The power of pictures

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Publication date:
2020

Document Version
Publisher's PDF, also known as Version of record

Link to publication in Tilburg University Research Portal

Citation for published version (APA):
Buitenweg, D. (2020). *The power of pictures: Co-creative development and evaluation of a visual and personalized quality of life assessment app for people with severe mental health problems*. Proefschriftenmaken.nl.

THE POWER OF PICTURES

Co-creative development and evaluation of a visual and personalized quality of life assessment app for people with severe mental health problems

DAVID BUITENWEG

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Co-creative development and evaluation of a visual and personalized quality of life assessment app for people with severe mental health problems

David Buitenweg

The research described in this thesis was performed at department Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, the Netherlands.
This research was funded by a grant from the Netherlands Organisation for Scientific Research (NWO, grant number 319-20-005).

Printing of this thesis was financially supported by Tilburg University.

Cover Design: Roy Hendrikx
Lay-out: Proefschriftmaken.nl
Printing: Proefschriftmaken.nl

ISBN: 978-94-6380-999-3

The power of pictures

Co-creative development and evaluation of a visual and personalized quality of life assessment app for people with severe mental health problems

Proefschrift

ter verkrijging van de graad van doctor
aan Tilburg University,
op gezag van de rector magnificus,
prof. dr. K. Sijtsma,

in het openbaar te verdedigen ten overstaan van een door het college voor promoties
aangewezen commissie in de Aula van de Universiteit
op vrijdag 13 november 2020 om 10.00 uur

door

David Christiaan Buitenweg,
geboren te Nieuwegein

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Chapter 1

General introduction

Quality of Life in mental healthcare

Over the past decades, the concept of Quality of Life (QoL) has made its mark on mental health services [1-5]. Developments such as the ongoing deinstitutionalization, the growing focus on recovery and a more positive conception of health - that goes beyond the absence of symptoms - continue to reaffirm the importance and relevance of QoL [4; 6-8]. QoL serves as an important outcome measure and benchmark for evaluating the effects of treatment interventions in the contexts of individual treatment, scientific research, and health policy [9-12].

The exact definition and constituents of QoL, however, remain vague and are still frequently debated in the scientific literature [2; 13-15]. Several authors have pointed to the need for conceptual clarity surrounding QoL [2; 13]. Moons and colleagues [2] introduced a typology comprising various potential conceptual approaches to QoL. In light of several critical conceptual issues, they selected the *Satisfaction with life* approach as the most fitting. In this approach, QoL is understood to refer to an individual's subjective evaluation of his/her personal life [2]. This understanding of QoL ties in with the way QoL is generally comprehended in mental health and aligns with the aforementioned developments. To capture the broad effects of severe mental health conditions, QoL within mental health entails an individuals' subjective evaluation of diverse life domains such as *Family relations*, *Finances, Physical health*, and *Safety* [4; 5; 16; 17]. The *Satisfaction with life domains* approach to QoL will guide the research described in this thesis.

Examples of prominent QoL instruments used in mental healthcare include the Lancashire Quality of Life Profile (LQoLP; [5]) and its shortened version the Manchester Short Assessment of Quality of Life (MANSA; [17]). These QoL assessment tools have greatly aided our understanding and ability to accurately assess QoL in mental health care. Nevertheless, room for further improvement still exists within three areas of QoL assessment in people with severe mental health problems. First, the recognition that QoL is a subjective concept that derives its meaning from an individual's values and priorities [18-21] conflicts with a procrustean assessment approach in which every individual is required to answer to a fixed set of mandatory QoL domains. A QoL assessment instrument that enables respondents to select domains based on their personal values and priorities does more justice to the subjective nature of QoL. The second area of improvement relates to the language-based character of QoL assessment instruments, which is virtually universal in QoL assessment. This language-based approach likely does not fit with (a subgroup of) people with severe mental health problems. Three specific subgroups of people with severe mental health problems are of interest in this thesis: 1) people with severe psychiatric problems, 2) people treated in forensic psychiatry and 3) people who are homeless. These groups may have difficulty with traditional language-based QoL assessment due to experiencing fewer educational opportunities [24-26], co-occurring intellectual disabilities [22, 23, 26], and compromising psychiatric symptoms [59, 60]. A QoL instrument that employs alternative modes of communication by using audio or visuals may enable this group to engage more easily in QoL assessment. Third, QoL assessment ideally benefits the treatment of individuals and simultaneously informs scientific research and policy [22]. This requires a personalized QoL instrument that recognizes the idiosyncratic nature of QoL but also comprises general content that may be used to enable the comparison of individuals and groups. Such an instrument may combine a mandatory core of fixed content with a flexible shell that consists of facultative content that is to be chosen by individual respondents.

A digital application (app) offers the required flexibility to enable personalization and allows for the incorporation of diverse forms of multimedia such as audio and video that enable apps to move beyond language-based communication. In addition, a QoL assessment app may empower patients as they can use the app in their own place and time using their own device [23]. Therefore, a digital, web-based QoL assessment instrument has the required characteristics to enable further improvement in QoL assessment for people with severe mental health problems.

Digital revolution

Advancements in (mobile) digital technology have been the driving force behind profound changes in healthcare at large and mental health services in particular [24-26]. In 2017, the World Psychiatry Association-Lancet psychiatry commission on the future of psychiatry declared the arrival of the digital psychiatry revolution [27]. According to the commission, digital tools and techniques such as smartphone apps, virtual reality, machine learning and data analytics yield promising new possibilities for psychiatry [27]. Several developments lie at the basis of this digital revolution, with the rapid adoption of smartphones being especially important [28]. In the global population, smartphone ownership rates were expected to rise to 80 percent in 2020 [29]. Several studies conducted in 2015 and 2017 report smartphone ownership rates ranging from 27 to 88 percent among people with mental health problems [30-32]. Based on the decreasing costs and increasing availability of smartphones, ownership is expected to rise even further in the coming years [29; 30].

The use of apps and other digital tools in psychiatry, commonly referred to as e-mental health, promises benefits in three main areas. First, e-mental health promises to increase the availability and accessibility of mental health resources [33; 34]. Services may be offered outside of the confines of the clinic or treatment center [33-35], information and other resources may be more easily and widely available [35] and populations that have difficulty accessing traditional mental health resources are provided with more opportunities to do so [34]. An additional benefit of the increased availability of e-mental health lies in the opportunity to enhance care after formal treatment has ended [35]. A second promise of e-mental health revolves around its cost-effectiveness [35-37]. By incorporating e-mental health apps into treatment, less face-to-face sessions may be required [35]. In addition, costs related to travel, scheduling and administration may be cut. By providing aftercare using e-mental health, therapeutic effects may be perpetuated [40]. The flexibility of e-mental health in general and e-mental health apps in particular form a third advantage. This flexibility enables the tailoring of e-mental health apps and interventions to the needs and tastes of patients [38-41]. The app SIMPLe [40], a platform for psychoeducation targeting people with bipolar disorder, provides an excellent example of the flexibility of apps. The application offers psychoeducational content and risk alerts based on a user's response to daily and weekly tests. An algorithm determines what content is most relevant for the user [40]. The sharp increase in smartphone ownership among people with mental health problems, combined with the promises that e-mental health apps yield, has fueled an interest in the development of e-mental health apps. These apps serve a number of purposes, including treatment, providing information, self-assessment, and self-management and are developed for the entire spectrum of psychiatric diagnoses [25; 42; 43].

Only a small minority of e-mental health apps, however, are successfully used in the daily practice of care professionals, patients or other stakeholders. This absence of impact has prompted researchers to investigate factors related to the successful development and implementation of e-mental health apps [44-46]. They conclude that the involvement of end-users in the development of an e-mental health app is a vital prerequisite for achieving impact [45; 47-49]. End-users should be involved in this development through co-creation. In co-creative development, stakeholders (patients) do not only contribute in the latter phases of prototype testing but are viewed as active contributors with valuable skills and knowledge throughout the development process [50; 51]. Co-creative development of mental health apps aids the usability of the app and helps keep the development user-centric [45; 47; 48]. In addition to co-creative development, excellent usability is another requirement for generating impact. Therefore, various authors have reported usability guidelines for the design of e-mental health apps [52-54].

To summarize, a digital QoL instrument that does not rely solely on a language-based assessment approach, is personalized, and serves all involved stakeholders will advance QoL assessment in people with severe mental health problems. To maximize potential impact on practice, research and policy, this instrument should be developed co-creatively and its usability ought to receive sufficient attention during development.

Goals of this thesis

This thesis pertains to the development and evaluation of a digital QoL assessment app for people with severe mental health problems: the QoL-ME[1]. The QoL-ME has three main goals: 1) increasing the personalization of QoL assessment, 2) providing an alternative to language-based QoL assessment, and 3) providing patients, professional caregivers, researchers and policy makers with a practically valuable instrument.

Two innovative characteristics of the QoL-ME are directed towards the aforementioned goals of the app. First, the structure of the QoL-ME allows for a combination of the 'best of both worlds' in QoL assessment. It consists of a core version that involves a few mandatory domains of QoL found to be of specific use when data on an aggregated level are of interest. The core version is therefore especially relevant for researchers and policy makers. This core version may be supplemented with any combination of additional modules based on their relevance to the respondent. The additional modules, therefore, are particularly suitable for devising, monitoring and fine-tuning of individual treatment and are of specific relevance for patients and professionals. Second, the QoL-ME provides respondents for whom conventional, language-based QoL assessment may not fit optimally with an alternative form of communication as the QoL-ME features a pictorial approach to QoL assessment.

The QoL-ME will target the three aforementioned populations of people with severe mental health problems: 1) people with severe psychiatric problems, 2) people treated in forensic psychiatry and 3) people who are homeless.

The QoL-ME is developed and evaluated in a linear process involving five studies[2]. The outline of this thesis matches these studies. The content of the QoL-ME was developed in the first two studies. **Chapter 2** details the development of the content of the QoL-ME's core version on the basis of a quantitative analysis. To this end, a large database of data collected with the LQoLP, a structured interview developed to assess the QoL of people with severe mental illness, was used. This database was subjected to a latent class analysis. Univariate entropy was used to select the LQoLP domains that make up the core version of the QoL-ME. The contents of the additional modules of the QoL-ME are based on the results of a visual conceptualization of the meaning of QoL for people with severe mental health problems that is covered in **Chapter 3**. Participants provided pictures depicting important aspects of QoL. These pictures were sorted and processed statistically to generate a visual concept map. The results of the first two studies formed the basis of the development of the QoL-ME that is described in **Chapter 4**. In this study, the QoL-ME was developed co-creatively together

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[1] Phonetically: call me!

[2] In three chapters, the reader is referred to supplementary files in the form of Supporting Information (Chapter 3), Multimedia Appendices (Chapter 4 and Chapter 6) or Additional Files (Chapter 5). These supplementary files are available on the website of the journals.

with patients in an iterative process consisting of six iterations. In the final two iterations, the usability of the QoL-ME was systematically assessed. The third study resulted in the QoL-ME, which was evaluated both quantitatively and qualitatively in the final two studies. First, the reliability, validity and responsiveness of the QoL-ME were assessed in a quantitative study as described in **Chapter 5**. Second, the degree in which the QoL-ME matches patients' needs and preferences was evaluated qualitatively in **Chapter 6**. The extent to which the QoL-ME is beneficial and actionable for patients received special attention in this chapter. The main results are summarized and discussed in **Chapter 7**. This final chapter also involves a discussion of the strengths and limitations of the thesis, implications for policy and clinical practice, directions for future research and a main conclusion.

