LEIDEN UNIVERSITY MEDICAL CENTER

Measuring the effects of health interventions on subjective well-being comprehensively: The development and validation of the "SWB-xD"

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Goal of our project

Goal:

Develop a generic utility measure that captures a broad and diverse spectrum of domains of QoL/well-being

Background:

Commonly used generic utility measures (e.g., EQ-5D) are too narrowly focused. For example, they mainly focus on determining the physical effects of cure-related treatments

Research steps:

1. Identify all potentially interesting domains of QoL >> literature search
2. Identify the essential domains of QoL >> Delphi consensus procedure
3. Construct and validate a new questionnaire (i.e., SWB-xD)

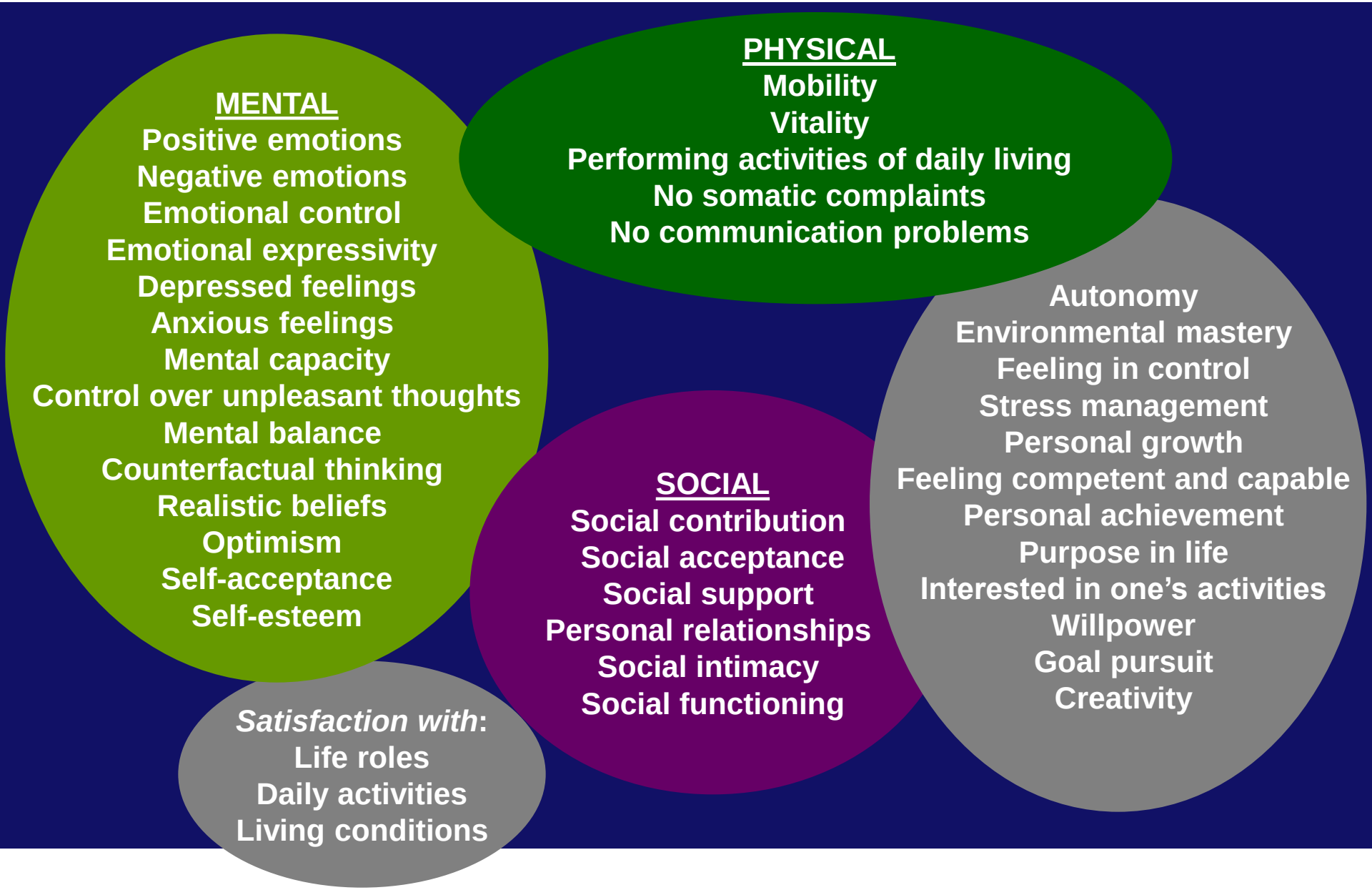
Literature search

We focused on identifying domains that are part of:

- Most frequently used health-related QoL utility measures (i.e., EQ-5D, SF-6D, HUI2, HUI3, 15D, QWB-SA and AQoL)
- General psychological and sociological measures of Qol/well-being >> used the online archive of the ***Australian Centre on Quality of Life***

Finally we ended up with **40 domains of QoL**

Literature search – 40 Domains of QoL



Delphi consensus procedure

Three stage procedure >> iterative approach that allows participants to adjust their opinions when needed and to obtain feedback about the opinions of other people

Participants

- patients (N = 38)
- family members of patients (N = 33)
- clinicians and clinical psychologists (N = 34)
- scientific experts (N = 32)
- general population (N = 33)

