Developments in outcome measurement for mental health services: The story of a fruitful collaboration in Austria

Judit Simon

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2Visiting Professor, Department of Psychiatry, University of Oxford
Mental health services evaluations aim...

- to **improve care**
- to understand **input and processes** which contribute to better care
- to measure if the service produces **significant outcomes**
- to assess the **cost** of interventions/services and whether they offer value for money (**cost-effectiveness**)
- to **inform** mental health service investment decisions,
- to **raise awareness** among planners, policy makers, and politicians of service gaps.
What outcomes?

Objective outcomes
- Mortality rates
- Unemployment rates
- Suicide rates
- Readmission rates
- Clinical outcomes: biomarkers
- events (stroke, MI)

Clinician-rated measures
- GAF
- HDRS
- MADRS
- QIDS
- Mini-ICF

Subjective - PROMs
- Symptoms severity
- Impact of caring
- Satisfaction with services

Quality of life
- Health-related quality of life

Capabilities
- Generic PROMs
  - WHOQOL-BREF
  - EQ-5D, SF-36
  - 16D
  - QLS
- Disease-specific PROMs
  - SQLS
  - QoL.BD
  - QLDS
  - EDQLS

Univ.-Prof. Dr. med. univ. Judit Simon, BA BSc MSc DPhil FFPH
Department of Health Economics, Center for Public Health
Quality of life in mental health
• Well-being/Ill-being
• Control/Autonomy/Choice
• Self perception
• Belonging
• Loneliness/isolation/alienation
• Activity/Employment
• Hope and hopelessness

EuroQoL EQ-5D
• Mobility
• Self-care
• Daily activities
• Pain/discomfort
• Anxiety/depression

“...the EQ-5D did not detect any HRQoL losses for delusional or bipolar I disorders."

“It is sufficient to raise doubts about the use of generic measures of health like the EQ-5D and SF-36 in patients with schizophrenia."

The capability approach

• Amartya Sen in 1980’s

• Alternative approach to welfare/well-being assessment:
  • Not only functional outcomes but also capabilities (things that people are free to do or be) should be included

• Central concepts: intrinsic value of freedom of choice, multi-dimensionality, equity, objective valuation of welfare
Functioning vs. Ability to function

Fasting

Starvation

Anorexia nervosa
OxCAP-MH (Oxford CAPabilities questionnaire-Mental Health)

- Developed, applied and validated in the UK OCTET study for 336 severely ill, revolving door patients with psychosis (2008-2012)
- M. Nussbaum's central human capabilities
- 16 domains, 1-5 Likert scale
- Standardised score: 0-100

- Limitation of daily activities
- Suitable flat situation
- Less sleep over worried
- Enjoy love and support
- Enjoy free time activities
- Safety in neighbourhood
- Probability of assault
- Probability of discrimination
- Respect for people around
- Meet friends or family
- Decisions in local area
- Access to interesting activities
- Freedom of expression
- Creativity
- Appreciation of nature
- Freedom of deciding for yourself

Simon et al. (2013) Social Science & Medicine, 98: 187-196
Vergunst et al. (2017) Health and Quality of Life Outcomes, 15:250
This is how it began... (Email, 29 June 2014)
Cultural and linguistic transferability of the multi-dimensional OxCAP-MH capability instrument for outcome measurement in mental health: the German language version

Judit Simon¹,²,³*, Agata Łaszewska¹, Eva Leutner⁴ Georg Spiel⁵, David Churchman⁶ and Susanne Mayer¹
Development of the German OxCAP-MH

Coordinator
Oxford University Innovation
Professional translators
PharmaQuest Ltd

Coordinator
Oxford University Innovation
Professional translators
PharmaQuest Ltd
In-country investigator (Austria)
Judit Simon MUV
Developer
Judit Simon MUV, University of Oxford
Research group (Germany) - University of Hamburg

12 patients
4 carers
pro mente Carinthia

Simon et al. BMC Psychiatry, 2018
Cognitive Debriefing (12 patients)
Respondents identifying problems with the piloted questions