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Chapter 2

Subjectively different but objectively the same? Three profiles of QoL in people with severe mental health problems

This chapter has been published as:
Buitenweg, D. C., Bongers, I. L., Van de Mheen, D., Van Oers, H. A., & Van Nieuwenhuizen, Ch. (2018). Subjectively different but objectively the same? Three profiles of QoL in people with severe mental health problems
Quality of Life Research, 27(11), 2965-2974. doi: 10.1007/s11136-018-1964-7

Abstract

Purpose: Quality of life (QoL) is a broad outcome that is often used to assess the impact of treatment and care interventions in mental health services. QoL, however, is known to be influenced by individual values and preferences. To investigate this heterogeneity on the individual level, this study aimed to distinguish classes with distinct QoL profiles in a broad group of people with severe mental health problems and to identify the QoL domains that are most strongly related to the classes.

Methods: QoL data of seven studies that used the Lancashire quality of life profile (LQoLP) were used in a latent class analysis. Sociodemographic variables, health-related variables, and measures of well-being were used to characterize the classes. Additionally, univariate entropy scores were used to assess the strength of the association between the ten LQoLP domains and the latent classes.

Results: Two of the three indices of fit pointed towards a three-class model. The three classes differed significantly on all of the LQoLP domains, on well-being, and on ‘being in an intimate relationship’. No differences were found for the majority of the health-related and socio-demographic variables. The LQoLP domains ‘family relations’, ‘positive self-esteem’, and ‘negative self-esteem’ were most strongly related to the latent classes.

Conclusions: The identification of three distinct classes of QoL scores re-emphasizes the heterogenic nature of QoL. The lack of differences in sociodemographic or health-related characteristics between the three classes suggests that QoL is primarily determined by subjective, personal evaluations, rather than by objective characteristics and circumstances.

Introduction

Since the 1980s, quality of life (QoL) has become increasingly important as a patient-reported outcome (PRO) in mental health services [1-4]. In mental health, QoL is defined as an individuals' subjective evaluation of various life domains, such as physical health, family relations, finances, and well-being [5; 6]. Scores on these domains are often combined to form a global QoL score [4]. Due to its broad scope, QoL assessment in mental healthcare is useful for evaluating the impact of treatment and care interventions [7; 8]. The use of QoL data in mental health may even improve patients' satisfaction with care [9; 10]. As a consequence, QoL is widely regarded as an important, if not essential, outcome measure for people with mental health problems [9; 11; 12]. The broadness of QoL is one of its main strengths, but it also introduces complexity and results in a multitude of scores on the domain and global level [13]. The strong subjective aspect of QoL enhances this complexity. The concept is known to be influenced by individual priorities and values and differs between individuals [14] and even - because of response shift - within individuals [15-17].

To improve our understanding of the QoL of people with mental health problems, and to facilitate the interpretation of QoL scores, many researchers have investigated the relationships between QoL and demographic, clinical, and personal variables, such as age [18], country of residence, employment, accommodation [19], frequency of contact with family [20], severity of symptoms [20-22], insight [21], coping [18; 21], and medication adherence [18]. While these studies have advanced our understanding of the factors influencing QoL in mental health, such studies disregard potential heterogeneity on the individual level as they are focusing on average group scores.

The importance of the heterogeneity of QoL has been underlined in recent research [21; 23; 24]. Three studies illustrate how QoL differs within groups as a function of individual characteristics. Priebe and colleagues [23], for instance, identified a significant association between employment and QoL. This association was stronger for patients with neurotic disorders compared to patients with mood disorders or schizophrenia. A similar difference was found for the association between symptom levels and QoL [23]. A study by Montemagni and colleagues [21] provides a second example. The researchers investigated the associations between QoL and negative symptoms, insight, and coping strategies in a group of outpatients with schizophrenia. Their results indicate that correct attribution of symptoms to illness positively influences QoL in patients with mild negative symptoms, but not in patients with severe negative symptoms [21]. In an attempt to gain more insight into the heterogeneity in QoL scores, De Maeyer and colleagues [24] used Latent Class Analysis (LCA) to explore classes with distinct QoL-profiles within a homogeneous sample of opiate-dependent individuals. The three classes identified using LCA were characterized using socio-demographic, drug-, health-, and person-related variables. The first class consisted of individuals living in marginal conditions who had problems regarding housing, judicial problems, and frequently demonstrated injecting behavior. Another class involved socially included opiate dependent individuals whom experienced problems with severe mental health problems, goal fulfilment and employment. Hence, the identification of classes with distinct QoL-profiles may be beneficial to the ability to interpret and apply QoL data in an individualized way.

The aim of this study is to investigate classes with distinct QoL-profiles in a broad group of people with severe mental health problems. Furthermore, to facilitate the interpretation of QoL scores, the QoL-domains that are most strongly related to the classes will be identified.

Materials and methods

Sample

This study involved a secondary analysis of QoL data collected with the Dutch version of the Lancashire Quality of Life Profile (LQoLP). The LQoLP is a structured interview specifically developed to assess the QoL of people with severe mental health problems [25; 26]. To identify relevant data sets, a number of colleagues were consulted by telephone and email. Inclusion criteria were that the data sets targeted people with severe mental health problems and used the original Dutch version of the LQoLP [4] or the extended Dutch version of the LQoLP [26]. Data sets fitting these criteria were collected and combined into a single database.

Seven data sets were included [5; 24; 26-30]. In the case of a longitudinal design, only the measurement at the first time point was used. LQoLP data for 1,277 persons with psychiatric problems were available. The data sets were collected between 1997 and 2014. Table 1 provides an overview of the characteristics of the seven included studies.

Table 1. Study characteristics of the seven included studies.

Study	Sample size	Research design	LQoLP version
Proost [30]	116	Cross-sectional	Original
Van Nieuwenhuizen *et al. [26]*	487	Cross-sectional	Original
Barendregt *et al*. [27]	172	Longitudinal	Extended
De Maeyer *et al*. [24]	159	Cross-sectional	Extended
Bouman *et al.* [28]	135	Cross-sectional	Extended
Harder *et al.* [29]	164	Longitudinal	Extended
Van Nieuwenhuizen and Nijman [5]	44	Cross-sectional	Extended

Lancashire Quality of Life Profile

The LQoLP measures an individuals' satisfaction with ten different life domains, as well as their general well-being. The LQoLP contains both objective items ('Do you have a paid job?') and subjective items ('How satisfied are you with your monthly income?'). The LQoLP generates a QoL profile that is based on 58 subjective items. Objective items are included in the interview because variance in global well-being has been found to be mediated by both objective and subjective well-being [25] and to serve as a primer.

All of the ten LQoLP-domains comprising the subjective QoL profile were used in the analysis: (1) 'physical and mental health,' (2) 'leisure and social participation,' (3) 'finances,' (4) 'safety,' (5) 'living situation,' (6) 'family relations,' (7) 'positive self-esteem,' (8) 'negative self-esteem' (Domain 7 and Domain 8 were measured using a modified version of the Self-Esteem Scale [31]), (9) 'framework' and (10) 'fulfilment' (Domain 9 and Domain 10 were measured by the Life Regard Index [32]). Both the Self-Esteem Scale and the Life Regard Index are part of the LQoLP [26]. Domain scores were calculated by averaging item scores.

The first six domains cover tangible aspects of QoL and are measured on a 7-point Likert scale, ranging from 'cannot be worse' (1) to 'cannot be better' (7). The last four domains involve intangible, self-related aspects of QoL and are measured on a 3-point Likert scale: 'disagree' (1), 'I do not know' (2), and 'agree' (3). To allow comparison between all domains, scores on the last four domains were transformed using the following transformation *M' (transformed mean score) = (M (mean score)/3) * 7* [4]. A QoL score of below 4 has been defined as a low QoL score and a QoL score of 4 or higher has been designated as a high QoL [5]. The LQoLP also contains two measures of global well-being in the form of Cantril's Ladder [33] and an average Life Satisfaction Score (LSS; 'how satisfied are you with life as a whole?'). Additionally, the LQoLP includes a Happiness Scale that asks respondents to report how happy their life has generally been on a 5-point Likert scale. Several variables of the LQoLP, including sociodemographic variables, health-related variables, and measures of well-being were used to characterize the classes. For an overview of these variables, see Table 4.

Psychometric properties (internal consistency, reliability and validity) of both the original LQoLP and its (extended) Dutch version have been demonstrated to be satisfactory [4; 25; 26]. The Cronbach's alpha for the 58-item QoL score was 0.93 and eight of the ten domains had an alpha of more than 0.70 [26]. The Intraclass Correlation Coefficients (ICC) for the 58-item QoL score was 0.92, while seven of the ten domains had an ICC of > 0.80. The content validity was guaranteed through the construction process and the construct validity was examined by computing correlations between the 58-item QoL score and the Satisfaction With Life Scale (r = 0.71) and a single-item Life Satisfaction Scale (r = 0.73) [26].

Missing data

Due to differences between the original and extended versions of the Dutch LQoLP, three of the ten domains contained missing data. Specifically, two types of missing data were encountered and dealt with using two different methods. First, in the extended version of the Dutch LQoLP, two out of six items in the domain ‘living situation’ were dropped because they applied to less than 25 percent of the respondents [26]. Consequently, all of the data for the extended Dutch LQoLP was missing on these two items. Due to the large number of cases with missing data on these items, domain scores for all participants were computed based on the four remaining items in the extended Dutch LQoLP. Second, in the extended Dutch version of the LQoLP, items were added to the domain ‘family relations’ (four items) and the domain ‘safety’ (three items), because of the relatively low reliability of these two domains in the original version [26]. Consequently, all data for the original LQoLP version contained missing data on these newly added items. Because missing items were explained by the difference in LQoLP versions, full information maximum likelihood (FIML) was used to address missing data. FIML estimates a likelihood function for every individual, based on the data available for that individual. Model fit information is derived by summing these individual likelihood functions. FIML has been found to be a reliable method when missing data is missing at random (MAR) [34; 35].

Statistical analysis

To identify classes with distinct QoL-profiles based on the patterns of scores on the ten LQoLP domains, an LCA was performed. In LCA, the modelled latent variable is assumed to be categorical, consisting of multiple classes. Individuals are assigned to one of the classes by examining the underlying structure of categorical data [36; 37]. The current analysis consisted of three steps. In the first step of the analysis, LCA models with a varying number of classes were estimated and compared. The analysis started by estimating a model with a single class. Next, models with k+1 classes were estimated, up to k=6 classes. These models were compared using three indices of model fit: the Bayesian Information Criterion (BIC), the Vuong-Lo-Mendell-Rubin (VLMR) likelihood ratio test and entropy. The BIC is an indicator of relative model fit. Lower values indicate a better fit of the model to the data. The VLMR likelihood ratio test compares the relative fit of a model with k classes and a model with k-1 classes. A significant result on the VLMR test result indicates a better fit of the model with k-1 classes. Entropy is a measure for the distinctiveness of the classes. Values range from 0 to 1 and a value of 0.8 or higher is generally considered desirable as it indicates a clear delineation of the classes [38]. Model selection depended on these three indices of fit, as well as a theoretical interpretation of the classes. Additionally, univariate entropy [39] was used to assess the contribution of the ten LQoLP domains to the classification. Univariate entropy is a measure of how well the latent indicators identify the latent classes.

