyes." They may seem detached, unable to find pleasure in anything, numb. Patients take a long time to response to stimuli (e.g. have difficulty keeping up a conversation). In theory, extreme case might exhibit catatonic states of near complete unresponsiveness. Dissociative Amnesia: RSSS PTSD patients may be unable to recall facts or events associated with their surgery. These effects are produced primarily by the cognitive effects of the stressor (and need not be produced by tranquilizers given on the day of surgery). Moreover, Dissociative amnesia is not limited to the day of surgery, but can occur with post-op visits or RGP fittings. Feelings of Unreality (Derealization): RSSS PTSD patients may feel as if time has slowed down, as if the surrounding world is somehow unreal ("Twilight Zone effect"), or that they are living in a dream Feelings of unreality are characteristic of DSM-IV Acute Stress Disorder and PTSD. Feelings of unreality are exacerbated by visual aberrations, which distort perception and add to feelings of surrealness. **Feelings of Depersonalization.** RSSS PTSD patients may feel that they are looking at the world

from outside their bodies, or that they are someone else ("I didn't believe it could be happening to

me"), or that they are functioning like an automaton or machine.

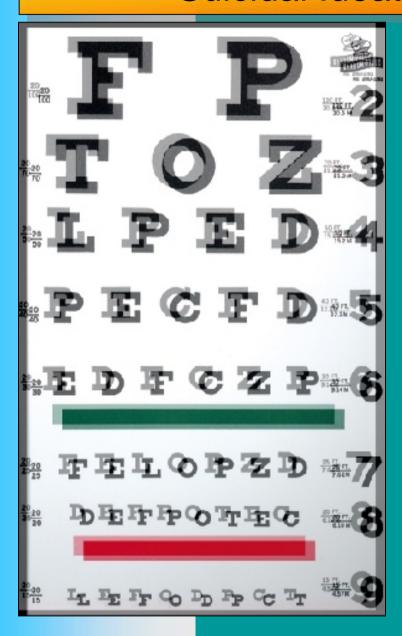
#### **RSSS: Substance Use Disorders**



#### **RSSS: Self-Destructive Behaviors**

- Self-Destructive behaviors are the result of intense self-blame, or even self-hatred, induced by RS complications.
- Self-blame and self-hatred result from a sense of shame and powerlessness.
- Some self-destructive behaviors also function as a "cry for help."
- Some self-destructive behaviors are intended to produce a crisis that can distract the patient from the agony caused by their vision.
- Some patients have pre-existing self-destructive traits which are amplified by RS complications (e.g. Borderline personality traits), however, pre-existing self-destructive traits are not necessary for self-destructive behaviors to be produced by complications.
- Receiving hostility or blame from others (i.e., family members or medical professionals) escalates the desire to do harm to oneself.
- Self-destructive behaviors include: Self-mutilation (cutting), eating disorders, sexual promiscuity, and potentially life-threatening activities, such as excessive drug or alcohol use (including the development of addictions) reckless driving (e.g., driving in conditions that are hazardous given the RSSS patient's visual competency), gambling, buying sprees, suicidal gestures, and possibly domestic violence.
- Self-destructive behaviors may spontaneously appear or exacerbate on the anniversary of the patient's LASIK.

#### Suicidal Ideation with 20/20 Vision



- Visual acuity is meaningless as a predictor of psychological adjustment post-Lasik.
- Patients can have 20/20 or better vision, and still experience the desire to end their own life.
- Suicidal ideation expresses a desire for relief.
- In general, patients who are more damaged will have more suicidal ideation.
- Patients who are told that "nothing is wrong with your eyes" experience feelings of helplessness and hopelessness, which escalate suicidal ideation (see Suicidal Cognitions slide).
- Patients whose visual complaints are validated by medical professionals probably experience less suicidal ideation ("Finally, someone understands!")
- In general, the less predictable the patient's vision, the greater the level of suicidal ideation (and of all RSSS symptoms).
- Patients who have fluctuating vision are likely to experience greater levels of suicidal ideation, because they experience greater loss of control over their own lives.
- Patients who receive higher levels of social support at home and at work can be expected to experience lower levels of suicidal ideation.