<table>
<thead>
<tr>
<th>Item</th>
<th>Content</th>
<th>Patients</th>
<th>Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>Daily activities</td>
<td>1/12</td>
<td></td>
</tr>
<tr>
<td>Q2</td>
<td>Social networks</td>
<td>3/12</td>
<td>√</td>
</tr>
<tr>
<td>Q3</td>
<td>Losing sleep</td>
<td>3/12</td>
<td>√</td>
</tr>
<tr>
<td>Q4</td>
<td>Enjoying recreation</td>
<td>0/12</td>
<td>√</td>
</tr>
<tr>
<td>Q5</td>
<td>Suitable accommodation</td>
<td>0/12</td>
<td>√</td>
</tr>
<tr>
<td>Q6</td>
<td>Neighbourhood safety</td>
<td>1/12</td>
<td></td>
</tr>
<tr>
<td>Q7</td>
<td>Potential for assault</td>
<td>1/12</td>
<td></td>
</tr>
<tr>
<td>Q8</td>
<td>Discrimination</td>
<td>0/12</td>
<td></td>
</tr>
<tr>
<td>Q9a</td>
<td>Influencing local decisions</td>
<td>8/12</td>
<td></td>
</tr>
<tr>
<td>Q9b</td>
<td>Freedom of expression</td>
<td>1/12</td>
<td></td>
</tr>
<tr>
<td>Q9c</td>
<td>Appreciate nature</td>
<td>0/12</td>
<td></td>
</tr>
<tr>
<td>Q9d</td>
<td>Respect and appreciation</td>
<td>0/12</td>
<td></td>
</tr>
<tr>
<td>Q9e</td>
<td>Love and support</td>
<td>0/12</td>
<td>√</td>
</tr>
<tr>
<td>Q9f</td>
<td>Planning one’s life</td>
<td>0/12</td>
<td></td>
</tr>
<tr>
<td>Q9g</td>
<td>Imagination and creativity</td>
<td>0/12</td>
<td></td>
</tr>
<tr>
<td>Q9h</td>
<td>Access</td>
<td>0/12</td>
<td></td>
</tr>
</tbody>
</table>

9 of 16 questions entirely clear for 100% of patients
6 of 16 questions entirely clear for 75-92% of patients
1 question problematic to 66% of patients
Carers considered potential difficulties with 6 questions
### OxCAP-MH

In diesem Fragebogen geht es um Ihre Lebensqualität insgesamt.

<table>
<thead>
<tr>
<th>Frage</th>
<th>Antwortmöglichkeiten</th>
<th>Optionen</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Wenn Sie sich mit gleichaltrigen Menschen vergleichen, schränkt Ihr Gesundheitszustand Ihre Alltagsaktivitäten auf irgendeine Weise ein?</td>
<td>Immer</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Meistens</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Manchmal</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Selten</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Nie</td>
<td>5</td>
</tr>
<tr>
<td>2. Können Sie Freunde oder Verwandte in geselligem Rahmen treffen?</td>
<td>Immer</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Meistens</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Manchmal</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Selten</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Nie</td>
<td>5</td>
</tr>
<tr>
<td>3. Wie oft haben Sie in den vergangenen 4 Wochen weniger Schlaf gefunden, weil Sie sich Sorgen gemacht haben?</td>
<td>Immer</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Meistens</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Manchmal</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Selten</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Nie</td>
<td>5</td>
</tr>
<tr>
<td>4. Wie oft konnten Sie in den vergangenen 4 Wochen Ihre Freizeitaktivitäten genießen?</td>
<td>Immer</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Meistens</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Manchmal</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Selten</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Nie</td>
<td>5</td>
</tr>
<tr>
<td>5. Wie geeignet oder ungeeignet ist Ihre Wohnsituation für Ihre derzeitigen Bedürfnisse?</td>
<td>Sehr geeignet</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Ziemlich geeignet</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Weder geeignet noch ungeeignet</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Ziemlich ungeeignet</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Sehr ungeeignet</td>
<td>5</td>
</tr>
<tr>
<td>6. Bitte geben Sie an, wie sicher Sie sich fühlen, wenn Sie allein in der Nähe Ihrer Wohnung zu Fuß unterwegs sind:</td>
<td>Sehr sicher</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Ziemlich sicher</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Weder sicher noch unsicher</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Ziemlich unsicher</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Sehr unsicher</td>
<td>5</td>
</tr>
</tbody>
</table>