In the second step of the analysis, individuals were assigned to one of the classes on the basis of posterior class membership probabilities. The third step of the analysis involved the characterization of the classes by relating class membership to: 1) socio-demographic variables, 2) health -related variables, and 3) measures of well-being. Differences between the classes were investigated using Chi-square tests (for dichotomous variables) or a one-way Analysis of Variance (ANOVA). For variables that violated the assumptions of ANOVA, a non-parametric alternative in the form of a Kruskal-Wallis Test [40] was used. The LCA was performed using M-plus 7.3 [41]. All other analyses were run using SPSS, version 19 [42].

Results

Sample Characteristics

Participants were predominantly male (72 %), with a mean age of 35.16 years (SD = 15.01, range = 12–85). The majority (81.9 %) of participants were of Dutch nationality, 16.4 percent of the respondents were employed, and about a third (29.8 %) were in an intimate relationship at the time of the interview.

Latent Class Analysis

Fit statistics for latent class models with 1-6 classes are presented in Table 2. Bayesian information criterion (BIC) values decreased across the tested models, which suggested that the 6-class model provided the best fit. The results for the Vuong–Lo–Mendell–Rubin (VLMR) likelihood ratio test, however, revealed that models with more than three classes overfit the data because the test returned a non-significant result for these models (p-value ≥ 0.05). The three-class model had both a lower BIC score (BIC = 64303.46) and a higher entropy (0.86) than the two-class model (BIC = 64515.92, entropy= 0.83). Although the four-class model had the most favorable entropy (0.9), it also produced a non-significant result on the VLMR likelihood ratio test and contained a relatively small fourth class. Therefore, the three-class model fit the data best. Average QoL scores on the ten LQoLP domains differed significantly between the three classes and can be found in Figure 1 and Table 3.

A chi-square test for equality of distributions revealed no significant differences in how participants from the seven samples were distributed over the three classes χ^2 (12, N = 1277) = 10.92, *p* = 0.54.

Table 2. Fit statistics for latent class models with 1 to 6 classes (N = 1277).

Number of classes	BIC*	Entropy	Vuong-Lo-Mendell-Rubin test p-value
1	68,016.76		
2	64,515.92	0.83	0.00
3	64,303.46	0.86	0.013
4	62,662.29	0.90	0.131
5	62,083.98	0.85	0.485
6	61,830.01	0.84	0.186

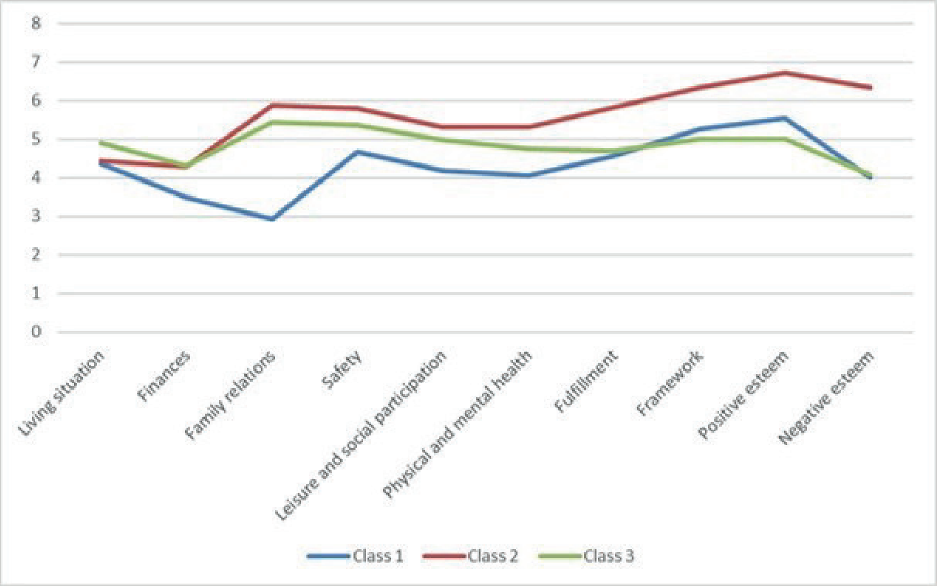

Figure 1. Mean LQoLP domain scores for the three classes identified with the LCA.

Table 3. LQoLP domain scores for the three classes.

LQoLP domain	Class 1 (n = 358)	Class 2 (n = 342)	Class 3 (n = 577)	F statistic (df = 2)	Group differences
Living situation (SD)	4.38 (1.46)	4.45 (1.53)	4.91 (1.3)	16.69*	3 > 2,1
Finances (SD)	3.49 (1.31)	4.3 (1.51)	4.31 (1.31)	46.7*	3,2 > 1
Family relations (SD)	2.93 (1.05)	5.88 (0.75)	5.44 (0.85)	1,162.65*	2 > 3 > 1
Safety (SD)	4.68 (1.23)	5.81 (0.71)	5.37 (.92)	113.44*	2 > 3 > 1
Leisure and social participation (SD)	4.19 (1)	5.33 (0.75)	4.98 (0.85)	160.8*	2 > 3 > 1
Health (SD)	4.07 (0.98)	5.33 (0.77)	4.76 (0.88)	176.44*	2 > 3 > 1
Fulfilment (SD)	4.58 (0.92)	5.83 (0.8)	4.71 (0.73)	264.1*	2 > 3,1
Framework (SD)	5.26 (0.98)	6.34 (0.77)	5.01 (0.76)	284.54*	2 > 1 > 3
Positive esteem (SD)	5.54 (1.16)	6.72 (0.49)	5.02 (0.87)	377.34*	2 > 1 > 3
Negative esteem (SD)	4.01 (1.25)	6.35 (0.85)	4.08 (0.85)	668.29*	2 > 3,1

*= p = < 0.001.

Class description

Class 1 (n = 358) comprises 28 percent of the sample and encompasses people with severe mental health problems with the lowest score on all of the LQoLP domains, except for two of the intangible domains ‘framework’ and ‘positive esteem’. Individuals in this class reported low scores on the domains ‘family relations’, and ‘leisure and social participation’. Moreover, they score relatively low on the domain ‘health’ despite not receiving more care than the other two classes. Therefore, Class 1 was labelled ‘socially isolated individuals with unmet care needs’.

Involving nearly 27 percent of the sample, Class 2 (n = 342) includes people with severe mental health problems with the highest score on every life domain, except on two of the tangible LQoLP domains ‘living situation’ and ‘finances’. Individuals in this class report especially high scores on the domains of the LRI and are therefore labelled ‘individuals with an overall good QoL having a meaning in life’.

Class 3 (n = 577; 45.2%) is the largest class and involves people with severe mental health problems who are characterized by the lowest scores on the ‘framework’ and ‘positive esteem’ domains and by the highest scores on the life domains ‘living situation’ and ‘finances’. On the other six domains, individuals in Class 3 report an intermediate score. Since individuals in this class report satisfactory scores on the six tangible domains, but relatively low scores on the domains of the LRI and a high degree of negative affect, Class 3 was labelled ‘individuals with a good overall QoL but lacking a meaning in life and struggling with affect’.

Class comparison

As can be seen in Table 4, there were no significant differences between the classes on most of the socio-demographic variables. No differences were found between the classes for mean age, gender distribution, nationality, and mean age for cessation of formal education. The classes differed on having an intimate relationship, but post-hoc tests revealed no significant differences between pairs of classes. The classes also did not differ significantly with regard to having structured daily activities, receiving social benefit, living alone, and marital status.

As displayed in Table 4, the classes did not differ significantly on any of the health-related variables. No significant differences were identified for receiving professional help or being hospitalized due to psychological complaints during the past year, nor did the classes differ on taking medication for psychological complaints during the past year, being admitted to a psychiatric ward or hospital, age at first admission, or being unable to gain professional help for their health during the past year.

Table 4 reveals that the classes differed significantly on three of the four measures of well-being. Individuals in Class 2 reported a significantly higher LSS than individuals in Class 1. Moreover, individuals in Class 2 and Class 3 scored significantly higher on Cantril's Ladder than individuals in Class 1. Additionally, individuals in Class 2 reported significantly less negative effect than individuals in the other two classes. No significant differences were identified for the Happiness Scale.

Table 4. Associations between the three latent classes and socio-demographic variables, health-related variables, and measures of well-being.

Variable	Class 1 (n = 358)	Class 2 (n = 342)	Class 3 (n = 577)	Statistic[1] (p-value)	Group differences
Socio-demographic variables					
Mean age (SD)	35.16 (14.7)	35.18 (15.5)	35.11 (14.6)	χ^2(H)=0.05 (0.974)	-
Male	72.8 %	74.3 %	71.1 %	χ^2=1.15 (0.562)	-
Dutch nationality	82.7 %	82.2 %	84.4 %	χ^2=0.85 (0.655)	-
mean age for cessation of formal education (SD)	15.88 (5.2)	15.52 (6.3)	16.21 (6.7)	F=1.35 (0.259)	-
Intimate relationship	28.4 %	35.4 %	27.4 %	χ^2=.9.52 (0.049)	-
Structured daily activities	78.5 %	77.0 %	76.9 %	χ^2=0.355 (0.837)	-
Social benefit	62.1 %	57.8 %	60.3 4	χ^2=1.375 (0.503)	-
Living alone	28.8 %	29.8 %	30.3 %	χ^2=0.258 (0.879)	-
unmarried	74.4 %	76 %	76.9 %	χ^2=0.737 (0.603)	-
Health-related variables					
Saw a psychiatric care professional during the last year	62 %	61.7 %	57.2 %	χ^2=2.87 (0.238)	-
Hospitalized for psychological complaints during the past year	19 %	23.1 %	21 %	χ^2=1.778 (0.411)	-

Variable	Class 1 (n = 358)	Class 2 (n = 342)	Class 3 (n = 577)	Statistic[1] (p-value)	Group differences
Medication for psychological complaints during the last year	59.5 %	59.4 %	57.4 %	χ^2=0.56 (0.757)	-
Admitted to psychiatric hospital/ward	50.7 %	55 %	53.6 %	χ^2=1.372 (0.504)	-
Age at first admission to psychiatric hospital/ward (SD)	25.3 (11.9)	24.8 (12.2)	25.4 (11.4)	F=0.166 (0.847)	-
Unable to gain professional help for health during past year	76 (21.2%)	72 (21.2%)	122 (21.3%)	χ^2=0.00 (0.998)	-
Measures of well-being					
Life Satisfaction Score	4.17 (1.24)	4.42 (1.22)	4.33 (1.22)	F=3.74 (0.024)	2 > 1
Cantril's ladder (SD)	50.67 (23.4)	57.61 (23.1)	54.53 (22.7)	F=7.8 (< 0.001)	2 > 1, 3 > 1
Happiness Scale (SD)	2.89 (1)	2.93 (1)	2.95 (1)	F =0.44 (0.643)	-
Negative affect (SD)	4.89 (1.96)	4.53 (1.57)	5.08 (1.65)	F=10.96 (< 0.001)	2< 1, 2 < 3

[1] Depending on the variable, an ANOVA (F), Chi-square test (χ2), or Kruskall-Wallis test (H) was used.