## RSSS: Cognitions Associated with Suicidal Ideations

"There will never be a "There is nothing I enjoy "Nobody understands what I'm going through." in life anymore." solution." "I will never be the same "My doctor just wants to get again." rid of me." "People hate me because "I am the victim of a of what happened" medical cover-up" Suicidal Ideation "I will never fulfill my "I can never make enough purpose in life." money to get fixed." "Why did God allow this to "I can't take another day of happen to me?" this." "The industry doesn't care "I am completely alone in And many, many more... about patients." this"

# Refractive Surgery Shock Syndrome:

**Emotional Aspects** 

### **Emotional Aspects**

Shame Guilt Anger Frustration Disappointment Hopelessness and Helplessness Defectiveness or Worthlessness Victimization **Nihilism** 

# Refractive Surgery Shock Syndrome:

## Intrapsychic Effects

(effects internal to the mental functioning of the person)

### RSSS: Effects on Self-Image and Self-Esteem

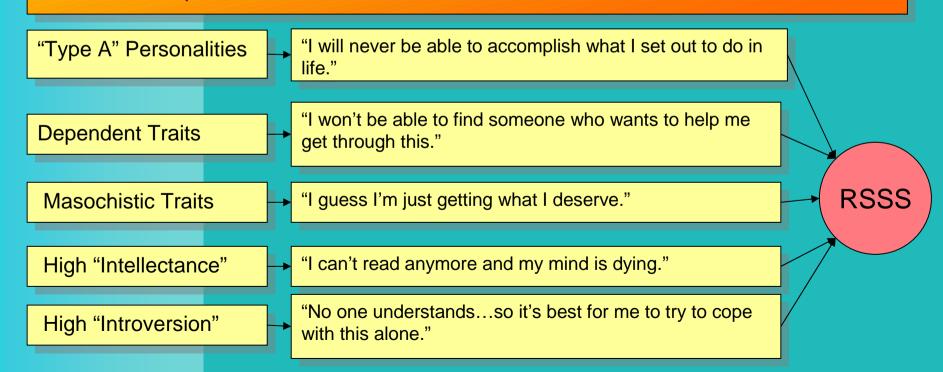
Feelings of Worthlessness	
Feelings of Uselessness	
Feelings of Intense Shame	
Feelings of Nihilism	
☐ "My life has been for nothing"	
Unable to accomplish personal goals in life.	
🔲 "I am a failure."	
☐ "I will never live up to my potential as a human being."	
"I will never amount to anything."	
Feelings of being unwanted by others, or no longer esteemed by them.	
"I can never make my parents or spouse or children proud of me."	
= "I am a burden to those who love me."	
"I have let my parents or spouse or children down."	
Feelings of being trapped in a situation no one understands.	
"No one understand what I'm going through."	
"No one cares about me enough to take time to understand."	

## Psychological Defense Mechanisms in RSSS: Cognitive Dissonance and 20/Denial

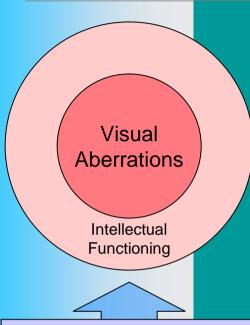
- Cognitive Dissonance (Festinger, 1957) is one of the most widely discussed theories in social psychology.
- CD holds that inconsistency between attitudes and behaviors produces internal psychological conflict, which must be reduced. The intensity of the dissonance is affected by the number of dissonant beliefs and the importance attached to these beliefs.
- Examples of Dissonance:
  - "Yeah, I have to use eye drops all day, but I'm still glad I had LASIK."
  - "I have double vision, but at least I don't wear glasses anymore."
  - Some patients are genuines successes, but an unknown number are in 20/Denial.
  - Those in denial do not contribute to complication rates, and make the surgery appear safer and better than it really is.
- Denial is an adaptive psychological defense intended to prevent psychological collapse following LASIK complications.
  - Patients who are in denial probably need denial.
  - Confronting patients in denial may lead to anger and increased denial, or increased psychological symptoms.
  - Probably best to leave denial intact and let such patients cope on own timetable.

# Personality Traits Channel Manifestations of Symptoms of RSSS

- Personality functions as the "immune system" of an individual's "total psychological matrix," therefore...
- Individuals with difference personality traits develop different mediating cognitions, and may go down somewhat different psychological pathways in the development of RSSS.



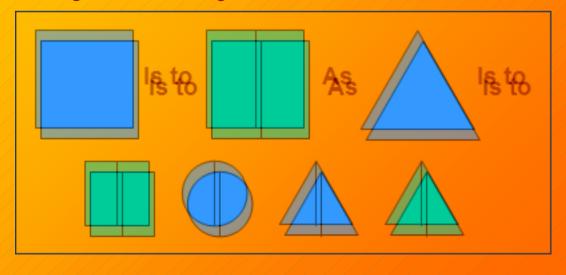
### RSSS: Level of Intellectual Functioning: #1



In the Multiaxial Model of the DSM, Axis II is concerned personality and intellectual functioning.

- Effects on Intellectual Function are both Direct and Indirect.

  Because intellectual functioning rests on the ability to synthesize sensory information accurately across a variety of sensory modalities, RS casualties can be expected to perform lower on IQ tests than before surgery.
- In particular, perceptual speed can be dramatically reduced.
- Test anxiety may be severe, since patient is worried about performing at pre-RS level.
- Patients may seems confused because the visual information they are receiving is confused: Hard to distinguish what is signal and what is noise.

