



# University Health Network

Toronto General Hospital Toronto Western Hospital Princess Margaret Hospital

## **QUALITY OF LIFE IN EPILEPSY**

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# OUTLINE

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- Background about epilepsy/treatment
- Impact of epilepsy/treatment on quality of life
- Previous Research
- Testing theory of Illness Intrusiveness in Epilepsy
- Clinical Implications & Future Directions

# BACKGROUND

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- Epilepsy- Occurrence of repeated unprovoked seizures
- Seizure- Abnormal hypersynchronous electrical discharge involving part or all of the brain, which results in a physical or behavioral alteration in an individual's state.
- Prevalence: 1-2 % of general population
- Treatment: Pharmacological & Surgical

# PSYCHOLOGICAL CHALLENGES IN EPILEPSY- STRESSORS

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- Unpredictable/ uncontrolled seizures
- Cognitive changes
- Reduced physical strength & memory
- Vocational & economic strains (social life & employment)
- Mood
- Dependencies on treatment modalities

# ILLNESS INTRUSIVENESS

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- “Illness-induced disruptions to valued activities, interests that limit the availability of personally rewarding experience and compromise quality of life” (Devins, 1983).

# PREVIOUS RESEARCH:

## Impact of Epilepsy on Quality of Life (QOL)

- Disease factors (seizure frequency, severity)
- Treatment effectiveness (pharmacological, surgery)
- Adverse effects of anti-epileptic medications
- Possible complications of surgery (for intractable seizures).

# Other Studies- continued

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- Stigmatization
- Sense of loss of control
- Social isolation
- Depression
- Degree of seizure control & QOL

(Hermann et al.,1990; Baker et al., 1996; Gilliam F, 2002; Vickrey et al.,1993; Wiebe et al., 2001; Leidy et al., 1999).

# Impact of Treatment on HRQOL

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- *Pharmacological Treatment:* Seizure freedom reporting HRQOL similar to general population (Leidy et al., 1999).
- More limited HRQOL benefits with reduced seizure frequency (Chadwick, 1997; Birbeck et al., 2002).

# Impact of Treatment on HRQOL

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- *Surgical Treatment:* Anterior temporal lobectomy- Seizure freedom or isolated seizures.
- Improved HRQOL

# Impact of Treatment on Mood, HRQOL

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- *Surgical Treatment:* Mood status, adverse medication side effects improved (Gilliam et al., 2002).
- Depression was inversely correlated with HRQOL (even after controlling for seizure frequency, severity, psychosocial variables). (Lehrner et al., 1999).  
(*Cross-sectional study and no seizure-free group*).

# EPILEPSY AND QUALITY OF LIFE

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- Many studies show improved psychological functioning with reduced seizures.
- However, improved seizure control not always correlated with well-being.
- Furthermore, there is some evidence that improved psychological outcomes sometimes follow surgery, even with no change in seizure control.
- Therefore, seizure frequency alone may not completely explain QOL in epilepsy.

# Impact of Epilepsy on QOL:

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- *Factors that enhance QOL:* ( such as, social and family support, religion or spirituality, leisure, mental health, employment).
- *Factors that compromise QOL:* (such as, psychological distress, worry of seizure occurrence, transportation, stigma).
- Compromising factors may influence enhancing factors
- Consistent with Illness Intrusiveness framework.

