

*PEF Symposium: A critical review of oral health-related  
quality of life: Where are we now?*

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# Conceptual development of “oral health-related quality of life”

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# Presentation objectives

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- Development of PBO research in dentistry
- Critical overview of research to date
- Unresolved conceptual issues
- Future directions

# Seminal papers

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Cohen L. & Jago J. 1976

Sheiham A. & Croog S. 1981

Reisine S. 1981

Nikias M. 1985

Locker D. 1988

# Preliminary measures

*Socio-dental-indicators; Subjective oral health indicators; Self-perceived oral health measures*

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Socio-dental indicators	1984
Geriatric oral health assessment index	1990
Subjective oral health status indicators	1992
Oral health impact profile	1994
Oral impacts on daily performance	1997

*Generic; ad hoc, expert-based, classical test theory, acceptable properties, widely used*

# North Carolina Conference 1997

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- Terminological shift – OHRQoL
  - political/policy resonance and appeal
  - similar shift in medicine
  - broadened analytic task from impacts to QOL
  - compatible with new models of disease and its outcomes with QOL as end point (e.g. Wilson and Cleary, 1995)

Methodological and measurement implications of adoption of the concept QOL ignored

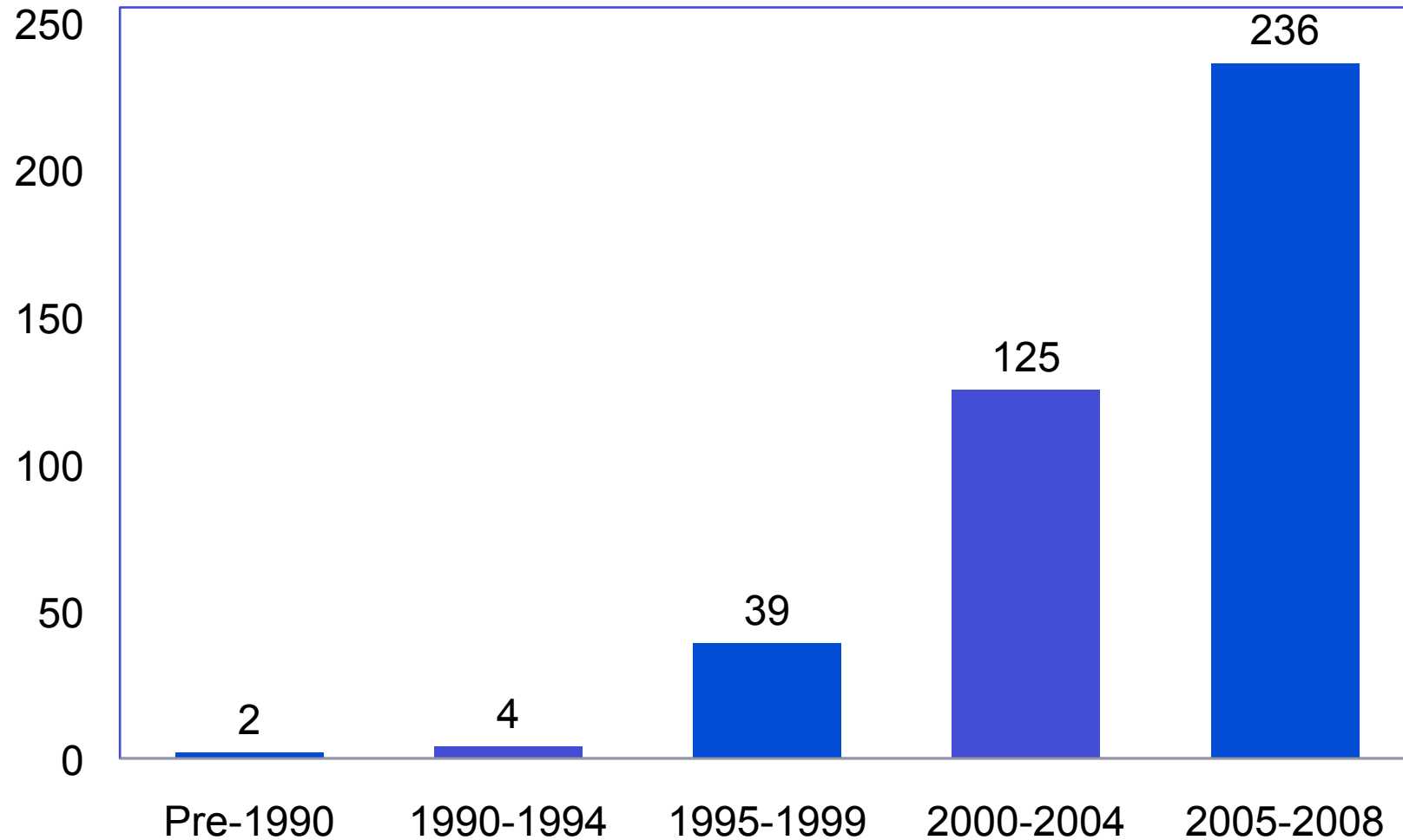
# Post -1997 oral health outcome measures