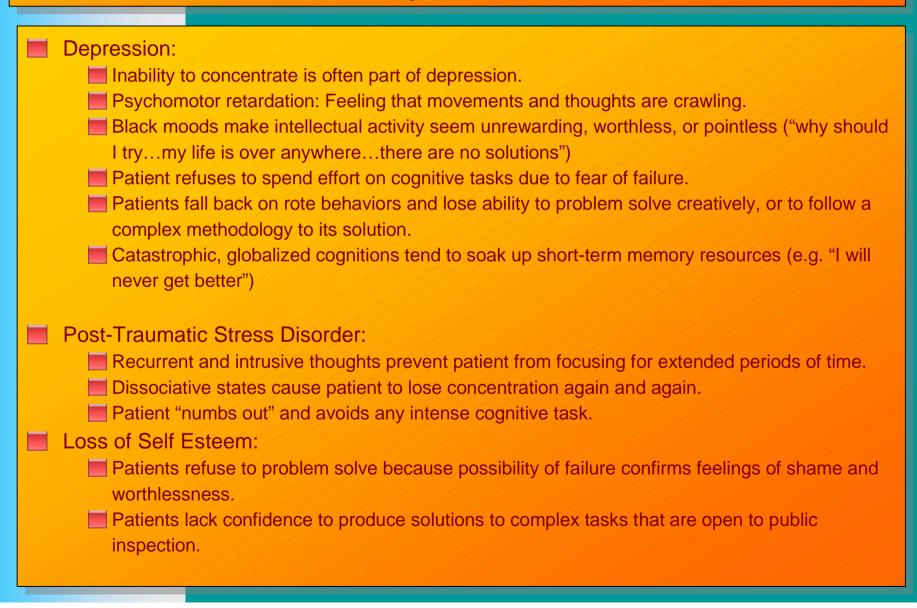


# RSSS: Effects on Intellectual Functioning also Mediated by DSM Disorders

#### Depression:

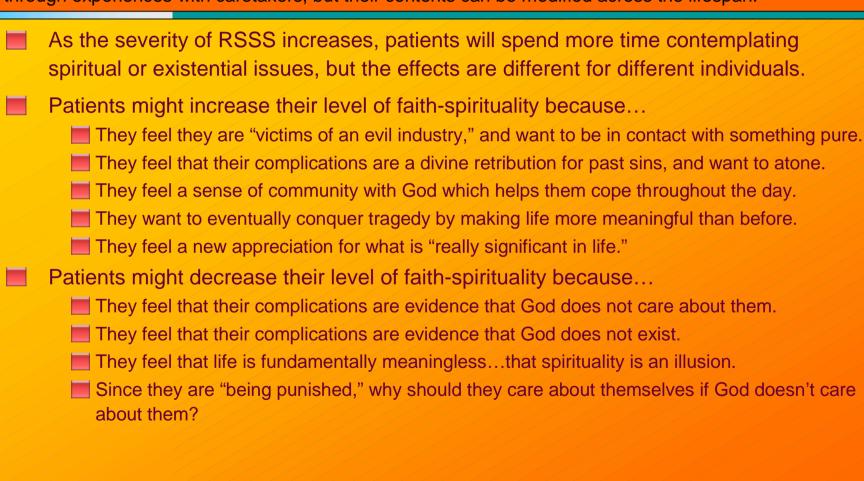
- Inability to concentrate is often part of depression.
- Psychomotor retardation: Feeling that movements and thoughts are crawling. ("I just can't think anymore.")
- Black moods make intellectual activity seem unrewarding, worthless, or pointless ("why should I try...my life is over anywhere...there are no solutions")
- Patient refuses to spend effort on cognitive tasks due to fear of failure, or because failure would provide objective confirmation regarding loss of ability.
- Patients fall back on rote behaviors and lose ability to problem solve creatively, or to follow a complex methodology to its solution.
- Catastrophic, globalized cognitions tend to soak up short-term memory resources (e.g. "I will never get better")

# RSSS: Effects on Intellectual Functioning also Mediated by DSM Disorders



#### RSSS and "Core Beliefs": God

NOTE: "Core beliefs" are present in the personality structure of every human being, but cannot be proven or disproven on an empirical basis. Most of these beliefs are formed during early childhood through experiences with caretakers, but their contents can be modified across the lifespan.



#### RSSS and "Core Beliefs": Human Nature

NOTE: "Core beliefs" are present in the personality structure of every human being, but cannot be proven or disproven on an empirical basis. Most of these beliefs are formed during early childhood through experiences with caretakers, but their contents can be modified across the lifespan.