Literature search results formed the input for round 1

Delphi consensus procedure – Round 1

- 40 questions concerning specific domains of QoL (endpoints 1 [*not important*] 4 [*very important*])
- open-ended questions

The open-ended suggestions resulted in adding 7 new domains:

- Independence
- Acceptation of the situation
- Enjoying the little things in life
- Being understood by one's environment
- Meaningfulness
- Future perspective
- Satisfaction with the balance between obligations and leisure

Delphi consensus procedure – Round 2 & 3

Round 2

- Participants re-rated the domains of round 1 for which no consensus was reached and rated the added and altered domains
- Maximally 42 questions (endpoints 1 [*totally not important*] to 7 [*very important*])

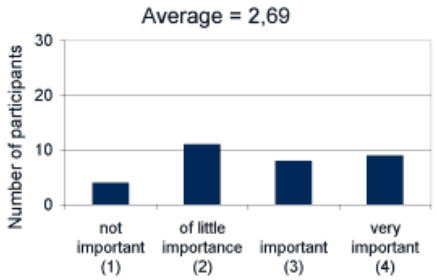
Round 3

- Participants were also asked to indicate which five domains (top 5) they perceived as most important aspects of QoL of all 42 domains
- Next, participants were asked to rank these five domains from least important aspect of QoL to most important

Domains of Mental Well-Being

Below you find a number of domains of mental well-being. **Could you please indicate for each domain, to what extent you believe this is an important domain?**

	Totally not important	1	2	3	4	5	6	7	Very important
Being well able to handle depressed feelings		○	○	○	○	○	○	○	
Being well able to handle anxious feelings									
Optimism									
Acceptation of the situation									
Enjoying the little things in life									
Self-acceptance									
Mental capacity									
Mental balance									
Realistic beliefs									
Control over unpleasant thoughts									
Emotional control									
Being well able to handle negative emotions									
Self-esteem		○	○	○	○	○	○	○	
Emotional expressivity									
Experiencing positive emotions									
Counterfactual thinking									



Your answer was: 3.

Emotional expressivity is the tendency to show one's own emotions to other people. It means that people do not try to cover up their emotions.

If you have any comments on one of the domains of mental well-being, as listed above, please write them down below.

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Delphi consensus procedure – Results

Striking findings:

- Scientists reached consensus that many domains are not important and did not attain consensus for many other domains
- For all other groups it can be stated that many/almost all domains are perceived as important (high means)

To get a more in depth understanding of similarities and differences between groups we looked at:

1. 10 domains with the highest mean ratings (for each group)
2. 10 domains most frequently mentioned in the top five of each group

→ *Which domains do the majority of groups (3, 4 or 5 groups) rated as highly important?*

Delphi consensus procedure – Results

Domains with the highest mean ratings

	Patients	Family of patients	Clinicians	Scientists	General population
Physical Domains					
• Being able to perform activities of daily living	**6.51 [2]**	6.15 [1]	**5.94 [2]**	**6.03 [2]**	**6.24 [2]**
• Independence	**6.59 [2]**	**6.27 [2]**	5.66 [3]	4.97 [-]	**6.06 [3]**
Mental Domains					
• Mental balance	**6.22 [1]**	**6.20 [1]**	5.81 [2]	5.41 [-]	**6.00 [2]**
• Self-acceptance	**6.45 [1]**	**6.42 [1]**	**6.38 [1]**	**5.66 [2]**	**6.47 [1]**
• Self-esteem	**6.36 [1]**	**6.36 [1]**	**6.33 [1]**	5.69 [-]	**6.31 [1]**
• Acceptation of the situation	**6.38 [2]**	**6.36 [3]**	5.33 [-]	5.10 [-]	**5.97 [3]**
• Enjoying the little things in life	**6.65 [2]**	**6.33 [2]**	5.90 [2]	**5.62 [3]**	**6.36 [2]**
Interface of Mental and Social Domains					
• Autonomy	**6.22 [1]**	**6.26 [1]**	**6.33 [1]**	5.62 [-]	**6.26 [1]**
• Purpose in life	6.03 [1]	5.89 [1]	**6.06 [2]**	**6.18 [1]**	**6.31 [1]**
Other Domains					
• Satisfaction with daily activities	6.16 [2]	**6.36 [1]**	**6.07 [3]**	**5.66 [2]**	**6.05 [1]**
• Satisfaction with life roles	**6.22 [1]**	6.10 [1]	**6.18 [1]**	**6.13 [1]**	5.69 [3]

Delphi consensus procedure – Results

Domains most frequently mentioned in top five

	Patients	Family of patients	Clinicians	Scientists	General population
All groups					
• Self-esteem	6	6	6	6	1
• Good social contacts	7	10	8	7	7
4 groups					
• Self-acceptance	7	-	12	6	15
• Independence	15	11	6	-	7
3 groups					
• Being able to perform activities of daily living	15	6	6	-	-
• Optimism	-	6	-	6	7
• Autonomy	8	-	6	6	-
• Purpose in life	-	6	-	12	6

Mental and social domains are perceived as more essential than physical domains.

Discussion

The Delphi-procedure results show that the inclusion of social and mental domains in health-related QoL measures is of key importance in order to capture aspects of QoL that are essential to people.

Future steps:

Add (more) mental and social domains to existing health-related QoL utility measures. This will result in a more comprehensive operationalization of health-related QoL.

To better judge the effectiveness of health interventions, measures need to go beyond the traditional health-related QoL utility measures.

Questions, suggestions?