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- OHQoL-UK
- Child Oral Health Quality of Life Questionnaires
- Child OIDP
- OHRQOL for Dental Hygiene
- Orthognathic QOL Questionnaire
- Surgical Orthodontic QOL Outcome Questionnaire

*Disease or population specific questionnaires; not markedly different from the preliminary measures*

# Patient-based outcome research in dentistry: Number of papers published by year



# Contributions of research to date

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- Paradigm shift – from biomedical to biopsychosocial model of oral health
- Expanded understanding of oral disorders: functional and psychosocial consequences
- Legitimacy of the patients' perspective – needs for and outcomes of therapy

# Critical reviews of HRQoL and QOL research in medicine

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Gill and Feinstein, 1994

Dijkers M, 1999

Guyatt G, Cook D, 1994

Carr A, Higginson I, 2001

Leploge A, Hunt S, 1997

Prutkin and Feinstein, 2002

Hunt, 1997

O'Boyle C, 2005

Fitzpatrick et al, 1998

Mooney A, 2006

# Conceptual imprecision/confusion /inconsistency

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- Terms (oral health, OHRQoL, QoL) treated as synonymous and interchangeable
- Rarely defined
- When defined no consensus on what they refer to

# Conceptual imprecision /confusion

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- Discourse on OHRQoL characterised by rhetoric and sloganizing
  - positive health/positive oral health
- QoL used as a universal suffix
  - smile related quality of life
  - nutrition related quality of life
  - oral quality of life

# Uncritical acceptance of current and commonly used measures

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- Initial set of measures still used (GOHAI, OHIP, OIDP)
- Research to refine, improve performance not undertaken
- Content validity not examined re: aims/measurement goals
- Limitations of measures not considered

# Limitations of the OHIP-14

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- Inappropriate for some population groups
  - no denture related or chewing items
- Significant floor effects – large percentage scoring zero, even those rating OH poor
- Poor responsiveness – less so than OHIP-49 or other short forms

# Percent with zero OHIP-ADD scores

## Canadians aged 50 and over

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	All subjects	Rating OH fair or poor
OHIP-49	2.0	1.4
OHIP-14 (A-R)	33.5	14.3
OHIP-14 (C-I)	2.5	3.6

# Pre-post implant treatment OHIP effect sizes

Allen & Locker, J Public Health Dent 2002

OHIP version	Effect size
OHIP- 49	1.0
OHIP- Edent	0.9
OHIP-14	0.3

Implications of these limitations for particular study?  
7 and 5 item short forms?

# Limited research designs/analytic strategies

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- Majority cross-sectional, descriptive studies
- Analysis generally limited to assessment of construct validity and/or association with clinical variables
- Studies lack a clear purpose – measurement for measurements sake
- Fail to address clear theoretical, policy or clinical question

# Clinical outcome studies

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- Analysis limited to simple comparison of pre-post treatment mean scores/effect sizes – analysis masks as much as it reveals
- Individual variations in treatment response not acknowledged – negative change scores hidden
- Significance of effect based on statistical criteria. *Minimal important difference* – one way in which size of the effect at the group-level can be interpreted is ignored
- Global transition judgments (patient-level assessments of direction, magnitude and meaning of change) not used

# Inappropriate disciplinary base

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- Epidemiology rather than social sciences
- Unit of analysis is the 'case' – you have it or you don't
- Reduction of complex human experiences to binary variables is questionable
- Cannot deal with core sociological concepts central to health and quality of life – *meaning and values*

# Prevalence of impacts using the OHIP-14

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- Case – reporting one or more OHIP-14 impacts ‘fairly often’ or ‘very often’ in past year

*An impact is deemed to be significant based on its frequency without consideration of what it means to the individual affected*

# Prevalence of impacts using the OHIP-14

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- Case – reporting one or more OHIP-14 impacts ‘fairly often’ or ‘very often’ in past year

*An impact is deemed to be significant based on its frequency without consideration of what it means to the individual affected*

*Expert-centred definitions appropriate when object is biological (disease); inappropriate when object is subjective (HRQoL, QoL)*

# Lack of scholarship

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- Unfamiliar with research into HRQoL and QoL in disciplines other than dentistry
- Unfamiliar with conceptual debates
- Unaware of emerging issues in QOL research
  - response shift, IRT, DIF, item banking, minimal important differences .....