Because of the inadequacy of informed consent and RS advertising, individuals who held strong beliefs that human nature is fundamentally good may suffer greater intensity of RSSS symptoms. Individuals who believed that human nature is fundamentally good may modify their beliefs: They now believe that only some human beings are fundamentally good, whereas others are fundamentally greedy, selfish, or evil. Ironically, individuals who previously believed that human nature was ultimately selfish may be somewhat immunized against the development of PTSD symptoms: There is less trust to break. Individuals who report greater feelings of deception and betrayal from the medical community are less likely to continue to believe that human nature is fundamentally good. Individuals who feel they have received care and compassion from the medical community are more likely to retain their belief that human nature is fundamentally good. Individuals who receive greater social support at home and at work are more likely to retain their belief that human nature is fundamentally good.

### RSSS and Acquired Beliefs: The FDA

NOTE: Beliefs and truth are fundamentally different. Truth is an epistemological construct, whereas belief is a psychological construct. Whether a belief is true is irrelevant to its status as a psychological construct. Some beliefs will find consensual support and be termed "true," others will not, and still others will become highly controversial.

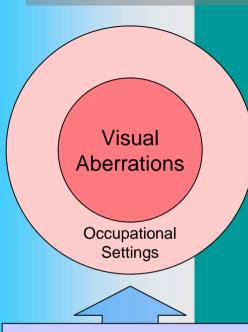
The greater the degree of visual damage, the more likely it is that patients will feel that the FDA
Is inadequate as a protector of the public trust.
Is corrupted by special interests and insider relationships.
Does not understand how complications really affect one's life.
Is exceedingly narrow in its view of what constitutes a complication.
Approves the use of medical devices based on inadequate science.
Does not care about patients.
Responds to medical crises only when it is too late.
Is simply ineffective in its role.

# Refractive Surgery Shock Syndrome:

# Interpersonal and Contextual Effects

- Interpersonal Behavior
- Social Cognition
- Marital and Family Effects
- Effects in Occupational Settings

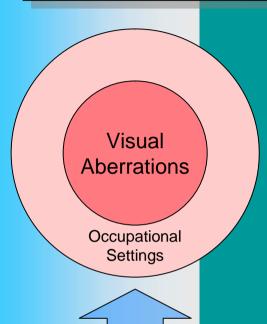
#### RSSS: Effects at Work



In the Multiaxial Model of the DSM, Axis IV is concerned with the psychosocial environment. Axis IV contextualizes the conditions of Axes I, III, and III, changing their meaning, manifestation, course, and severity. Occupational settings are considered to be part of Axis IV.

- Co-workers do not understand what the patient is going through.
- Patients will receive sympathy at first, but sympathy can turn to anger if patient is perceived as chronically "not pulling your weight."
- Tactless co-workers exacerbate RSSS by saying, "I had LASIK and mine turned out just fine!"
- Bosses become frustrated because they feel they can no longer count on the employee.
- Patients worry about letting down those they admire.
- Patients feel frustrated by their vision, and worry about falling behind and about increasing pressure to perform at premorbid levels of functioning.
- Patients may spend incredible amounts of psychological energy trying to "put on a happy face," and eventually collapse under the burden.
- Patients worry they will no longer be able to fulfill their potential in life, but instead must just try to "hang on."
- Patients worry that bosses will tire of granting them time off to pursue solutions that never seem to work.
- Patients worry that their situation is the object of office conversation behind the scenes, and frequently it is.
- Patients worry that if they lose their job, they will never get another one, or will get a bad recommendation.

### RSSS: Effects on Interpersonal and Social Skills



In the Multiaxial Model of the DSM, Axis IV is concerned with the psychosocial environment. Axis IV contextualizes the conditions of Axes I, III, and III, changing their meaning, manifestation, course, and severity. Interpersonal and social skills are, by definition, relevant to Axis IV.

- The DSM disorders which underlie RSSS have broad implications in the interpersonal domain.
  - Research shows that depressed persons eventually elicit anger from others if depression does not abate.
  - Significant others may feel rejected by patients who talk about their suicidal ideations: "You mean, you think our relationship isn't worth sticking around for?"
  - Much, much more.
- Some interpersonal consequences are mediated by cognitive effects of RSSS, so that RSSS patients simply have less sensitivity to subtle interpersonal cues than before refractive surgery.
  - Patients may be unable to discern facial expressions accurately at a conversational distance, or unable to see faces at any distance.
  - Patients are distracted by their visual distortions. These distractions compete for short-term memory resources and prevent patients from responding to subtle social cues.
  - Patients may seem pre-occupied with their visual problems, further distancing them from others.
  - Effective interpersonal behavior requires accurate internal models representing the mind state and motivations of others. Patients may be unable to "finish the processing" of interpersonal events due to intrusive thoughts and imagery.