Domains contributing to the class differentiation

Table 5 provides the univariate entropy values for the ten LQoLP domains. Univariate entropy values range between 0.041 (domain 'living situation') and 0.368 (domain 'family relations'). The average univariate entropy is 0.177 (SD = 0.112). The domains 'family relations' (0.368), 'positive self-esteem' (0.366), and 'negative self-esteem' (0.231) have the highest univariate entropy values and are most useful for identifying the latent classes.

Table 5. Univariate entropy values for the ten LQoLP domains (N = 1277).

Quality of life domain	Univariate entropy
Living situation	0.041
Finances	0.056
Family relations	0.368
Safety	0.061
Leisure and social participation	0.131
Health	0.142
Fulfilment	0.180
Framework	0.198
Positive self-esteem	0.231
Negative self-esteem	0.366

Discussion

Several studies have underlined the heterogeneity and idiosyncratic nature of QoL, warranting a differentiated approach to interpreting and applying QoL data. This study aimed to investigate classes with distinct QoL-profiles in a broad group of people with severe mental health problems. To further facilitate the interpretation of QoL scores, the QoL-domains which are most strongly related to these classes were examined. Utilizing a person-centered method in the form of LCA, three classes with distinct QoL-profiles were identified. The results further accentuate the individual nature of QoL, a finding that is in confirmation with previous studies [23; 24].

Closer inspection of the classes based on the ten subjective LQoLP domains, sociodemographic variables, health-related variables and measures of well-being suggests that QoL is primarily determined by subjective, individual aspects rather than by objective circumstances. Three findings support this notion. First, participants from the seven included studies were divided evenly over the three classes, even though some samples cover (forensic psychiatric) inpatients, whilst other samples involve outpatients. Differences regarding the QoL of psychiatric inpatients and outpatients have been established in the past [5; 43]. The current results indicate that, even though group averages on the QoL domains may differ between groups, patients from different settings may have similar QoL-profiles. Second, the classes differed significantly on a single sociodemographic or health-related variable: 'having an intimate relationship'. Post-hoc tests, however, revealed no differences between pairs of classes on this variable. Many studies report a positive relationship between QoL and several sociodemographic or health-related variables, such as age, being in paid employment, symptoms of depression, and negative schizophrenic symptoms [18; 19; 21; 22; 43]. The lack of differences between the classes on sociodemographic and health-related variables in this study may appear counterintuitive, but many researchers have observed a weak association between objective conditions and an individuals' subjective appraisal of these conditions [44-46]. This phenomenon is known as the 'disability paradox' [47]. The results suggest that a disability paradox is present in the current sample. Third, significant differences were identified for Cantril's Ladder and the LSS, which reflect participants' subjective evaluations of their objective circumstances. Moreover, individuals in Class 2 reported significantly lower negative affect than the other classes, which is likely to contribute to their high scores on the ten LQoLP-domains. This explanation sits well with studies in which an association between affect and subjective QoL has been identified [48; 49].

The notion that QoL is primarily determined by subjective, individual aspects rather than by objective circumstances is in agreement with the theory of Subjective Well-Being (SWB) homeostasis [50; 51]. According to the theory of SWB homeostasis, an individuals' SWB is homeostatically regulated to vary within a relatively narrow range of genetically determined set-points [50; 52]. According to this theory, objective circumstances do influence SWB, but only within a genetically determined bandwidth. It is possible that the QoL-profiles identified in this study reflect different set-points rather than objective circumstances. Bartels [53] provided additional evidence for the genetic component of QoL and SWB. In a review of 30 twin studies on the genetic component of well-being, heritability estimates ranging from 17 to 56 percent for overall wellbeing, and 22 to 42 percent for QoL were identified.

To facilitate the interpretation of QoL scores, the LQoLP domains that were most strongly related to the classification were identified. Based on univariate entropy scores, the domains 'family relations' and 'self-esteem' were most useful for identifying the latent classes. This means that the classes are most clearly demarcated on these domains [38]. Individuals in Class 1 score exceptionally low on family relations (2.93), well below the cut-off score of 4 [5]. In contrast, Class 2 and 3 score very high on this domain. The large differences between the classes may be explained through the degree of support individuals receive from their family network, which has been found to influence the way patients evaluate their family situation [54]. Additionally, lack of support from family is related to internalized stigma [55]. Scores on Self-esteem (both positive and negative) also differ strongly between the classes. Individuals in Class 2 report significantly higher self-esteem than individuals in the other two classes. The polarizing role of self-esteem may be related to stigmatization, which is known to have a negative impact on self-esteem in people with severe mental health problems [16; 56].

The association between socioeconomic conditions and mental health and QoL is well documented [57-60]. The three profiles identified in this study, however, showed a marked difference in QoL, but not on sociodemographic characteristics. It is possible that the three profiles are indicative of a difference in resilience. Individuals in Class 2 may be better equipped to endure adversities caused by their poor mental health and socially adverse positions, whilst individuals in Class 1 and 3 are not as equipped to do so. The results suggest that the ability to discern meaning and purpose in one's life may be important in explaining this difference in resilience. Studies by Min and colleagues [61] and Wartelsteiner and colleagues [62] confirm this notion.

Strengths and limitations

The current study was based on a large database of LQoLP data. The comprehensiveness of the LQoLP and the rigidity of its development ensure data of high quality. The use of a person-centered method in the form of LCA enabled us to better capture the multidimensional nature of QoL. Apart from these strengths, three weaknesses should be kept in mind when interpreting the results. First, the analysis was limited to LQoLP data. These domains are based on thorough empirical research [25; 26], but as most QoL scales tend to assess slightly different QoL-domains, it is possible that classes with different profiles would have been found if another QoL measure had been used. The second limitation relates to the timespan in which data was collected. Data was collected in the period between 1997 and 2012, a span of 15 years. Changes in society and in mental healthcare [63; 64] may have influenced the meaning and composition of QoL for people with psychiatric problems, which might have biased the results. Third, no clinical data was available for the characterization of the classes. Past research indicates that variables such as type and severity of symptoms, style of coping, and adherence to treatment are related to QoL [20; 21; 46]. This type of data would have provided additional insight into the nature of the three classes, and future studies may include them.

Conclusion

The identification of three classes with distinct QoL-profiles for people with severe mental health problems further emphasizes the heterogenic nature of QoL in this population. The classes differed markedly on the subjective QoL domains, general well-being and negative affect, but not on the majority of the sociodemographic variables and objective indicators of QoL. This result suggests that, for people with severe mental health problems, QoL is primarily determined by individual, personal aspects rather than circumstances, and provides additional evidence for the disability paradox. Furthermore, the results stress the importance of subjective evaluations in the assessment of the QoL of people with severe mental health problems. The QoL-profiles may aid in the interpretation of QoL scores and the domains ‘family relations’ and the two domains related to self-esteem are especially useful in this regard.

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Chapter 3

Worth a thousand words? Visual concept mapping of the quality of life of people with severe mental health problems

This chapter has been published as:

Buitenweg, D. C., Bongers, I. L., Van de Mheen, D., Van Oers, H. A., & Van Nieuwenhuizen, Ch. (2018). Worth a thousand words? Visual concept mapping of the quality of life of people with severe mental health problems. *International Journal of Methods in Psychiatric Research, 27(3), e1721. doi: 10.1002/mpr.1721*

Abstract

Objectives: Conventional approaches to Quality of Life (QoL) measurement rely heavily on verbal, language-based communication. They require respondents to have significant cognitive and verbal ability, making them potentially unsuitable for people with severe mental health problems. To facilitate an alternative approach to QoL assessment, the current study aims to develop an alternative, visual representation of QoL for people with severe mental health problems.

Methods: An alternative, visual adaptation of the concept mapping method was used to construct this visual representation of QoL. Eighty-two participants (i.e. patients, care professionals and family members) contributed to this study. Results were processed statistically to construct the concept map.

Results: The concept map contains 160 unique visual statements, grouped into eight clusters labelled (1) *Support and Attention*, (2) *Social Contacts*, (3) *Happiness and Love*, (4) *Relaxation and Harmony*, (5) *Leisure*, (6) *Lifestyle*, (7) *Finances*, and (8) *Health and Living*. Examples of visual statements are pictures of family silhouettes, romantic couples, natural scenes, houses, sports activities, wallets and coins, smiley faces and heart shapes. The clusters were interpreted and labelled by participants.

Conclusions: Almost all of the statements correspond to clusters found in previous (non-visual) QoL research. Hence, QoL-domains can also be presented visually.

Introduction

Current QoL-related research focuses on improving our ability to measure QoL in a number of ways. First, researchers have developed and translated QoL scales [1-3]. Second, Rasch models and item response theory are often used to assess the psychometric properties of QoL scales [4; 5]. Third, the rise of Computerized Adaptive Testing (CAT; [6; 7]) has provoked an increase in CAT-related work, including the development of item banks [8; 9]. Finally, the accuracy of QoL measurement in different groups in the form of measurement invariance [10; 11], and over time in the form of response shift [12; 13], is now a major theme in QoL research. As a result of these efforts, our ability to measure QoL accurately and reliably has improved greatly.

Conventional methodologies for the conceptualization and measurement of QoL depend heavily on verbal communication and the ability of respondents to process complex written or oral information and to express themselves verbally. The majority of self-report QoL-measurement scales require respondents to answer a number of questions or statements by selecting one of several Likert options. Examples of frequently used scales utilizing this format include the Medical Outcomes Study (MOS) SF-36 and related measures [14], the EQ-5D and its numerous adaptations [15], and the MANSA [16]. Development of scales such as these often involves a conceptualization of QoL [17-19], in which participants are commonly asked to verbalize what QoL means to them in interviews or focus groups. These language-based approaches, both for the measurement and conceptualization of QoL, have been instrumental in the improvement of our understanding of QoL and how to assess it. They are especially effective in research which targets participants who function at a sufficient cognitive level and who have the ability to express themselves verbally.

People with severe mental health problems may experience a marginalized position in society. Examples of this marginalized position include fewer social support from family [20; 21], an increased risk of suffering from a substance abuse disorder [22-24], and being criminally victimized more frequently compared to the general population [25; 26]. Furthermore, people with severe mental health problems often have fewer educational opportunities [22; 24; 27] and occupational success compared to the general population [28-30].

