What does ‘quality of life’ refer to in bipolar disorder research? A systematic review of the construct’s definition, usage, and measurement

Emma Morton, PhD Candidate - @morton_emm
Erin Michalak, PHD
Greg Murray, PhD, FAPS
Faculty Disclosure

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<th>Company Name</th>
<th>Honoraria/Expenses</th>
<th>Consulting/Advisory Board</th>
<th>Funded Research</th>
<th>Royalties/Patent</th>
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Off-Label Product Use

Will you be presenting or referencing off-label or investigational use of a therapeutic product?

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X No

Yes, please specify:
Quality of Life in Bipolar Disorder

- Bipolar Disorder (BD) – chronic, relapsing
  - Relapse common even with best practice treatment (e.g., Gitlin, Swendsen, Heller, & Hammen, 1995)
  - Subsyndromal symptoms common (e.g., Judd et al., 2002)
  - Inter-episode impacts on functioning (e.g., Chengappa et al., 2005)
- Recovery movement – live well despite symptoms
- Quality of Life (QoL) – holistic outcome
- Treatment outcome most valued by consumers with BD (Maczka et al., 2010)
- Incorporating the consumer perspective/preferences (e.g. Milton, 2013)
Quality of Life –
Personal meanings to technical term

HAVE A BETTER QUALITY OF LIFE WITH A SMART WATCH
“Among the most inconsistently used terms within the human sciences is that of ‘quality of life’. Indeed, the words ‘quality of life’ are used with such abandon that readers must delve into the text to ascertain the intended meaning”

- Cummins, Gullone, & Lau, 2002
Systematic Review: How is QoL used/defined/measured in the BD literature?

• **Review Aim:**
  – Clarify use of the QoL construct in the BD literature

• **Method**
  – Systematic collection and interrogation of studies
    • 275 studies reported data on QoL in BD
  – Based on content analysis techniques

• **Investigated:**
  • A) Explicit discussion of QoL definition
  • B) Usage of the term QoL in the BD literature
Results

• Explicit Definition:
  – QoL rarely explicitly defined \((n = 36; 12\% \text{ articles})\)
  – No consensus
Implicit Meaning: Four major usage categories

QoL as related to *functioning* (103 articles)

QoL as related to *subjective experience* (81 articles)

QoL as related to *health* (91 articles)

QoL as related to *wellbeing* (44 articles)
Links to Measurement

• QoL as Functioning/Health
  - SF-36: “Does your health limit you now in these activities?”
  - EQ-5D: “Which statements best describe your own health today”

• QoL as Subjective Experience/Wellbeing
  - WHOQOL-BREF: “How good or satisfied have you felt?”
  - Q-LES-Q: “During the past week how satisfied have you been with your...”
Discussion

Ideographic/Evaluative

Subjective experiences
Satisfaction
Wellbeing
Positive Indicators

Normative/Descriptive

Health
Functioning
Disability and limitations
Deviations from ‘normal’ status
Discussion

• Differs from other fields:
  – Ageing: Positive psychology (flourishing, sense of meaning, autonomy) (e.g., Bowling, 2005)
  – Schizophrenia: Functioning & health often rated objectively, prominence of symptoms & side effects (e.g., Awad, 2012)
Implications

• Theoretical clarification of concepts related to QoL
• Recognition of diverse approaches to QoL when reviewing previous literature
• Consensus? Maybe not
  - Plurality of definitions not necessarily a weakness
  - Authors must be accountable – explicit definition necessary, justify measurement choice
Conclusion

• QoL rarely explicitly defined in the BD literature; multiple important constructs identified

• Quality of life may represent “a field of interest, rather than a single variable” (Katschnig, 2006)

• Diversity can be tolerated, if authors are explicit in definition

• Something to think about...
  - Possible to live with BD (Suto et al., 2010)
  - What do people with BD say is important to QoL? — Development of QoL.BD out of consumer voices (Michalak & Murray, 2010)
Questions?

“When I use a word,” Humpty Dumpty said in rather a scornful tone, “it means just what I choose it to mean—neither more nor less.”

“The question is,” said Alice, “whether you can make words mean so many different things.”

“The question is,” said Humpty Dumpty, “which is to be master—that’s all.”