# Recent Research

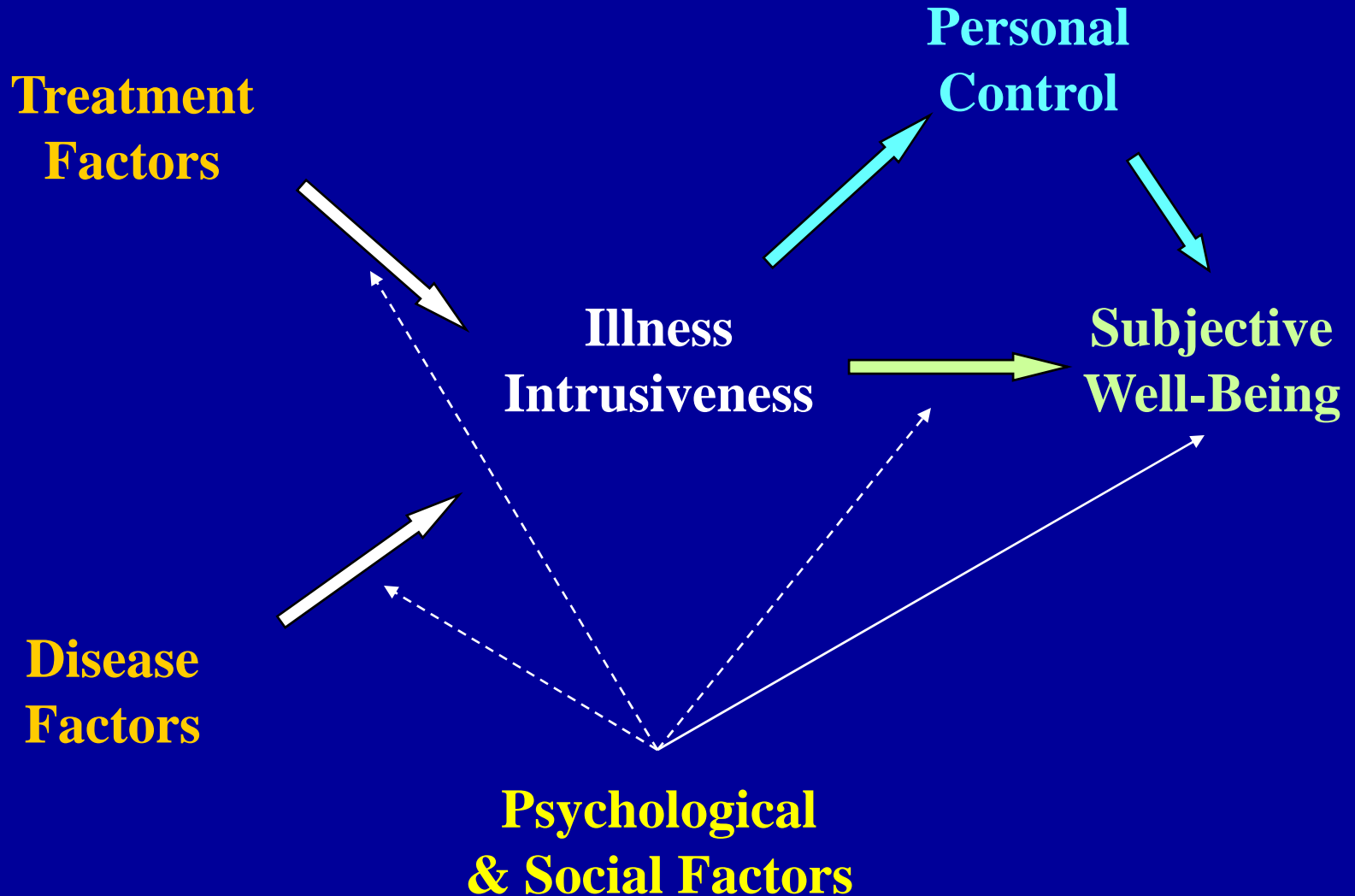
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## Illness Intrusiveness, Quality of Life and Self-Concept in Epilepsy

Sonia Poochikian-Sarkissian PhD Thesis, 2005

# Illness Intrusiveness Conceptual Model

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# QUALITY OF LIFE (QOL):

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- *Subjective well-being:*
  - *Psychological well-being*  
(*Affect, Happiness, Self- esteem*).
  - *Emotional distress (Depression)*
- **Research Study: 2 complimentary approaches:**
  - 1) *Subjective well-being,*
  - 2) *Disease-related QOL*

# PURPOSE

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- 1) to examine the impact of pharmacological and surgical treatments for epilepsy on quality of life through their effects on illness intrusiveness
- 2) to test the illness intrusiveness theoretical framework in epilepsy.