# Limitations of OHRQoL research

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- Conceptually imprecise, confused, inconsistent
- Uncritical acceptance of commonly used measures
- Limited research designs/analytic strategies
- Questionable disciplinary base
- Lack of scholarship

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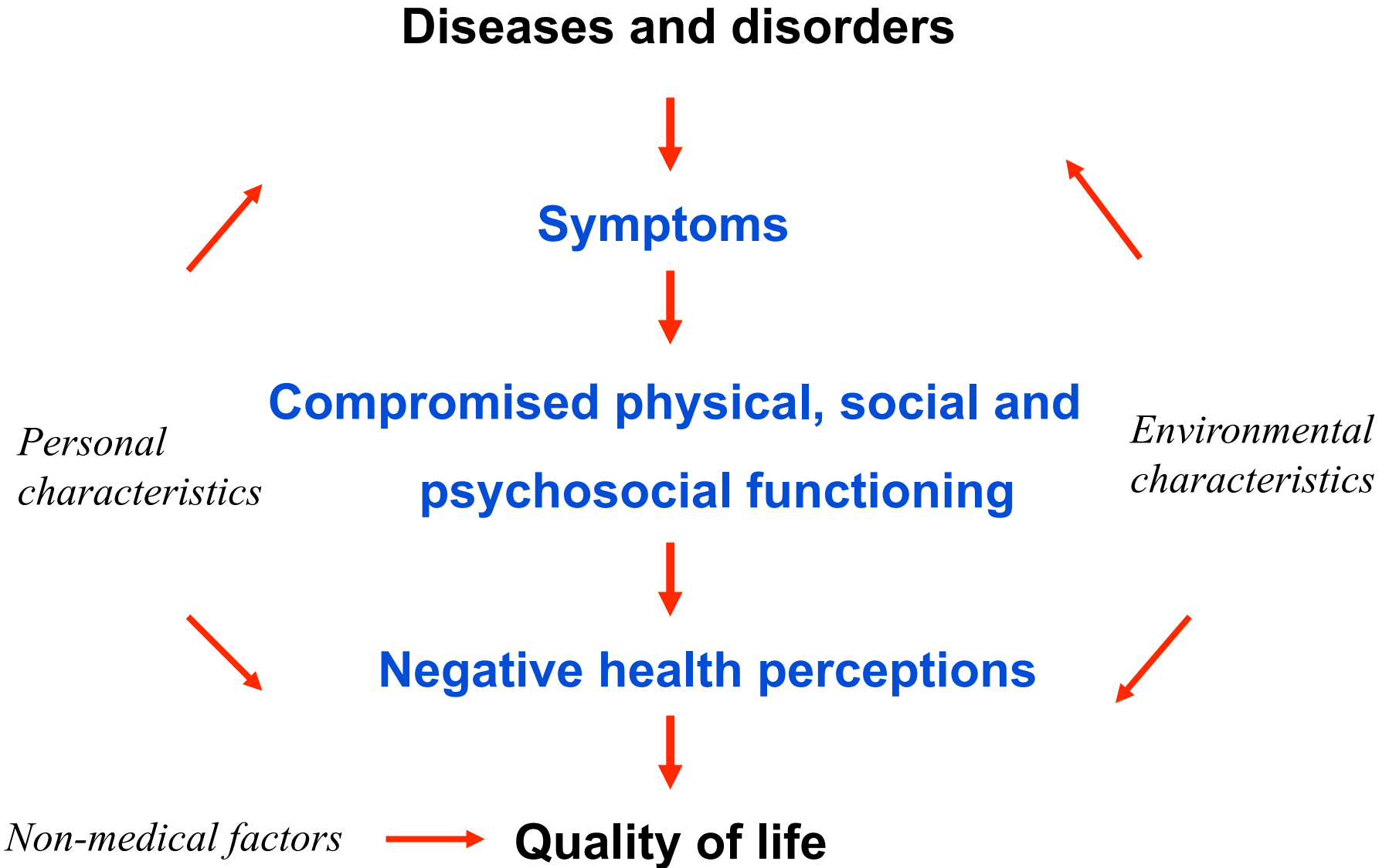
“It is the first tenet of any scientific enterprise where measurement is to be attempted is that the object of measurement be precisely and meaningfully defined and the measurement instrument be appropriate and valid for the task”.