Several empirical studies support the notion that people with severe mental health problems have difficulties engaging in conventional QoL assessment. Evidence gathered by Reininghaus and colleagues [31] suggests that the validity of a QoL measure for psychiatric patients may be compromised due to psychopathology. A study by Ogden and Lo [32] of a group of homeless people revealed a striking discrepancy between data obtained from Likert scales and data collected with free text questions. Hence, traditional language-based QoL assessment, which relies heavily on people's verbal and cognitive abilities, might be less appropriate for people with severe mental health problems. Visual communication could be a suitable alternative for those for whom the traditional approach does not fit. Using visual communication has a number of advantages over its verbal counterpart. Examples are its accessibility, better computational efficiency [33], and little to no requirement of analytical decomposition [34]. Various forms of visual communication have been successfully applied in healthcare and related fields, mainly with people for whom conventional, language-based methods of communication are inappropriate. Haque and Rosas [35], for example, investigated neighborhood factors that affect health and well-being using visual stimuli. A group of Canadian immigrants with various cultural and linguistic backgrounds shared their perceptions through photographs. The researchers conclude that their visual approach enabled participants from diverse backgrounds to actively contribute to the research, and provided the researchers with an opportunity to tap into participant understanding of complex phenomena, regardless of the linguistic diversity of the sample [35]. Other examples include the use of visual communication to enhance the health literacy of people with limited reading proficiency [36; 37], the use of pictures in a functional communication system for children with autism [38; 39] and Photovoice, a form of participatory action research in which participants use photography to express their point of view [40-42].These examples strongly indicate that a visual approach to the conceptualization and assessment of QoL may be beneficial for people with severe mental health problems.

To enable an alternative, visual approach for the assessment of QoL, the current study aimed to develop a visual representation of QoL utilizing a comprehensive method based on visual stimuli. Moreover, the validity of the visual representation of QoL was examined by comparing the results with previous—verbally oriented—QoL-research.

Method

Participants

The current study targeted people with severe mental health problems for whom conventional approaches to QoL measurement are likely to be suboptimal. Specifically, three populations were of interest: 1) people with psychiatric problems, 2) people treated in forensic psychiatry and 3) people who are homeless. In addition to patients' own perspectives on QoL, the perspectives of family members and care professionals were also explored. These non-patient groups were included because they possess valuable and unique insights regarding the QoL of people with severe mental health problems, as past studies have revealed [43; 44]. A new group of participants was recruited for every step of the concept mapping. In total, a group of 82 participants contributed to this study. Participants were recruited within six societal institutions that collaborated in a consortium to facilitate this research project, including a mental health institution, a hospital for forensic psychiatry, a day treatment center for young adults, a day center for people who are homeless and two research institutions that concentrate on lifestyle, homelessness and addiction.

Procedure

All of the participants were recruited with the help of the six societal institutions. Participants who contributed to the structuring and interpretation of statements (see below) received €10 in gift vouchers as compensation. The procedures of the specific concept mapping steps are outlined in detail below.

Ethical approval was obtained from the Ethics Committee of the Tilburg School of Behavioral and Social Sciences at Tilburg University (EC-2015.44). Informed consent was obtained from each participant. All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Concept Mapping

To construct a visual representation of QoL for people with severe mental health problems, a visual modification of the concept mapping method was used. Concept mapping is a structured mixed-methods framework for the conceptualization of complex multi-dimensional concepts [45; 46], based exclusively on participants' input. It has been used in fields such as mental health [47] and patient reported outcomes [48]. In concept mapping, a number of statements or interpretations of the target concept are elicited and structured. The results are processed using several multivariate statistical techniques, resulting in a final concept map that depicts all of the statements and the suggested relationships between them. Interpretation of the concept map clarifies the ideas underlying the concept and may form the basis for a theory [49], or development of a measure [50], or an intervention [51].

To suit the aim of the current study, a visual modification of the method described by Trochim [46] was used. The following four steps, derived from Trochim's method, are discussed below: 1) gathering statements, 2) structuring and prioritizing statements, 3) statistical analysis, and 4) interpretation of the concept map.

Step 1: Gathering statements

The concept mapping framework was modified substantially in this first step. Instead of verbal statements, visual statements in the form of drawings, pictures and photographs were collected. These visual statements were gathered using a website specifically developed for this study. Participants, who agreed to contribute to the study (N=50; 22 patients, 22 care professionals and six family members), provided their email address and then received a link to the website. The project's website consisted of three pages. The first page provided participants with a detailed description of both the goal of the study and what was required of them. The second page contained a number of basic demographic questions and required participants to provide their informed consent. The third page comprised further instructions and an online environment that allowed participants to produce visual statements by making a drawing, uploading a picture, or searching for a picture via Google Images at https://images.google.com/. Participants were requested to indicate what, according to them, was important for the QoL of people with severe mental health problems by providing three visual statements. Once this was done, participants were asked to leave the website. As the procedure outlined above required considerable computer skills, most of the participating patients received in-person assistance from one of the researchers.

Step 2: Structuring statements

The visual statements gathered in Step 1 were printed on paper cards. A new group of participants (N=17; nine patients and eight care professionals) was recruited and asked to cluster the entire set of cards, based on the life domain they felt was depicted. Structuring of the statements was done in three separate focus groups in which participants clustered the statements individually. Participants were free in the amount of clusters of cards they assembled and were required to assign every statement to a cluster.

Step 3: Statistical analysis

Binary Symmetric Similarity Matrices (BSSM) were computed for the individual cluster arrangements made by participants in Step two. These matrices contain a number of rows and columns equal to the number of previously collected and structured statements. Every cell of a BSSM indicates whether a pair of statements (corresponding to the row and column numbers) was placed in the same cluster. Through matrix addition, an aggregated BSSM was computed. Every cell of the aggregated BSSM indicates the supposed similarity of pairs of pictures. After processing the BSSM, it was decomposed using Principal Component Analysis (PCA). All of the 160 statements were plotted in a two-dimensional space, using the first two dimensions of the PCA solution as x- and y-coordinates. Rosas and Kane [52] assert that the quality of a concept map can be assessed by evaluating the congruence between participants' contributions (the aggregated BSSM) and the final representation (the concept map). To this end, R-squared was calculated for the PCA model. Hierarchical cluster analysis (using the average linkage method) was used to group the statements into a number of clusters.

Step 4: Interpretation of the concept map

To determine the optimal number of clusters, the authors compared several concept maps with different numbers of clusters. The average number of clusters constructed by participants in Step 2 (M) was used as a criterion to decide which concept maps were to be compared. Specifically, concept maps with (M ± 2.5) clusters were examined and compared by the authors. A deviation of 2.5 allows some variety in the concept maps to be compared, whilst not deviating too far away from the average.

A new group of participants (N=15 patients) was recruited to help with interpretation of the final concept map. Every cluster was separately printed on a paper sheet and presented to participants individually. Participants were requested to provide three interpretations for every cluster. These interpretations, along with the individual concept maps previously constructed, were used by the authors to interpret the final concept map.

Validation procedure

To examine its validity, the clusters and statements of the visual concept map were compared with the themes and subthemes of QoL identified by Connell and colleagues [53; 54]. In a review of thirteen qualitative studies pertaining to the meaning of QoL for people with severe psychiatric problems, Connell and co-workers [53] identified six major themes of QoL, each consisting of four to nine subthemes. The review was supplemented by a qualitative empirical investigation, which revealed a seventh theme and several additional subthemes [54]. This combined approach of a comprehensive literature review, supplemented by an empirical study, lends authority to the results by Connell and colleagues [53; 54] and ensures that their work is a credible standard for comparison.

Software

The BSSM matrices were constructed using Microsoft Excel, version 2010. All of the statistical analyses were carried out using R statistics, version 3.2.5 [55].

Results

Participants

A total of 82 participants contributed to this study. Table 1 displays how many patients, family members and care professionals contributed to the different steps of the study, and Table 2 shows their demographic characteristics. Fifty participants cooperated by providing visual statements: 22 patients, 22 care professionals and six family members. A little over half were male (58%); their mean age was 39.8 (SD = 12.5). Another group of 17 participants structured the statements, including nine patients and eight care professionals. Less than half (47%) were male; their mean age was 38.2 (SD = 10). A final group of 15 participants, all of them patients, contributed by interpreting the concept map. Eighty percent of them were male; their mean age was 49.7 (SD = 13.8).

Table 1. Number of participants from each subgroup per step of the concept mapping procedure

	N participants	Patients	Caregivers	Family members
Collection of statements	50	22	22	6
Structuring of statements	17	9	8	-
Interpretation of the concept map	15	15	-	-
Total	82	46	30	6

Table 2. Demographic characteristics of participants

	N participants	% Male	Mean age (SD)
Collection of statements	50	58	39.8 (12.5)
Structuring of statements	17	47	38.2 (10)
Interpretation of the concept map	15	87	41.8 (17.6)
Total	82	61	39.8 (13.1)

Concept mapping

A total of 167 visual statements was collected in the first step. Seven of these were duplicates, leading to a total of 160 unique statements. Participants provided 3.2 pictures on average (range = 1–11). The 160 statements can be found in the Supporting Information. The 17 participants who structured the statements in Step 2 created an average of 9.5 clusters (range = 3–20). An example of such a cluster can be found in Figure 1.

Every individual cluster arrangement was translated to a BSSM. The first two PCA-components of the decomposed aggregated BSSM were used to plot the statements in a two-dimensional space, resulting in a visual concept map that is displayed in Figure 2. Additionally, the Supporting Information includes a version of the visual concept map in high resolution.

Figure 1. Example of a cluster of visual statements made by one of the 17 participants in the structuring step of the concept mapping.

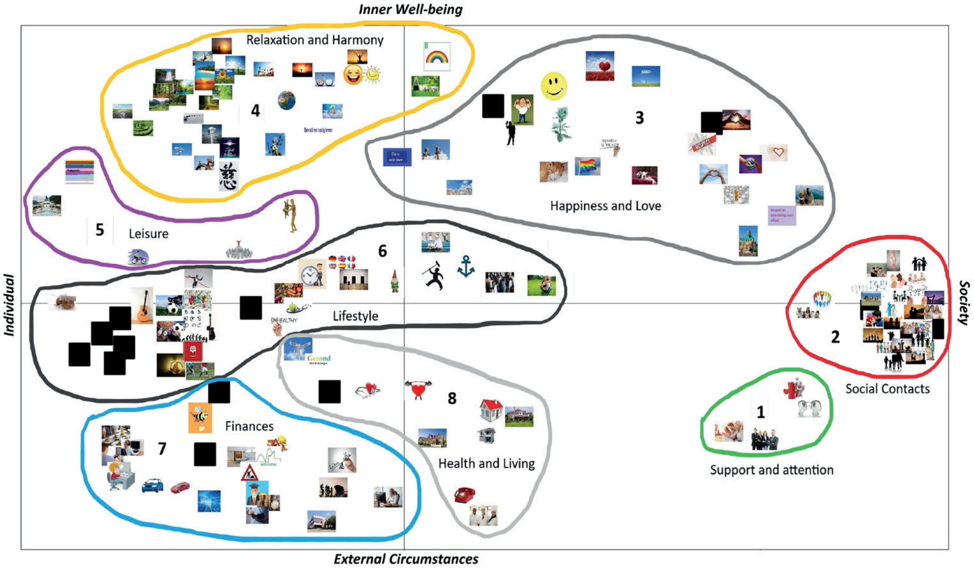

Figure 2. The final concept map, including interpretations for the eight clusters and two dimensions. The horizontal axis ranges from “Individual” to “Society,” whereas the vertical axis ranges from “Inner well-being” to “External circumstances.” Fourteen visual statements were replaced with black squares for reasons related to copyrights. A more detailed view of the visual statements can be found in the Supporting Information.