(Sarkissian, 2005)

# HYPOTHESES

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- 1)- Seizure frequency is positively associated with Illness Intrusiveness (II) (Hypothesis 1a).
  - Post-surgical patients report more positive QOL than those treated with pharmacological agents (Hypothesis 1b).
- 2) Illness intrusiveness will exert a direct, negative effect on QOL
- 3) QOL is associated with perceived control over important life domains.

(Sarkissian, 2005)

# METHODS

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- **Design:** Naturalistic cross-sectional
- **Groups:** EMU admissions-medically intractable, pharmacologic & post-surgical patients
- **Sample:** (145 patients)
  - A) EMU Patients- 40 (27.6%) (2 interviews- 20 identified as surgical candidates)
  - B) Pharmacologically Treated- 52( 35.8%)
  - C) Post-surgical – 53( 36.6%)

(Sarkissian, 2005)

# MEASURES

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- **Illness Intrusiveness Rating Scale (IIRS)**
- **Control Rating Scale**
- **Psychological Well-being & Emotional Distress:**
  - 1) Bradburn Affect Balance Scale (ABS)
  - 2) Atkinson Life Happiness Rating,
  - 3) Rosenberg Self-esteem Inventory.
  - 4) Centre for Epidemiologic Studies Depression (CES-D) Scale
- **QOL in Epilepsy: QOLIE-10**

(Sarkissian, 2005)

# RESULTS:

## Socio-demographic Characteristics (n=145)

- Female: 84 (58%)
- Male: 61 (42%)
- Mean Age: 38.21  
(S.D. 11.29)
- Married: 64 (44.1%)
- Single: 65 (44.8%)
- Separated: 14 (4.7%)
- Widowed: 2 (1.4%)

### **Education:**

- ≤ high school: 53 (36%)
- **College/University**  
77 (53%)
- Technical Training  
15 (10.3%)

### **Employment Status:**

- Unemployed : 73 (50.3%)
- Employed:
  - Part-time 23 (15.9%)
  - Full-time: 49 (33.8%)

(Sarkissian, 2005)

# RESULTS:

## Medical Characteristics (n=145)

- **Av. Age of diagnosis:** 18
- **Duration of seizures (yrs):** 19.6
- **Seizure Frequency:**
  - Seizure-free : 41 (28.3%)
  - Seizure-free with auras: 7 (4.8%)
  - < 3 Seizure/month: 9 (6.2%)
  - 3/yr – 5 /month: 52 (35.9%)
  - ≥ 6/month : 36 (24.8%)

- **# Failed AEDs :** 3.5
- **# Side-effects:** 3.16
- **Current # AEDs:** 1.7

## Post-Surgical Patients:

- Seizure-free (62%)
- Seizure-free with auras (13% )

(AED= Anti-epileptic Drugs)

(Sarkissian, 2005)

# **Hypothesis 1: Seizure frequency is positively associated with Illness Intrusiveness (II)**

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## **1a) Correlation of seizure frequency & II:**

**$r = .70$ ;  $p < .01$**

- **3 treatment groups differed significantly in II (ANOVA)**
- **Groups no longer differed when controlled for seizure frequency (ANCOVA)- treatment related differences attributable to differential effectiveness in achieving seizure control.**

## **1b) Post-surgical patients report more positive QOL than pharmacological.**

- **Post-surgical patients- most positive QOL > Pharmacological > EMU patients (ANOVA & ANCOVA).**

(Sarkissian, 2005)

# Benefits of seizure freedom:

- Improved quality of life
- Reduced mortality
- Reduced incidence of depression
- Higher rates of employment
- Independence
- Reduction/discontinuation of medications
- Reduced health care costs

# Illness intrusiveness and psychosocial outcome variables: Comparison of seizure-free and continued seizure groups

\* p≤ 0.01

Sarkissian, Sidani, Wennberg, Devins (2008). CJNS 35(3), 280-286.

