

# How can we measure the quality of life of high-risk groups in Norway?

Ashley Muller, Anne Bukten, Thomas Clausen

Folkehelsekonferanse 2019

## Background

- Currently a researcher at NIPH, Division of Health Services
- Norwegian Centre for Addiction Research
- Some overlap between research interests and personal life
  - Research: quality of life, exercise, substance use disorders
  - Personal: distance runner, immigrant in a few countries

# How can we measure what we want to measure in a QoL questionnaire?

# Strong measurement properties

- Valid
- Reliable
- Responsive

As few barriers as possible for respondents and administrators

- Easy to fill out
- Easy to score
- Easy to understand scores

# Extra barriers among inmates and substance patients

- + Less relevant questions?
  - «How satisfied are you with your transportation options?»
- + Difficulties reading or concentrating?
  - 33% ADHD among substance patients in Norway (Abel et al. 2017)
  - 6-14% dyslexia among inmates in Sweden (Samuelsson et al. 2009)
- + Worry that negative answers will have consequences?
  - Inherent power imbalances

# Among inmates and substance patients in Norway:

- What QoL tools are we using?
- How do they perform compared to a gold standard?
- Can we measure QoL better?

# Two national studies of high-risk groups

#### Substance use disorder patients



- 2012-2015, observational
- N=704
- 21 inpatient and outpatient facilities

#### **Inmates**

The Norwegian Offender Mental Health and Addiction Study -NorMA



- 2012-2013, observational
- N=1499
- 57 of 63 prisons
- 3 of 4 reported harmful substance use before prison

## Four QoL tools used

- 1. Single-item
- 2. QOL5
- 3. QOL10
  - 1. Social and overall domains
- 4. World Health Organization's WHOQOL-BREF (gold standard)
  - 1. Physical health, mental health, social relationships, environment domains

### Minimum standards for QoL tools

International Society for Quality of Life Research

 Was there a theoretical model used? Developing the tool Were participants involved? Was it piloted? • Smallest possible burden to respondents/admins.? • Is it reliable and responsive? Using the tool • Is it valid? • Smallest possible assessment burden to administrators? Can scores be understood? Interpreting the tool • Is there a minimum importance difference? Has it been properly translated?

**J J J J J** WHOQOL-BREF WHOQOL-BREF **JJJJ** WHOQOL-BREF **JJJJ** single item **VVV** WHOQOL-BREF

WHOQOL-BREF

# Validity

|                           | Variables tested among our cohorts |                  |                    |          |          |
|---------------------------|------------------------------------|------------------|--------------------|----------|----------|
|                           | substance<br>use                   | mental<br>health | physical<br>health | exercise | social   |
| Single item               | X                                  | ✓                | X                  | ✓        | X        |
| QOL5                      | <b>√</b>                           | <b>√</b>         | X                  | <b>√</b> | <b>√</b> |
| QOL10 social              |                                    | <b>√</b>         | X                  | X        |          |
| QOL10 overall             |                                    | <b>√</b>         | X                  | ✓        |          |
| WHOQOL-BREF physical      |                                    | <b>√</b>         | X                  |          | <b>√</b> |
| WHOQOL-BREF mental        |                                    | <b>√</b>         | X                  |          | ✓        |
| WHOQOL-BREF social        |                                    | <b>√</b>         | X                  |          | X        |
| WHOQOL-BREF environmental |                                    | <b>√</b>         | X                  |          | <b>√</b> |

## Summary

Single-item, QOL5, QOL10, WHOQOL-BREF

- How do these tools perform?
  - WHOQOL-BREF has highest overall quality
  - All have high validity
- Can we better measure QoL?
  - Yes: more attention to social factors

## Recommendations

Additional tools to try out in Norway

- Injecting Drug Users' Quality of Life Scale
- Forensic Inpatients Quality of Life Scale

### More information

(https://www.researchgate.net/profile/Ashley\_ley\_Muller)

Muller et al. BMC Medical Research Methodology BMC Medic https://doi.org/10.1186/s12874-019-0690-3 WHOQOL-BREF Performance of the WHOQOL-BREF among Norwegian substance use disorder patients BMC M€ QOL10 Validating the generic quality of life tool Confirming the factor structure of a generic "QOL10" in a substance use disorder quality of life instrument among pretreatment cohort exposes a unique treatment substance use disorder patients social construct International Journal of Prisoner Health Measuring the quality of life of incarcerated individuals Single item Many correlates of poor quality of life among substance users entering treatment are not addiction-specific Oual Life Res DOI 10 1007/s11136-017-1674-6

Reviews of tools

Measuring quality of life in opioid-dependent people: a systematic review of assessment instruments

INTERNATIONAL JOURNAL OF
OFFENDER THERAPY
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