### **RSSS: Effects on Social Cognition**





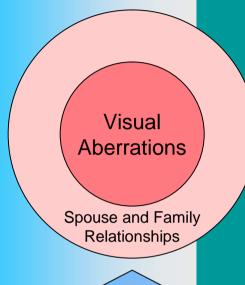


- Social cognition rests upon the ability to create accurate internal representations of the emotional states and agendas of others.
- Patients with RS complications may be unable to correlate facial expressions and emotional states, due to "visual interference."
- In general, the more subtle the emotional expression, the more visually damaged the patient, and the faster the pace of communication, the more difficult it is for the patient to behave with "social competence."
- Some patients may chronically "lag behind" when processing nonverbal cues…by the time the patient discovers what is happening, the conversation has moved on.
- RS-Induced deficits of social cognition have broad implications for performance in the workplace and in relationships, where accurate social cognition is paramount.
  - Such deficits affect how the patients responds to others.
  - And affect how others respond to the patient.

# Refractive Surgery Shock Syndrome:

Effects on the Family

### RSSS: Effects on Family Relationships



In the Multiaxial Model of the DSM, Axis IV is concerned with the psychosocial environment. Axis IV contextualizes the conditions of Axes I, III, and III, changing their meaning, manifestation, course, and severity. Spousal and Family relationships are considered to be part of Axis IV.

- Family members do not understand what the patient is going through.
- Patients will receive sympathy from family members at first, but this sympathy often turns to anger.
- Patients who cannot cope as well as family members would like may receive anger and rejection, leading to escalation of psychological symptoms in the patient, creating a vicious circle.
- Patients may be accused of being obsessed with their eyes.
- Patients may be told to simply "put it behind you."
- Anger about time and money consumed by search for solutions is manifested in relationships as loss of emotional intimacy and escalation of number and intensity of disagreements.
- Children may feel abandoned by the RSSS parent, and experience reduced educational achievement, or may even act out at home or at school.
- Non-RS spouse wonders "Where did my wife/husband go?" and resents caregiver burden.
- Both RSSS and non-RS spouse "want their old lives back," but neither knows how to achieve it.
- The RSSS spouse feels intense guilt as an emotional burden and monetary drain on the family.

### RSSS: Family and the Suicidal RS Patient

- RSSS family members may become depressed themselves because they cannot understand what has happened to their family, and do not want to "continue living like this."
- RSSS family members may no longer behave spontaneously around the patient, because they are too self-conscious about saying or doing something that might push the patient over the edge.
- RSSS family members worry about finding the patient dead, or have nightmares about finding the patient dead.
- RSSS family members may secretly try to prepare themselves emotionally for losing the patient.
- RSSS family members could sometimes secretly wish the patient would commit suicide, just so the family could have a sense of closure, and find emotional stability again. Such thoughts are normal, and most family members will instantly recoil in guilt when such thoughts cross their mind.
- RSSS family members may feel extreme guilt for not being able to help the patient, or find help for the patient.
- RSSS family members may feel abandoned by RSSS patients who talk about suicide...they may react with anger and distancing, even though the patient needs unconditional love and support.
- RSSS family members may become highly overprotective of the patient, refuse to allow the patient out of their sight, take total responsibility for the patient's needs, and otherwise "infantilize" the patient.

### RSSS PTSD: Family Exposure to Trauma

- The DSM-IV recognizes that learning of trauma to a loved one can be sufficient to cause produce symptoms of PTSD in family members.
- Spouse and children are exposed to RSSS PTSD through the RSSS patient.
- Because the RSSS patient is unable to recover, family may feel that the trauma is always in the present, even though the surgery occurred years ago.
- Family members may accuse RSSS patient of being irritable, easily enraged, unable to relax, distant or distracted, incapable of (or uninterested in) being sensitive to the needs of the family, unable to give love, preoccupied, or demanding.
- Family members may feel confused by, come to avoid, or even isolate the RSSS patient from family life.
- Family members may feel rejected because the RSSS patient wants to avoid talking about his or her feelings while being determined to avoid situations that are visually demanding (e.g. going out at night).
- The RSSS patient may be removed from family planning, because the RSSS patient feels life is over and there is nothing to look forward to.
- Family members may feel guilty and depressed because they are unable to help the RSSS patient, or because they must now manage family financial resources too closely to seek additional help for the RSSS patient (i.e., "enhancement" costs, contact lens fittings).
- Family members may feel betrayed because the RSSS patient is emotionally cold, isolative, and angry.
- If the RSSS patient is a primary financial resource, family members may worry about being helpless or stranded if the RSSS patient is no longer employable.
- Family members may find their own sleep disrupted by the RSSS patients nightmares, or inability to sleep due to dry eye pain (e.g. fumbling for eye drops in the middle of the night).