| <b>Variable</b>                       | <b>Seizure-free<br/>Mean (+/-SD)<br/>(n= 48)</b> | <b>Continued Seizures<br/>Mean (+/-SD)<br/>(n= 97)</b> | <b>t-value<br/>(df =143)</b> |
|---------------------------------------|--|--|------------------------------|
| <b>Illness Intrusiveness</b>          | 27.27 +/- 17.30                                  | 44.4 +/- 18.38   | 5.30 *                       |
| <b>Perceived Personal Control</b>     | 84.06 +/- 14.04                                  | 65.24 +/- 15.79  | 6.99 *                       |
| <b>CES-D (Depression Scale)</b>       | 10.52 +/- 9.40                                   | 19.36 +/- 12.84  | 4.69 *                       |
| <b>Happiness</b>                      | 8.29 +/- 1.70                                    | 6.76 +/- 2.27  | 4.53 *                       |
| <b>Self-esteem</b>                    | 32.90 +/- 4.57                                   | 28.59 +/- 5.83   | 4.86 *                       |
| <b>Positive Affect</b>                | 4.08 +/- 1.18                                    | 2.51 +/- 1.56  | 6.73 *                       |
| <b>QOLIE-10<br/>(QOL in Epilepsy)</b> | 18.60 +/- 5.58                                   | 27.75 +/- 8.22   | 7.88 *                       |

# Hypothesis 2: II will exert a direct, negative effect on QOL .

*In most cases high II significantly related to negative psychosocial outcomes.*

| <u>Instrument</u>         | <u>Pearson r</u> | <u>Partial r</u>  |
|---------------------------|------------------|-------------------|
| ABS <sup>a</sup>          | -.56***          | -.45***           |
| Self-Esteem <sup>a</sup>  | -.28**           | -.30***           |
| Happiness <sup>a</sup>    | -.49***          | -.37***           |
| CES-D <sup>a</sup>        | .50***           | .42***            |
| Control <sup>b</sup>      | -.61***          | -.45***           |
| Self-Concept <sup>c</sup> | -.25**           | -.15 <sup>T</sup> |
| QOLIE-10 <sup>d</sup>     | .70***           | .56***            |
|                           |                  |                   |

<sup>a</sup> Covariate = Seizure frequency ; <sup>b</sup> Covariate = Seizure frequency, Employment status ; <sup>c</sup> Covariate = Seizure frequency, Number of side effects;

<sup>d</sup> Covariate = Seizure frequency , Employment status, Number of side effects . \*p<.05 \*\* p< .01 \*\*\* p< .001 <sup>T</sup> .05< p< .10

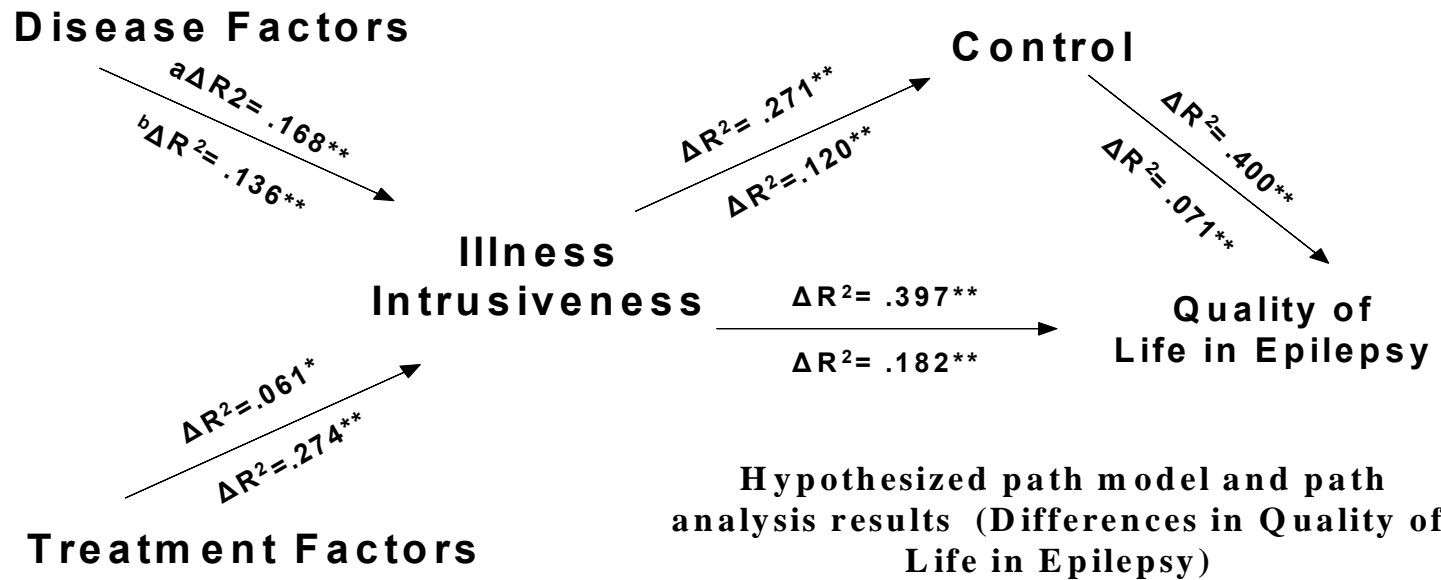
# Hypothesis 3: Quality of life is associated with perceived control over important life domains.