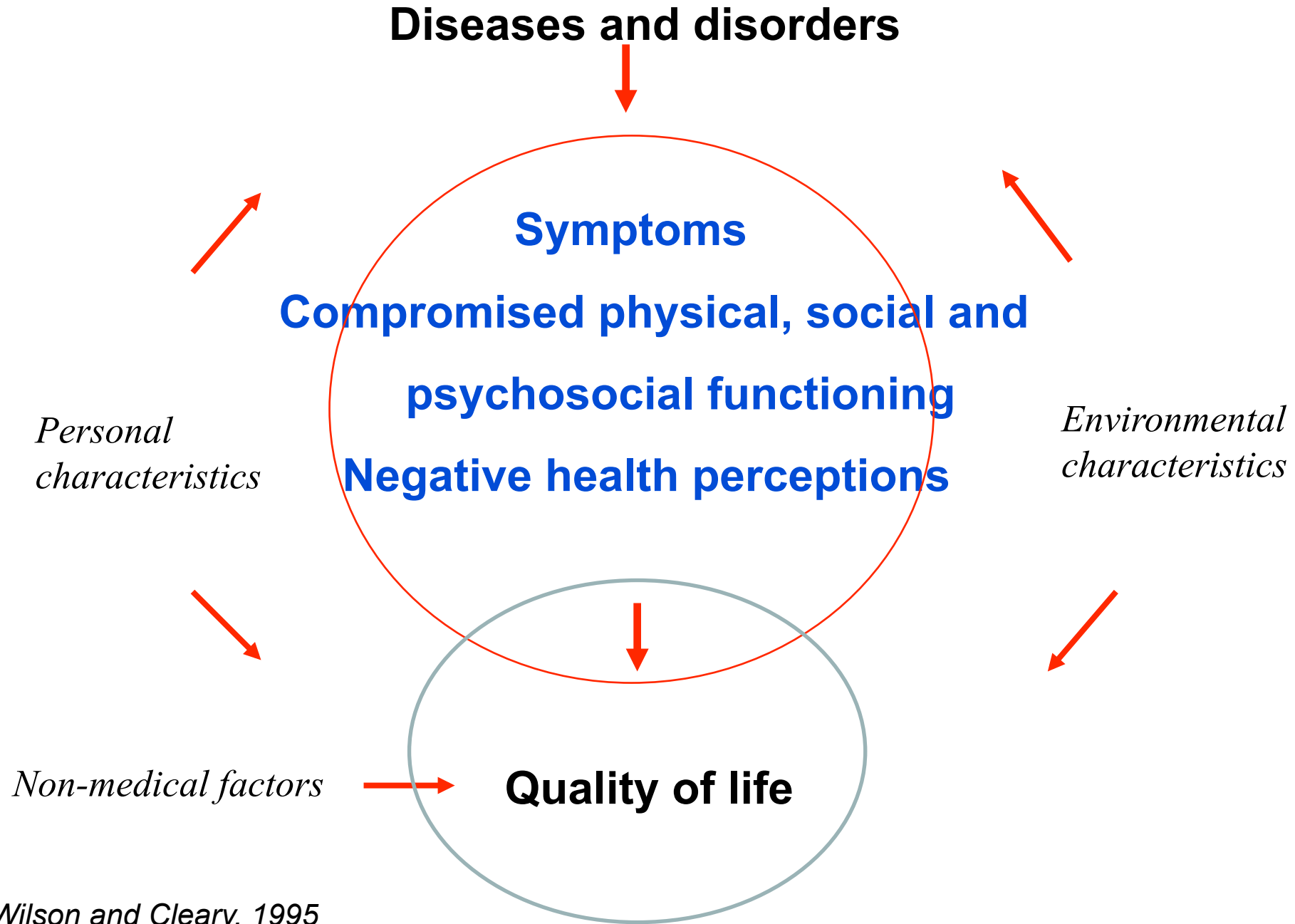
Hunt, 1997

# Resolving unresolved conceptual issues

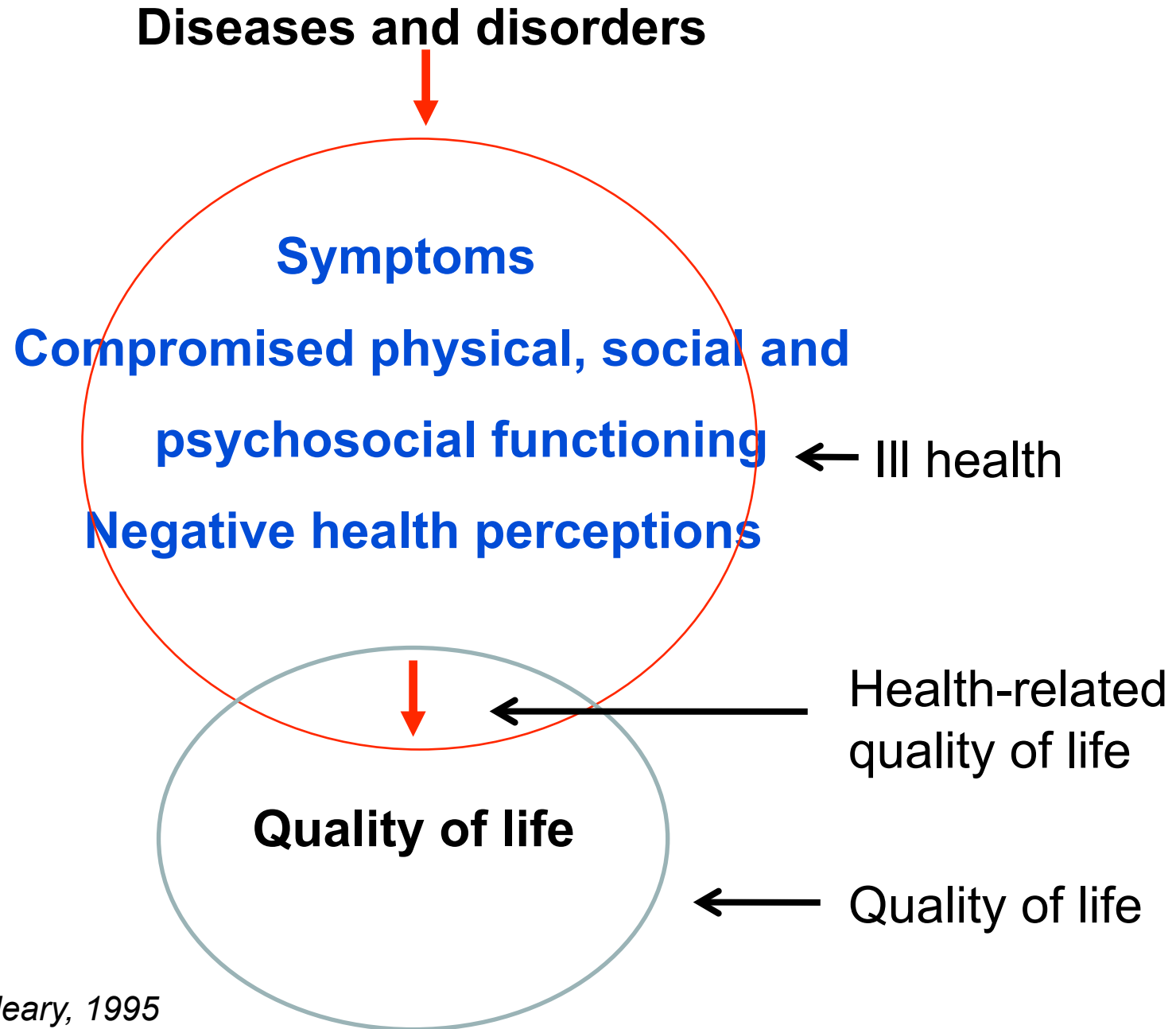
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- Identify a theoretical basis for set of core concepts
- Specify and define these concepts
- Indicate how these can be measured





*Wilson and Cleary, 1995*



# Mooney, 2006

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“Some definitions of health (WHO) are extremely inclusive and wide ranging..if the definition of health is too broad there is little conceptual space for HRQoL to cover”.

“If HRQoL is to mean anything at all it must mean something more than health”.

“It should be clear that HRQoL is not the same as QOL; the latter has a wider reach”.