## RSSS Families: Role of Feelings of Deception in Development of Family Trauma

- Just as Feelings of Deception and Betrayal play a role in the development of PTSD, they also play a role in the development of RSSS family trauma.
- Family members may be angry at medical professionals for "taking away my wife/husband," "destroying the life we had together," or "destroying our family."
- Family members may feel extreme outrage due to doctor behaviors that the patient alleges, or behaviors that family members state they have witnessed.
- Anger and outrage vacillate with hopelessness and helplessness.
  - Patients realize they lack the legal resources necessary to confront the RS industry
  - Patients realize that no legal verdict or money award will restore the patient's vision.
  - And that no legal verdict or money award will restore the family's life to normal.
- Family members feel bewilderment or anger that informed consent did not give appropriate weight to quality of life impacts (i.e., depression, PTSD, suicidal ideation, anxiety disorders, impact on work, home, and intimacy issues).
- Family members may develop a globalized mistrust of medical professionals in general and vow "never go to a doctor."

# Refractive Surgery Shock Syndrome:

Health Psychology

### RSSS and Changes in Health Status

- Patients who develop RSSS are more likely to experience changes in health status than those who do not.
- The greater the intensity of RSSS, the greater the risk for a major change in health status.
- Patients with RSSS have an overall poorer level of health after refractive surgery.
  - Patients tend to exercise less.
  - Patients lose interest in developing or maintaining a healthy diet.
  - Patients exhibit more apathy toward their health.
  - Patients may engage in substance use or risky behaviors that compromise their overall level of health.
  - Patients may fail to comply with drug regimens, particularly where these would be experienced as burdensome or complex before RS.
  - Patients have an overall lower level of immune functioning after RS than before.
  - Patients are simply sick more often than before RS.

#### Changes in Health Status Mediated by RSSS Symptoms

- Patients who develop RSSS Depression...
  - Develop a sense of apathy toward their own health and "stop taking care of themselves."
  - Lose the energy and motivation necessary to start or continue an exercise program.
  - Lose the self-discipline necessary to continue a dietary regimen.
  - Feel there is no need to safeguard their health, since their life is essentially over anyway.
  - Sometimes can't remember whether they've taken their medications, even where the motivation exists.
  - May simply wish they were dead, or subconsciously want to punish themselves.
- Patients who develop RSSS PTSD...
  - Feel a sense of "foreshortened future," such that their overall level of health is irrelevant.
  - Feel "numbed out" and unable to experience any joy or gain from exercising.
  - Avoid exercise if it was previously a strong part of their identity, simply because it constitutes a reminder of what their lives were like before RS.

# Origins of Refractive Surgery Shock Syndrome:

## Contributions of the RS Industry

- RS Advertising
- Inadequacies of Informed Consent
- Alleged Doctor Behaviors

### The Status Quo Contributes to RSSS

**DSM-IV Quote from PTSD section:** "The disorder may be especially severe or long-lasting when the stressor is of human design (e.g. torture, rape). The likelihood of developing the disorder may increase as the intensity of and physical proximity to the stressor increase."

- Feelings of Deception mediate the development of RSSS symptom expression in many cases.
  - Current Advertising of Refractive Surgery establishes unrealistic expectations which set patients up for severe psychological trauma.
  - Current Informed Consent cloaks real consequences of complication in medical terminology, without addressing quality of life in understandable language.
  - Post-op Discovery that "FDA approval" is almost meaningless, since scientific standards for vision quality are grossly deficient.
  - Post-op Discovery that what surgeons call a complication bears little resemblance to what patients call a complication.
  - Post-op Discovery that so-called "complication rates" are not really scientific, but skewed for marketing purposes.

## Contribution of RS Advertising to the Development of RSSS

"10 minutes painless surgery... wake up to perfect vision for the rest of your life."

"Dr. XXXX was a pioneer in the development of LASIK, and has done over X,XXX procedures."

#### **RSSS**

- Depression
- •PTSD
- Other Anxiety Disorders
- Substance Use

Use of "Star Power" to promote trust among the masses.

Use of testimonials establishes trust, while short-circuiting rational thinking about range of outcomes. Testimonials mention only positive effects on quality of life, never the effects of LASIK complications on quality of life.

## Contribution of Informed Consent to the Development of RSSS

Patients discover that the purpose of informed consent is legal, not psychological...that it is to protect the doctor, not to inform the patient.

Informed consent focuses on medical terminology, but excludes its quality of life consequences. In contrast, marketing focuses on quality of life, but excludes medical terminology.

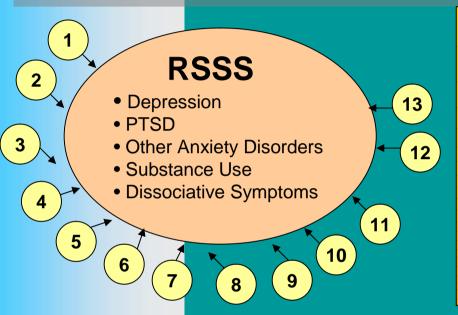
#### **RSSS**

- Depression
- •PTSD
- Other Anxiety Disorders
- Substance Use

Informed consent fails to mention Major Depression, suicidal ideation, PTSD, other anxiety disorders, substance use, and Dissociative conditions, although all of these are medical conditions. Patients are completely unprepared to confront these disorders.