R-squared revealed that the first two PCA-components explained 84.3 percent of the variance of the aggregated BSSM. Hierarchical cluster analysis was used to compute six different concept maps, containing 7 to 12 clusters (average number of clusters per participant ± 2.5). Based on the results of the hierarchical cluster analysis and input of participants in Step 2, an eight-cluster solution was determined to be the most fitting. The 15 participants, who interpreted the concept map in the fourth step, provided one to three interpretations for each of the eight clusters. In total, they provided an average of 36 interpretations per cluster (SD = 6.0, range = 23–43).

For every cluster, the three most frequently mentioned interpretations are displayed in Table 3. The final interpretations of the eight clusters was based on input from the participants and are displayed in Table 3.

Table 3. The three most frequently mentioned cluster interpretations and the final cluster labels.

Cluster #	Interpretation 1 (freq.)	Interpretation 2 (freq.)	Interpretation 3 (freq.)	Final cluster label
1	Help one another (8)	Personal attention (5)	Thoughts (2)	Support and Attention
2	Family (11)	Friendship (7)	Social network (4)	Social Contacts
3	Love (13)	Respect (12)	Appreciation (3)	Happiness and Love
4	Nature (11)	Liberty (5)	Fun (2)	Relaxation and Harmony
5	Holiday (13)	Travel (5)	Leisure (2)	Leisure
6	Sports (13)	Music (10)	Diet (5)	Lifestyle
7	Money (8)	Work (8)	Finances (5)	Finances
8	Health (14)	Living (9)	Housing (2)	Health and Living

Table 4 displays the number of statements contributed by the patients, care professionals and family members to the eight clusters. Only the two smallest clusters, *Support and Attention* and *Leisure*, do not include contributions by all three groups of participants (see Table 4).

Relative to the other two groups, the patients contributed the highest number of statements to the clusters *Relaxation and Harmony*, *Lifestyle*, *Finances*, and *Health and Living*. The care professionals relatively provided most statements to the clusters *Support and Attention*, *Social Contacts*, *Happiness and Love*, and *Leisure and Lifestyle*. The family members, being the smallest of the three groups, did not contribute the relative majority of statements to any of the clusters. Most of the statements provided by family members ended up in the clusters *Social Contacts* and *Relaxation and Harmony* (see Table 4).

Table 4. Number of statements contributed to the eight clusters per participant group.

Cluster name (# of unique statements[†])	# of statements patients (%)	# of statements care professionals (%)	# of statements family members (%)
Support and Attention (4)	0 (0)	4 (100)	0 (0)
Social Contacts (32)	7 (19)	24 (65)	6(16)
Happiness and Love (24)	8 (32)	13 (52)	4 (16)
Relaxation and Harmony (33)	14 (43)	12 (36)	7 (21)
Leisure (5)	1 (20)	4 (80)	0 (0)
Lifestyle (30)	14 (47)	14 (47)	2 (6)
Finances (21)	11 (52)	8 (38)	2 (10)
Health and Living (11)	9 (75)	2 (17)	1 (8)
Total (160)	64 (38)	81 (49)	22 (13)

[†] Due to duplicate statements, the number of unique statements per cluster and the total number of statements contributed is not always equal.

The final concept map contains two dimensions, corresponding to the first two dimensions of the PCA solution. These dimensions correspond to the horizontal and vertical axes in Figure 2. The horizontal dimension ranges from *Individual* on the left to *Society* on the right. The vertical axis ranges from *Inner well-being* at the top to *External circumstances* at the bottom. The two dimensions separate the concept map into four quadrants. The top left quadrant contains aspects of QoL related to individual inner well-being and encompasses the clusters *Leisure* and *Relaxation and Harmony.* The top right quadrant involves elements of QoL linked to external circumstances and society and involves the cluster *Happiness and Love* and *Social Contacts*. The bottom right quadrant covers societal and circumstantial components of QoL, comprising the clusters *Social Contacts*, *Support and Attention* and *Health and Living*. The final, bottom left quadrant consists of individual and circumstantial facets of QoL and includes the clusters *Lifestyle*, *Finances* and *Health and Living.*

Validation of the visual clusters

In Table 5, a comparison of the eight visual clusters and the main- and subthemes identified by Connell and colleagues [53; 54] is provided. Every visual cluster has a counterpart in the main- and subthemes reported by Connell and colleagues. Three examples are provided below. First, the statements in Cluster 2 that portray families, schematic overviews of social networks, (groups of) friends and romantic couples correspond to the *Belonging* and *Good Relationships* subthemes. Second, Cluster 4 includes statements depicting yoga stones, people relaxing in the grass, natural scenes and smiley faces, which are related to the *Enjoyment/Relaxation/Stability* subtheme. Third, the statements of Cluster 7 that depict individuals performing labor, a teacher handing out a diploma, and a wallet filled with money are related to the *Employment*, *Choice Related to Job Opportunities, and Choice Related to Finances* subthemes.

Table 5. Comparison of the present results and those identified by Connell and colleagues [53; 54].

Current cluster	Corresponding subtheme(s) identified by Connell and colleagues [53; 54]	Corresponding main theme(s) identified by Connell and colleagues [53; 54]
Support and Attention	Support, Acceptance & Understanding	Belonging Belonging
Social Contacts	Belonging, Good relationships, Love, Care & Affection, Company/Camaraderie	Belonging Belonging Belonging Belonging
Happiness and Love	Love, Care & Affection Personal Strength Well-being	Belonging Control/Autonomy/Choice Well-being/Ill-being
Relaxation and Harmony	Enjoyment/Relaxation/Stability Goals/Personal Achievement Self-esteem Choice	Well-being/Ill-being Hope & Hopelessness Self-Perception Control/Autonomy/Choice
Leisure	Enjoyable Activities	Activity/Employment
Lifestyle	General Activity Meaningful & Enjoyable Activities Physical Well-being Routine & Structure	Activity/Employment Activity/Employment Well-being/Ill-being Activity/Employment
Finances	Employment Choice Related to Job Opportunities Choice Related to Finances	Activity/Employment Control/Autonomy/Choice Control/Autonomy/Choice
Health and Living	Physical Well-being Physical health	Well-being/Ill-being Physical Health

Discussion

The current study aimed to lay the basis for an alternative, visual approach to QoL assessment by developing a visual representation of QoL for people with severe mental health problems. Utilizing an inclusive method in the form of a visual adaptation of the concept mapping method, a visual concept map was constructed. A diverse sample of 50 participants, consisting of people with severe mental health problems, care professionals and family members, supplied a total of 160 unique visual statements. The statements were plotted onto two dimensions and were grouped into eight clusters.

In general, the results confirm a number of widely established fundamental notions about QoL. First, the results point to the subjective nature of QoL [56-58], as different individuals supplied a tremendous variety of statements in response to the same question. Second, the present results underline the multidimensionality of QoL, [59; 60], as several distinct clusters were identified in the concept map. Third, the amount and nature of clusters identified in the concept map are comparable to the number of QoL domains that have been reported in the literature [44; 54; 61].

Virtually all of the aspects of QoL portrayed by the visual statements correspond to one or more subthemes identified by Connell and colleagues [53; 54]. The statements depicting houses, part of the cluster *Health and Living*, form the single exception, as these authors did not verify a (sub)theme related to housing or living situation. The importance of housing to the QoL of people with severe mental health problems has been researched extensively. In their review of the effects of housing circumstances on the QoL of people with severe mental illness, Kyle and Dunn [62] reviewed nine articles in which the effect of housing interventions on QoL in people with Severe Mental Illness (SMI) was investigated. The results seem to indicate a positive connection between improved housing and QoL. Further, Nelson and colleagues [63] tested the hypothesis that both perceptions of control over housing and perceived housing quality are positively associated with QoL in a longitudinal study among people with severe mental health problems. Their hypotheses were confirmed, providing more evidence for the importance of housing for the QoL of people with severe mental health problems. Additionally, living situation is frequently assessed in QoL measures specifically developed for people with severe mental illness [44; 61]. In light of these studies, it can be concluded that all of the visual statements and clusters identified in this visual exploration of QoL correspond to themes identified in previous studies. This means that the visual concept map forms an appropriate basis for the development of a visual QoL instrument for people with severe mental health problems.

The visual concept mapping method used in this study can be seen as an example of a visual research method. According to Bagnoli [64] and Rose [65], visual research methods may elicit information that language-based methods, such as surveys or interviews, cannot. The visual research method utilized in this study did not identify aspects of QoL beyond those reported in the literature [44; 53; 61].

Strengths and Limitations

The visual approach to the conceptualization of QoL in this study provided an opportunity for participants who may have otherwise experienced linguistic barriers to contribute by sharing their insights and can therefore be seen as a strength. Still, it is insurmountable that engaging in a research study does appeal to the verbal and cognitive capacity of participants. Participants gave their informed consent, were informed about the goal of the study, and were explained what was expected of them. Conscious of these potential barriers, the researchers facilitated participants as much as possible. This was done by providing in-person assistance to patients contributing to Step 1, and by making sure to explain the goal of the study and the role of participants in accessible terms.

Some limitations should be considered when examining results of the current research. First, the sample was collected using a combination of convenience sampling and stratified sampling. Initially, convenience sampling was adopted. Later, the sampling strategy was adjusted to stratified sampling to assure a reasonably representative sample. Additionally, the number of participants who structured the visual statements in Step 2

(17) was smaller than the average number of 24.6 reported by Rosas and Kane [52] The diversity in the gathered statements, however, indicates that the goal of capturing as many perspectives on QoL as possible was met. Additionally, a comparison of the visual statements provided by the last five participants with the material collected earlier revealed that data saturation had been achieved. Moreover, R-squared indicates good congruence between the aggregated BSSM and the final concept map. The relatively small number of family members who contributed to the first concept mapping-step can be viewed as a second limitation. The concept map reveals that the family members did not supply unique themes, as their visual statements are spread out over the existing clusters relatively evenly. It is therefore unlikely that significant aspects of QoL have been omitted due to the relatively small contribution of family members in this study. A third limitation pertains to the medium that was used to gather the visual statements. Most of the participants decided to provide statements that they found using Google's Image search, rather than by drawing or uploading their own pictures. The available pictures, therefore, were both limited and influenced by the algorithms used by Google. Participants, however, were instructed to select a picture corresponding to their own understanding of the QoL of people with severe mental health problems. Assuming that participants first came up with an idea and then turned to Google for visual material corresponding to that idea, the impact of Google's algorithms is likely to be minimal. The relatively small number of duplicate pictures provides evidence for this assumption. A fourth limitation relates to the structuring of visual statements in Step 2. It is possible that participants internally verbalized their impression of a statement prior to assigning the statement to a cluster, making the process more verbal and cognitive than intended. Future studies may assess to what degree participants have a verbal or visual cognitive style [66] to gain insight into whether participants mentally represent information in a visual or verbal way.