# Concepts and definitions

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## Oral ill-health:

The symptoms and negative functional and psychosocial impacts emanating from oral diseases and disorders as perceived by the patient or person

Locker & Allen, 2007

# Concepts and definitions

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## Quality of life:

An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their personal goals, expectations, standards and concerns

WHOQOL Group, 1995

# Concepts and definitions

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## Oral health-related quality of life:

The impact of oral diseases and disorders on aspects of everyday life that a patient or person values, that are of sufficient magnitude, in terms of frequency, severity or duration to *affect their experience and perception of their life overall*

*Explicitly links oral health to quality of life*

- Oral ill-health
  - *Description of a state of affairs*
  - *What I can and cannot do. What does/does not happen to me*
- Oral health-related quality of life/Quality of life
  - *Subjective appraisal of a state of affairs*
  - *What this means to me*

# So that.....

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- Since people's meanings, values, expectations and subjective appraisal of circumstances vary
- HRQoL and QOL unique to the individual
- Preservation of this uniqueness major methodological challenge in measuring HRQoL and QOL
- Measuring HRQoL and QOL requires individualized measures

Conforms to contemporary thinking re: HRQoL, QOL as outlined in the critical review papers

## *Development of OHRQoL measures*

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- Item content of current measures - assess oral ill-health
- If we want to assess OHRQoL- broaden conceptual basis of these measures
- In a manner that respects its individual and unique character – i.e. individualized measures

# Individualized measures

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Aim to capture individual's unique perspective

Individual controls the assessment process

Selects issues, concerns, life domains to be assessed and their relative importance

Rates their functioning/performance/satisfaction with respect to each

# Individualized measure of HRQoL

Gill & Feinstein, 1994

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- Questions derived from qualitative interviews to document impacts
- Frequency, severity and importance ratings for each question
- Open-ended questions to capture impacts not included – individual provides own items
- Frequency, severity and importance ratings for these additional items
- Global ratings of HRQoL and QOL

Cumbersome; difficulty of aggregating data; group/time comparisons

# Measuring HRQoL

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- Subjective (oral) health status measure
- Global ratings of HRQoL – impact of (oral) health state on QOL
- Global ratings of QOL

# Global ratings

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- Incorporate individual values, concerns and preferences
- Allow data on a unique and individual phenomenon to be grouped
- Give meaning to scores from oral health outcome measures
- “Allow adequate expression of the way in which individual patients determine their own quality of life” (Gill & Feinstein, 1994)

# Assessing the utility of global HRQoL/QOL ratings

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- National telephone interview survey – RDD
- Sample of Canadians 18 years and over (n=3005)
- Subjective oral health status measure - OHIP-14
- Those with impacts ‘occasionally’, ‘very often’, ‘fairly often’ asked 3 global HRQoL questions
- All asked 2 global QOL questions

# Global ratings of OHRQoL

Assess meaning and significance of OHIP impacts to the individual

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To what extent have you been bothered by these problems?

To what extent have they affected your life overall?

To what extent have they affected your quality of life?

Not at all, a little, somewhat, a fair amount, a great deal

# OHIP-14 – estimating prevalence

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Frequency

Percent reporting one of more impacts 'fairly often' or 'very often'

Meaning and significance

Percent responding 'somewhat', 'a fair amount' or a 'great deal' to the global OHRQoL questions

# *Prevalence of OHIP impacts*

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- Percent reporting one or more OHIP-14 impacts 'fairly often' or 'very often' in past year

*Prevalence – 18.6%*

# Response to global OHRQoL items

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	Somewhat/Fair amount/ Very much
Bothered	12.7%
Life affected	9.4%
QOL affected	7.5%

## Impact on QOL

No

Yes

Frequency

No

771

58

Yes

375

158

$K=0.25$

# Conclusions

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- PBO research in dentistry has made a substantial contribution – paradigm shift, patient perspective
- Characterized by a number of significant limitations
- Main one – inadequate conceptual and basis
- Resolved by drawing on the wider, critical literature regarding the measurement of HRQoL and QoL

# Conclusions

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- Failure to draw on this wider literature a major shortcoming of OHRQoL research
- Part of the problem is the limitations of intellectual vehicles used to disseminate our work
  - 10 minute IADR presentation
  - journal articles of 1,500-2,500 words
- Need to develop new vehicles of communication and dissemination which allow for scholarship and scientific discourse and debate

# Where now?

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- Develop a consensus regarding core concepts and their definition
- Revise current measures, or develop new ones, to measure those concepts appropriately
- Specify a research agenda that utilizes those measures
  - what do we need to know and why?
- Identify and pursue applications of those measures – contribute to theory, clinical and public health practice