*Those who perceived higher levels of control reported more positive QOL & psychosocial outcomes.*

| <b>Instrument</b>               | <b>Pearson <math>r</math></b> | <b>Partial <math>r</math></b> |
|---------------------------------|-------------------------------|-------------------------------|
| <b>ABS<sup>a</sup></b>          | <b>.53***</b>                 | <b>.40***</b>                 |
| <b>Self-Esteem<sup>a</sup></b>  | <b>.16<sup>T</sup></b>        | <b>.17 *</b>                  |
| <b>Happiness<sup>a</sup></b>    | <b>.52***</b>                 | <b>.40***</b>                 |
| <b>CES-D<sup>a</sup></b>        | <b>-.43***</b>                | <b>-.33***</b>                |
| <b>IIRS<sup>b</sup></b>         | <b>-.61***</b>                | <b>-.45***</b>                |
| <b>Self-Concept<sup>c</sup></b> | <b>.23 **</b>                 | <b>.10 ns</b>                 |
| <b>QOLIE-10<sup>d</sup></b>     | <b>-.71***</b>                | <b>-.55***</b>                |
|                                 |                               |                               |

<sup>a</sup> Covariate = Seizure frequency ; <sup>b</sup> Covariate = Seizure frequency, Employment status ; <sup>c</sup> Covariate = Seizure frequency, Number of side effects; <sup>d</sup> Covariate = Seizure frequency, Employment status, Number of side effects  
 .001      <sup>T</sup> .05 < p < .10      \*p < .05      \*\* p < .01      \*\*\* p < .001

# PATH ANALYSIS: Results were highly consistent across all analyses & psychosocial outcomes



Hypothesized path model and path analysis results (Differences in Quality of Life in Epilepsy)

\*p < .05  
\*\*p < .001

# CONCLUSIONS:

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- **Post-surgical patients reported more positive QOL.**
- **Results replicated previous findings: Illness intrusiveness associated with increased depressive symptoms & decreased QOL in epilepsy.**
- **Most robust benefits of decreased II in epilepsy occur when treatment leads to complete seizure control.**
- **Seizure-freedom:**
  - **significantly associated with lower levels of illness intrusiveness, depression,**
  - **benefits to perceived personal control, happiness, self-esteem, positive affect , HRQOL.**

(Sarkissian, 2005)

# CLINICAL IMPLICATIONS AND FUTURE DIRECTIONS:

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- Screen for high levels of Illness Intrusiveness (II).
- Offer psychosocial interventions to improve coping skills and achieve improved adaptation
- Adjunctive psychological treatment
- Support in identifying new interests and activities that are compatible with epilepsy and its constraints.
- Educational programs- facilitate adaptation, compliance and independence.

Therefore, consider biomedical & adjunctive psychosocial interventions to reduce II , improve QOL and facilitate adaptation to chronic disease like epilepsy.

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(Sarkissian, 2005)

Thank You!