### Aus welcher der folgenden Gründe ist es Ihrer Meinung nach, dass Sie diskriminiert werden?

<table>
<thead>
<tr>
<th>Optionen</th>
<th>Wert</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sehr wahrscheinlich</td>
<td>1</td>
</tr>
<tr>
<td>Ziemlich wahrscheinlich</td>
<td>2</td>
</tr>
<tr>
<td>Weder wahrscheinlich noch unwahrscheinlich</td>
<td>3</td>
</tr>
<tr>
<td>Ziemlich unwahrscheinlich</td>
<td>4</td>
</tr>
<tr>
<td>Sehr unwahrscheinlich</td>
<td>5</td>
</tr>
</tbody>
</table>

### Bitte geben Sie an, wie sehr Sie den folgenden Aussagen zustimmen oder nicht zustimmen:

<table>
<thead>
<tr>
<th>Optionen</th>
<th>Wert</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sehr zu</td>
<td>1</td>
</tr>
<tr>
<td>Ziemlich zu</td>
<td>2</td>
</tr>
<tr>
<td>Weder noch</td>
<td>3</td>
</tr>
<tr>
<td>Ziemlich nicht zu</td>
<td>4</td>
</tr>
<tr>
<td>Sehr nicht zu</td>
<td>5</td>
</tr>
</tbody>
</table>

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https://healtheconomics.meduniwien.ac.at/downloads/oxcap-mh/
This is how it continued...
Measuring broader wellbeing in mental health services: validity of the German language OxCAP-MH capability instrument

Agata Łaszewska¹ · Markus Schwab² · Eva Leutner³ · Marold Oberrauter³ · Georg Spiel²,³ · Judit Simon¹,⁴,⁵,⁶

Accepted: 17 April 2019 / Published online: 27 April 2019
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Validity in the evaluation of mental health services in Austria

• Does OxCAP-MH measure broader dimensions of quality of life compared to the commonly used EQ-5D instrument?

• Is OxCAP-MH a feasible and psychometrically valid tool for the use in routine mental health services evaluation?
Study design

• Sozialpsychiatrischer Dienst pro mente kärnten
• adults, various diagnoses of mental disorders
• Assessment baseline, 1 month, 6 months
• Evaluated instruments: OxCAP-MH & EQ-5D
• Other instruments:
  - WHOQOL-BREF
  - BSI-18
  - MINI-ICF-APP
  - GAF
  - WHO-DAS 2.0

Clients approached Around 400
Completed baseline 159
Completed second assessment 69
Completed 6-month follow-up 127

1 month
6 months
Methods

- Reliability
- Construct validity
- Discriminative ability
- Sensitivity to change
- Reproducibility
- Exploratory factor analysis

German OxCAP-MH

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Department of Health Economics, Center for Public Health
Sensitivity to change

Baseline

6M
Exploratory factor analysis

<table>
<thead>
<tr>
<th>Domain</th>
<th>Factor 1</th>
<th>Factor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EQ-5D-5L</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mobility</td>
<td>-0.85</td>
<td></td>
</tr>
<tr>
<td>self-care</td>
<td>-0.67</td>
<td></td>
</tr>
<tr>
<td>daily activities</td>
<td>-0.73</td>
<td></td>
</tr>
<tr>
<td>pain/discomfort</td>
<td>-0.74</td>
<td></td>
</tr>
<tr>
<td>depression/anxiety</td>
<td>-0.68</td>
<td></td>
</tr>
<tr>
<td><strong>OXCAP-MH</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>limit daily activities</td>
<td>0.73</td>
<td></td>
</tr>
<tr>
<td>meet socially with friends or family</td>
<td>0.62</td>
<td></td>
</tr>
<tr>
<td>less sleep over worries</td>
<td>0.57</td>
<td></td>
</tr>
<tr>
<td>enjoy free time activities</td>
<td>0.63</td>
<td></td>
</tr>
<tr>
<td>safety in neighbourhood</td>
<td>0.56</td>
<td></td>
</tr>
<tr>
<td>probability of assault</td>
<td>0.33</td>
<td></td>
</tr>
<tr>
<td>probability of discrimination</td>
<td>0.48</td>
<td></td>
</tr>
<tr>
<td>suitable flat situation</td>
<td></td>
<td>0.43</td>
</tr>
<tr>
<td>local decisions</td>
<td></td>
<td>0.46</td>
</tr>
<tr>
<td>freedom of expression</td>
<td></td>
<td>0.38</td>
</tr>
<tr>
<td>appreciation of nature</td>
<td></td>
<td>0.81</td>
</tr>
<tr>
<td>respect for people around</td>
<td></td>
<td>0.86</td>
</tr>
<tr>
<td>enjoy love and support</td>
<td></td>
<td>0.57</td>
</tr>
<tr>
<td>freedom of deciding for yourself</td>
<td></td>
<td>0.60</td>
</tr>
<tr>
<td>creativity</td>
<td></td>
<td>0.75</td>
</tr>
<tr>
<td>access to interesting activities/employment</td>
<td></td>
<td>0.58</td>
</tr>
</tbody>
</table>