Conclusion

The inclusive method used in this study led to the development of a visual representation of QoL that corresponds well to results identified in earlier language-based research. The results not only confirm the legitimacy of existing conceptualizations of QoL, but also provide a valuable framework for the development of an innovative, alternative, visual approach to QoL assessment for people with severe mental health problems that is based upon the input of relevant participants.

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Chapter 4

Co-creative development of the QoL-ME: a visual and personalized quality of life assessment App for people with severe mental health problems

This chapter has been published as:

Buitenweg, D. C., Bongers, I. L., Van de Mheen, D., Van Oers, H. A., & Van Nieuwenhuizen, Ch. (2019). Co-creative development of the QoL-ME: A visual and personalized quality of life assessment app for people with severe mental health problems. *JMIR Mental Health, 6(3), e12378. doi: 10.2196/12378*

Abstract

Background: Quality of Life (QoL) is a prominent outcome measure in mental health. Conventional methods for QoL assessment, however, rely heavily on language-based communication, and may therefore not be optimal for all individuals with severe mental health problems. In addition, QoL assessment is usually based on a fixed number of life domains. This approach conflicts with the notion that QoL is influenced by individual values and preferences. A digital assessment app facilitates both the accessibility and personalization of QoL assessment and may, therefore, help to further advance QoL assessment among individuals with severe mental health problems.

Objective: This study focused on the development of an innovative, visual and personalized QoL assessment app for people with severe mental health problems: the QoL-ME.

Methods: A group of 59 participants contributed to the six iterations of the co-creative development of the QoL-ME. In the brainstorm stage, consisting of the first iteration, participants' previous experiences with questionnaires and mobile apps were explored. Participants gave their feedback on initial designs and wireframes in the second to fourth iterations that made up the design stage. In the usability stage that comprised the final two iterations, the usability of the QoL-ME was evaluated.

Results: In the brainstorm stage, participants stressed the importance of privacy and data security, and of receiving feedback when answering questionnaires. Participants in the design stage indicated a preference for paging over scrolling, linear navigation, a clean and minimalist layout, the use of touchscreen functionality in various modes of interaction, and the use of visual analogue scales. The usability evaluation in the usability stage revealed good to excellent usability.

Conclusions: The co-creative development of the QoL-ME resulted in an app that corresponds to the preferences of participants and that has strong usability. Further research is needed to evaluate the psychometric quality of the QoL-ME, and to investigate its usefulness in practice.

Introduction

Quality of Life (QoL) has risen to prominence as an outcome in mental healthcare. Still, many authors agree that there is further room for improvement in the field of QoL assessment, especially regarding the instruments used to assess QoL [1; 2]. Several possibilities for advancement have been pointed out in the literature. First, it is important that instruments are frequently updated to maintain their applicability in our fast-paced society. Examples of developments that may influence the meaning of QoL for people with severe mental health problems include an increasing emphasis on empowerment [3-5] and the advancing digitalization of society [6]. Second, research has indicated the need for personalization of QoL instruments, as QoL differs within groups and between individuals [7; 8]. This notion calls for a QoL instrument that enables respondents to select and answer questions on domains of QoL that are relevant for them personally. Third, traditional language-based QoL assessment, which relies heavily on people's verbal and cognitive abilities, might be less appropriate for people with severe mental health problems [9; 10]. Visual communication may provide a suitable alternative as it does not require the mastery of a certain language. In addition, visual information may be easier to process by people with severe mental health problems than verbal information [11; 12]. Several characteristics of digital technologies make them potentially useful for tackling the aforementioned issues in QoL assessment. A digital instrument has the flexibility to allow for the increased personalization of QoL assessment. In addition, digital technologies facilitate the use of audio and visual multimedia such as images and video, which may improve the accessibility of a digital QoL instrument and help circumvent language-based communication. Furthermore, a digital instrument can easily be updated to incorporate new aspects of QoL that become important as a function of societal changes.

Over the last few years, many digital electronic health (eHealth) technologies for use in mental healthcare have been developed [13]. People with severe mental health problems use eHealth to obtain information, for Web-based treatment and as a source of support [13; 14]. eHealth for people with severe mental health problems initially focused on the design and development of websites used for treatment, for communication, and to provide information [15-17]. Recently, the rising popularity of mobile devices such as smartphones and tablets has facilitated a shift from websites to mobile health apps for mobile devices such as smartphones and tablets. These mobile health apps have been developed for a variety of psychiatric problems including anxiety [18], bipolar disorder [19] and schizophrenia [20] and serve a number of purposes, such as treatment, providing information, self-assessment and self-management [21-25].

Previous studies reveal that websites and apps that are well designed for a general public may not be appropriate for people with severe mental health problems

[26-29]. In response to these findings, several authors have reported best practices and guidelines for the design and development of eHealth apps for people with severe mental health problems [21; 29-31]. Ben-Zeev and colleagues [30] list a number of specific recommendations for how eHealth apps may best be developed. They stress the importance of working in multidisciplinary teams and of involving intended users in the development [30]. Furthermore, Rotondi and colleagues [31] developed the Flat Explicit Design Model (FEDM) to guide the design of eHealth for people with severe mental illness. The model contains 18 variables, grouped into three usability dimensions: 1) page complexity, 2) navigational simplicity and 3) comprehensibility. Examples of variables include minimizing potential distractors, limiting navigational elements, fixing the location of navigational elements, and minimizing page length. Empirical evidence for the usefulness of the FEDM in reducing cognitive effort for users has been found [31]. These design recommendations are likely to benefit the usability of eHealth technologies for people with severe mental health problems.

The current research covers the co-creative development of a QoL assessment app that does not rely solely on language-based communication, facilitates personalization, and is useful for both patients and clinicians: the QoL-ME. The aforementioned design recommendations will be taken into account, but the development of the QoL-ME will primarily be based on the input of end-users, which continues to be the standard in design in general [32; 33], and in the design for people with severe mental health problems in particular [21; 30; 34-37]. This article aims to describe the development of the QoL-ME, with special attention to patients' design-related preferences.

Methods

Participants

This study targeted three groups of individuals with severe mental health problems: 1) people with psychiatric problems, 2) people treated in forensic psychiatry and 3) people who are homeless. Homeless individuals were included in this study due to the high prevalence of severe mental health problems in this group [38-40]. There are several reasons for suspecting that these groups may have difficulty with traditional language-based QoL assessment. First, they experience fewer educational opportunities [40-42]. Second, mild intellectual disabilities occur relatively frequently in these groups [40; 43; 44]. Third, psychopathology itself may compromise individuals' ability to engage in QoL assessment [9; 10].

Participants were recruited with the help of six societal institutions that collaborated in a consortium to facilitate this research project, including a mental health institution, a hospital for forensic psychiatry, a multimodal day treatment center for multi-problem young adults, a day center for people who are homeless and two research institutions focusing on lifestyle, homelessness and addiction.

Development of the QoL-ME

The QoL-ME was co-creatively developed in an iterative development process in which the three aforementioned groups of people with severe mental health problems played an essential and indispensable role. The process consisted of six iterations divided over three stages: 1) brainstorm stage, 2) design stage, and 3) usability stage. Theoretically, the development process fits in the *explore, approximate, refine* framework as part of participatory design [45]. A study by Ben-Zeev and colleagues [20] employs a similar approach consisting of three steps that correspond to this framework. A schematic overview of the developmental process is provided in Figure 1.

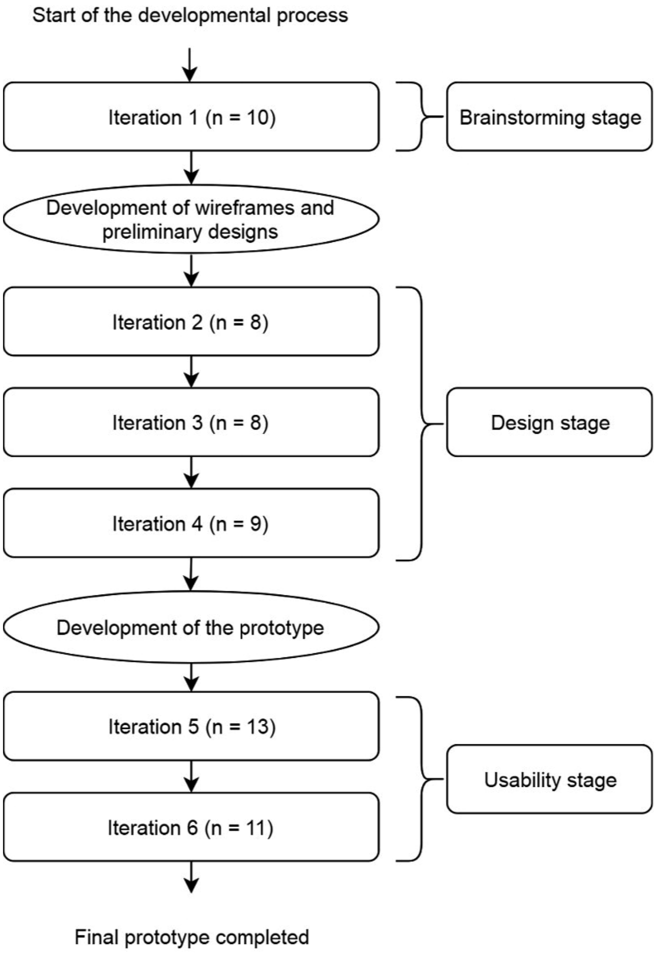


Figure 1. Schematic overview of the development of the QoL-ME, involving three stages and six iterations.

Every iteration involved three separate user test sessions, and the total number of test sessions was 18. A new group of participants was recruited in every test session. The three target groups were involved in every single iteration. In addition, the age distribution of participants was roughly the same in every iteration. Between two and five individual participants contributed in every test session. The feedback, tips and insights of end-users gathered during test sessions were of vital importance and were fed back to the professional designers who took care of the technical side of the development. In between iterations, the researchers and professional designers discussed the feedback gathered during the previous iteration. If the end users' opinions and preferences contradicted each other, an attempt at a synthesis was made during these discussion. If necessary and possible, two rivalling preferences were tested in the next iteration. In all stages of the development, the input and opinions of end-users were instrumental and were used to expand and refine the initial designs and early versions of the app.

The brainstorm stage involved Iteration 1. In this stage, participants were invited to share their past experiences with apps, share ideas regarding the improvement of QoL assessment, and to comment on basic initial designs. The topic list that was used during the brainstorm stage is available in Multimedia Appendix 1. Based on the ideas that were gathered in this stage, combined with design-related recommendations found in the scientific literature [21; 31; 35], a number of designs and interaction mechanisms were developed for testing.

The design stage covered Iterations 2, 3 and 4. Initially, paper sketches (wireframes) were used to test alternative navigational structures, various possible page-layouts, and possible forms of interaction for the app. In the remainder of the design stage, digitalized versions of these wireframes were gradually refined, expanded and made functional. Finally, a first prototype was developed.