Informed consent fails to prepare patients for co-morbidity of complications, the fact that a single complication makes others much more likely. Patients get 3,4, or 5 complications, without realizing this is even possible. Example: GASH.

## Contribution of Alleged "Doctor Behaviors" to the Development of RSSS



- 9. Hearing similar stories from other patients who have the same surgeon.
- 10. Abandonment of patient.
- 11. Charging patients whose lives have been destroyed even more money for dubious experimental treatments.
- 12. Creating unrealistic hope: "Don't worry, the technology to fix you is right on the horizon"
- 13. Hearing or seeing the same RS ads to which the patient initially responded.
- 1. Patients told there is nothing wrong with their eyes.
- 2. Patients referred for "bogus 2<sup>nd</sup> opinion."
  - 3. Patients told they are being perfectionistic about their vision.
- 4. Patients greeted with coldness and hostility when attempting to discuss their complications.
- 5. Patients greeted with an attitude that minimizes the severity of their complications.
- 6. Patients told that their complications can be cured with a contact lens...that never works out.
- 7. Patients subjected to an "enhancement" that makes their vision worse.
- 8. Patients told their complications will abate with time...which may or may not occur.

## How Alleged Doctor Behaviors Contribute to RSSS: A Cognitive Model

"There's nothing wrong with your eyes!"

Alleged doctor statements set off an interconnected chain of cognitions about the world, self, and future which induce predictable emotional states.

#### PATIENT THINKS...

- "My doctor doesn't understand..."
- "My doctor is protecting his ass..."
- "I will have to live with this forever..."
- "No one believes me."
- "There will never be any relief."
- "How in the world can I cope with this?"

#### PATIENT FEELS...

- Helplessness
- Hopelessness
- Uncertainty
- Shame
- Guilt
- Anxiety
- Loss of Control
- Loss of Self Esteem
- And much, much more.

## Severity of RSSS PTSD and Closeness of Relationship with Medical Professionals

Research Hypothesis: Severity of RSSS PTSD will increase, not only with severity of visual damage, but also with the level of trust felt toward the refractive surgeon or comanaging optometrist prior to surgery.

- The more years the patient has known the surgeon or comanaging optometrist, the greater the level of premorbid trust, and the greater the severity of RSSS PTSD symptoms.
- Patients who indicate they respect their surgeon or optometrist more prior to surgery will develop greater levels of RSSS PTSD symptoms.
- Patients who have known their surgeon or optometrist since childhood will develop greater levels of RSSS PTSD than those who have not.
- In contrast, patients who know their surgeon or comanaging optometrist less well tend to develop greater levels of self blame ("Damn me...I should have checked it out more thoroughly!"

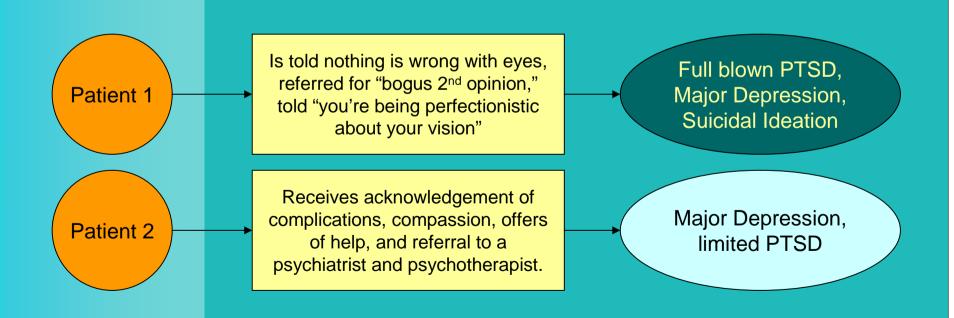
# Refractive Surgery Shock Syndrome:

Psychological Aspects of Treatment

## Identical Complications, Different Outcomes

#### **DSM-IV** Quote from PTSD section:

"The disorder may be especially severe or long-lasting when the stressor is of human design (e.g. torture, rape). The likelihood of developing the disorder may increase as the intensity of and physical proximity to the stressor increase."



## RS-Induced Disorders are Extremely Difficult to Treat with "Conventional Approaches"

- There is no known psychological treatment which is effective for RSSS, because patients cannot "get away from their eyes." Accordingly, the immediate cause of the disorder cannot be removed.
   Comorbidity of DSM Disorders makes RSSS much more difficult to treat.
- RSSS PTSD can be expected to be more difficult to treat than "ordinary PTSD," since in RSSS PTSD, the cause of post-traumatic stress cannot be removed, but fills the patient's every waking moment.
- Because RSSS is often at least in part the by-product of broken trust between doctor and patient, patients may find it impossible to establish trust or confidentiality with a psychotherapist, psychiatrist, or other mental health professional.
- Patients with PTSD symptoms will find it especially difficult to pursue solutions that involve visiting a refractive surgeon, and possibly any eye care professional.
- Because psychiatric drugs that might relieve RSSS also affect tear volume and pupil size, the very drugs intended to relieve depression can make patients more suicidal, even where patients have no previous history of psychological disorders.
- Many patients face "money problems" after RS complications, which can greatly narrow the range of psychological treatment options.