Cronbach’s alpha 0.87 0.80
### Discriminative validity

<table>
<thead>
<tr>
<th>Gender</th>
<th>Diagnosis</th>
<th>Age</th>
<th>Education</th>
<th>Living situation</th>
<th>Family situation</th>
<th>Source of income</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men (n=57)</td>
<td>Single diagnosis (n=103)</td>
<td>Age 18-30 (n=27)</td>
<td>Hauptschule (n=25)</td>
<td>Wohnen (n=21)</td>
<td>Familienverband (n=21)</td>
<td>Arbeitslosengeld (n=14)</td>
</tr>
<tr>
<td>Women (n=97)</td>
<td>Multi-morbid diagnoses (n=45)</td>
<td>Age 30-45 (n=41)</td>
<td>Lehre (n=36)</td>
<td>in Partnerschaft lebend (n=24)</td>
<td>Pension (n=42)</td>
<td>Lohn (n=30)</td>
</tr>
</tbody>
</table>

* *p≤0.05, **p≤0.01, ***p≤0.001*
The next steps...
Since 2019:

1. Investigating the transferability of the instrument to middle and low income settings
2. Researching potential validity of the measure beyond MH care setting
3. Development of a value set in Austria
Cultural and linguistic adaptation of the multi-dimensional OXCAP-MH for outcome measurement of mental health among people living with HIV/AIDS in Uganda: the Luganda version

Kenneth R. Katumba¹, Yoko V. Laurence², Patrick Tenywa³, Joshua Ssebunya⁴, Agata Laszewska⁵, Judit Simon⁵,⁶, Anna Vassall², Eugene Kinyanda³ and Giulia Greco²
Implementation in COVID-19 research

Impacts of the Covid-19 lockdown and relevant vulnerabilities on capability well-being, mental health and social support: an Austrian survey study

Judit Simon\textsuperscript{1,2}, Timea M. Helter\textsuperscript{1}, Ross G. White\textsuperscript{3}, Catharina van der Poel\textsuperscript{2}, and Agata Laszewska\textsuperscript{1}
OxCAP-MH value set development for Austria

Helter et al. (submitted for publication)

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Department of Health Economics, Center for Public Health

Limit daily activities
Meet socially with friends or family
Less sleep over worries
Enjoy free time activities
Suitable flat situation
Safety in neighbourhood
Probability of assault
Probability of discrimination
Local decisions
Freedom of expression
Appreciation of nature
Respect for people around
Enjoy love and support
Freedom of deciding for yourself
Creativity
Access to interesting activities/employment

General population  Psychiatric patients  Mental health experts
And the icing on the cake...
PECUNIA

Programme in Costing, resource use measurement and outcome valuation for use in multi-sectoral national and international health economic evaluations

www.pecunia-project.eu

• EC H2020 project, €3 million
• 42M (2018-2021), 10 partners, 6 countries
• Development of standardised, harmonised, multi-sectoral, multi-national, multi-person costing and outcome assessment systems, methods and tools
• Enable comparability, applicability and transferability of (mental) health economic evaluations across the EU

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No. 779292
Establishing a comprehensive list of mental health-related services and resource use items for HSC, CJ, ED, PFI sectors in Austria

Expert review results (295 items, 18 experts)

- **Clarity & Accuracy**: 260 items and descriptions (88%) were considered clear by all experts.
- **Relevance**: 111 items (38%) were prioritized regarding their frequency use.
- **Completeness**: 13 items were suggested to be added.
- **Existence within the national context**: 40 items (14%) were considered not existing in Austria by at least one expert.

Fischer et al. (submitted for publication)
The future...

PECUNIA
Final Workshop
2nd June, 2021
Virtual

www.pecunia-project.eu

Assessing the costs and outcomes of healthcare for economic evaluations in Europe

Zoom Webinar | June 2, 2021 | 09:00 – 14:30 CET
Herzlichen Glückwunsch!