## Contact Lens Fittings can be Highly Stressful for RSSS Patients

Contact lens fittings is a high stakes game in which the patient's vision may be completely or partially restored. Because RS complications affect the patient's whole life, the patient's whole life is at stake with each fitting. Patients who experience RSSS are at risk for exacerbation of depression, suicidal ideation, PTSD, and other symptoms following a "failed fitting." Patients who are known suicide risks should be observed carefully before leaving the clinical setting. Ethically, doctors should inquire about the intensity of suicidal ideation in such patients. Patients who admit to having a suicide plan may need to be hospitalized. Patients who are fitted unsuccessfully over and over again may... Develop increased RSSS symptomatology. Protect themselves with "defensive pessimism," and actually expect failure. Withdraw from the process of visual rehabilitation, afraid to try again. Because of money spent (most patients have "money problems" after failed RS). Due to hostility from others (spouse, boss) for "wasted" time and resources. Because of fear that another unsuccessful fitting could make symptoms worse.

### Restoration of Vision Reduces RSSS severity, But does not eliminate RSSS symptoms

- While Restoration of Vision can be expected to reduce symptoms of RSSS, it is expected that an underlying vulnerability to the disorder may continue for the rest of the patient's life. RSSS is not just about vision...broken trust is core to the disorder. Trust is hard to re-establish once broken Patients who develop RSSS are "psychologically fragile" and may continue to be plagued by symptoms of PTSD, depression, and other RSSS DSM disorders. Patients whose vision has been restored may feel "on edge," constantly alert to minor fluctuations in their vision that could indicate that something has gone wrong again. Patients know other patients who eyes have gotten worse over time for reasons unknown, creating massive uncertainty about the future: "Which way is it going to go for me??" Patients who develop PTSD may have a sense of impending doom which does not abate, particularly when restoration of vision is partial rather than complete. Patients whose vision is partially restored live in constant fear of again losing any degree of visual functioning, and can develop exacerbation of RSSS symptoms if they think this might be occurring, even if it really isn't. Patients whose vision is partially or completely restored do not have their lives restored. Patients must start over in rebuilding their lives occupationally and financially. Some have even been divorced by their spouses.
  - Patients face tremendous obstacles that would adversely impact even individuals with perfect vision.

# Refractive Surgery Shock Syndrome:

Research Directions

### Famous Philosophers of Science

### Karl Popper

According to the eminent logician and philosopher of science Karl Popper, the purpose of good scientific research should be to falsify existing scientific theory. Science is a series of successive approximations to objective truth.

#### Thomas Kuhn

- Science necessarily takes place in a sociological context, within a community of scientists who articulate a core set of beliefs that describe their subject domain.
- Kuhn states that so-called Normal science "is predicated on the assumption that the scientific community knows what the world is like"
- "Normal science often suppresses fundamental novelties because they are necessarily subversive of its basic commitments."
- Scientific Research is "a strenuous and devoted attempt to force nature into the conceptual boxes supplied by professional education"

## Research Directions: Medical Ethics Must Become an Empirical Science

- Because there was no empirical research on what candidates for RS would want in their informed consent, psychological variables were uncontrolled.
- Before a consumer-oriented procedure can launch, the FDA should research what patients want to know about risk.
  - "If LASIK could lead to feelings of depression or PTSD, would you want to know?"
  - "If LASIK could lead to feelings of suicide, would you want to know?"
- Failure to conduct such research has led to weird doctrines such as "remote risks do not need to be revealed to patients."
- Such research should be conducted and published immediately, providing a compelling empirical basis on which to revise informed consent nationwide.
- Research on RSSS is important in the development of medical ethics as an empirical science, but requires that patients' feelings of deception be confronted with scientific honesty and integrity.

## Survey Questions: Medical Ethics as an Empirical Science

"If LASIK complications could cause you to want to commit suicide, would you want to know?" YES NO Results are Candidates fictional, but as you can see, the N outcomes presents a new Post-op and interesting Successes direction for Ν medical ethics. with broad Post-op implications for Casualties consumer medicine.

#### Thank You

- If you are a casualty, my hope is that you found validation and perhaps some relief from your suffering.
- If you are a doctor, my hope is that you learned that LASIK complications affect the entire life of the individual, not just their eyes. Remember, casualties need not only your clinical skills, but also every ounce of compassion in your being if they are to recover from the psychological syndromes that are caused by visual aberrations, ocular conditions, and behaviors they have allegedly experienced with other medical professionals.