In Iterations 5 and 6, which together formed the usability stage, the prototype was subjected to usability testing. Participants were invited to complete a single task: to fill out the QoL-ME. To test if participants were able to use the prototype independently, no explanation regarding the QoL-ME was provided. The usability of the prototype was systematically assessed using a modified Dutch version of the System Usability Scale (SUS) [46-48].

Measures

In seven of the 12 test sessions participants consented to audio recordings. In the other five test sessions, the researchers took extensive notes. The researchers made an elaborate summary of every test session of the first four iterations, based on either the recordings or the notes. The summaries included all of the participants' insights, ideas and feedback, and were discussed together with the designers. Based on these discussions, the designers elaborated, adjusted and polished the QoL-ME.

The English version of the SUS was developed by Brooke [47] and has since been used frequently to assess the usability of a variety of technologies such as websites, operating systems and hardware [48]. The SUS contains ten items, scored on a five-point Likert scale ranging from 'strongly disagree' (1) to 'strongly agree' (5). Its psychometric properties have been investigated by Bangor, Kortum and Miller [46], who analyzed SUS data of 2,324 participants and found a Cronbach's Alpha of .911. In addition, the authors report strong face validity, high sensitivity and good concurrent validity [46]. The SUS has been translated into several languages, including Dutch [48]. To facilitate people with severe mental health problems, all of the items of the Dutch SUS were worded positively in this study, as advised by Sauro and Lewis [49]. In addition, three items that contained complex terms were modified slightly without altering their content. Total SUS scores range between 0 and 100. Based on the analysis of a large amount of SUS data, scores above 73 are considered to indicate *good* usability, while scores above 85 are considered *excellent* [50].

Procedure

At the start of every test session, the researcher explained the goal of the research project and how participants were invited to contribute. Next, participants gave their informed consent and were asked if they consented to the audio recording of the test session. To prevent acquiescence bias, the researcher emphasized that they did not create the designs or prototypes themselves. In addition, the researcher stressed that there were no right or wrong answers, but that participants' opinions, ideas and insights counted. In the brainstorm stage, participants were asked a number of questions after which they were invited to comment on a number of basic initial designs. In the design stage, participants were invited to comment on the layout of the wireframes, and to test various forms of interaction and navigation. In the usability stage, participants were invited to use the QoL-ME and to fill out the SUS afterwards. At the end of a session, participants were asked if they had any additional feedback, tips or questions. Moreover, the researchers explained that participants' feedback was used to refine the designs, and participants received a €10 gift voucher.

All designs and prototypes were tested using an Apple iPad Air 2 which had a 9.7-inch touchscreen display. The researcher provided this iPad.

Ethical approval was obtained from the Ethics Committee of the Tilburg School of Behavioral and Social Sciences at Tilburg University (EC-2015.44). Informed consent was obtained from each participant. All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Structure and content of the QoL-ME

The results of the development of the QoL-ME app are difficult to interpret without additional knowledge of the structure and content of the QoL-ME. To enable an adequate understanding of the results of this study, the conceptual framework underlying the QoL-ME is described in this section.

The QoL-ME consists of 2 main components: a core version and additional modules. The core version comprises a fixed set of universal QoL domains, and every respondent is required to answer questions on these domains. Research indicates that having meaning in life is especially important for people who are homeless [51; 52]. The QoL-ME, therefore, encompasses 2 separate core versions. The first core version targets people with psychiatric problems and people treated in forensic psychiatry and includes 3 domains of the Lancashire Quality of Life Profile (LQoLP) [53]: *safety, living situation*, and *finances*. A recent study indicates that these 3 LQoLP domains are universal for people with psychiatric problems and people treated in forensic psychiatry [54]. The LQoLP uses a 7-point Likert scale, ranging from cannot be worse (1) to cannot be better (7). The second core version is tailored to people who are homeless and comprises the Dutch version of the Meaning in Life Questionnaire, a 10-item measure that assesses both the presence of meaning in one's life and the search for meaning in life [55]. The Meaning in Life Questionnaire also uses a 7-point Likert scale, ranging from *completely disagree* (1) to *completely agree* (7).

The additional modules serve to ensure the personalization of the QoL-ME. Every module corresponds with a domain of QoL, and users are free to select any combination of the eight modules. The following eight domains of QoL are included: (1) Support and Attention, (2) Social Contacts, (3) Happiness and Love, (4) Relaxation and Harmony, (5) Leisure, (6) Lifestyle, (7) Finances and (8) Health and Living. These domains were identified in a visual concept mapping study of the QoL of people with severe mental health problems [56]. Domains are assessed using two to four visual items. Every visual item contains three pictures that together denote an aspect of QoL. Users respond to these items using a visual analogue scale (VAS scale) with visual anchors.

This structure, involving both a core version and additional modules, makes for a flexible QoL assessment app. The core version is useful in contexts where group-level data are of interest, such as comparisons of the QoL of different client populations. The additional modules are especially suitable for use in individual care planning.

Results

Participants

A total of 59 participants contributed to the development of the QoL-ME. Their mean age was 40.8 years (SD = 15), and over 80 percent were male (see Table 1). The mean age of the 10 participants who engaged in the brainstorm stage was 34.2 years (SD = 12.8), seven of whom were male. In the design stage, a group of 25 people with severe mental health problems participated. Their mean age was 37.7 years (SD = 14.3), and 88 percent were male. In the usability stage, 19 of the 24 participants (79 %) who contributed were male. Their mean age was 46.8 years (SD = 14.4). The number of participants who contributed to the development process is displayed in Table 1.

Table 1. Basic demographic characteristics of participants per iteration of the development of the QoL-ME.

	N participants	% Male	Mean age (SD)
Brainstorm stage			
Iteration 1	10	70	34.2 (12.8)
Design stage			
Iteration 2	8	87.5	32.8 (13.6)
Iteration 3	8	87.5	38.9 (12.8)
Iteration 4	9	91.7	41 (14.9)
Total	**25**	**88**	**37.7 (14.3)**
Usability stage			
Iteration 5	9	66.7	42 (17.5)
Iteration 6	15	84.6	49.7 (11.3)
Total	**24**	**79.2**	**46.8 (14.4)**
Total entire development	**59**	**81.4**	**40.8 (15)**

Development of the QoL-ME

Participants in the brainstorm stage reported using apps primarily for communication and maintaining social relations. In addition, four younger participants treated in forensic psychiatry reported using apps for services such as internet banking and Web-based shopping. The single most important factor for why participants used certain apps over others was their confidence in the trustworthiness of the apps. The majority of participants indicated having privacy concerns when using apps, but these did not seem to deter them from using apps frequently.

All participants had prior experience with questionnaires, primarily in the context of professional care or research. Participants reported several annoyances regarding their previous experiences with questionnaires, two of which were relevant for the development of the QoL-ME: (1) lack of feedback, and (2) lack of transparency regarding data use. These considerations were fed back into the development of the QoL-ME. In practice, a feedback module that provided users with insight into their scores was implemented, and special consideration was given to the issue of data ownership, leading to the decision that users retain the ownership of their data.

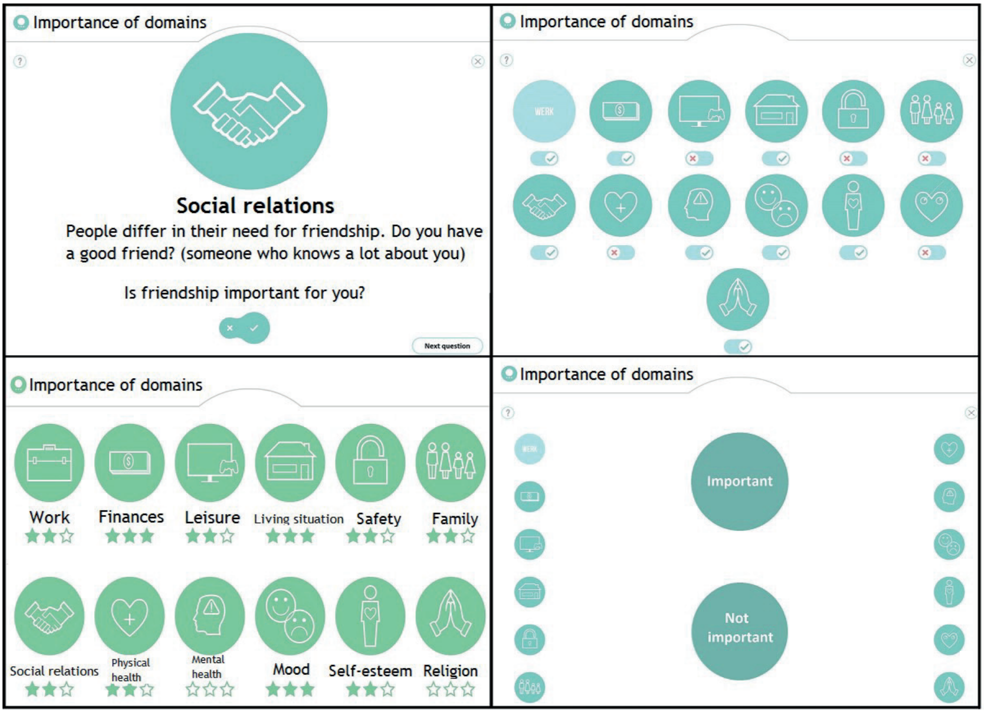
The participants in the brainstorm stage had a number of ideas regarding the QoL-ME. Some participants indicated a preference for the personalization of the app's appearance, by selecting a personal background or by changing the colors of the application. In addition, participants pointed out that not every patient has their own device and therefore advocated a multi-platform application. Furthermore, a combination of visual- and language-based communication was proposed, and some participants even indicated a preference for audio. Whenever possible, these ideas were incorporated into the initial designs of the QoL-ME that were tested in the subsequent iterations.

As displayed in Table 2, the feedback received on the designs that were tested in the three iterations of the design stage cover four main categories: 1) functionality of the QoL-ME, 2) navigation, 3) personalization, and 4) appearance.

Table 2. Overview of the feedback obtained during the three iterations of the design stage of the development of the QoL-ME.

Category	Subcategory	Feedback
Functionality	Interaction: selecting additional modules	Swiping icons preferred in domain selection
	Interaction: items additional modules	VAS scales preferred to answer questions of additional modules
	Input	Most participants had no difficulty with the touchscreen, but some did: enable alternative options such as keyboard and mouse.
	Feedback	Simple visualization of results, avoiding graphs
Navigation	Linear structure	Inevitable choices in hierarchical structure were confusing, preference for linear structure
	Confirming choices	Confirmation of choices (next, previous) was appreciated
	Size and position of buttons	Large buttons with fixed sizes (bottom left and bottom right of screen)
Personalization	Creating user profiles	Too much effort, no added value
	Personalization of background and colors	No added value
Appearance	Layout	Calm and professional layout was evaluated positively
	Font size	Large font was advised
	Contrasts	Sufficient contrast between text and background

First, participants commented on the functionality of the QoL-ME. Specifically, these comments were related to different forms of interaction, operating the app, and receiving feedback. Several mechanisms for selecting the additional modules of the QoL-ME were tested. Figure 2 displays four of these possible modes of interaction. Note: as the QoL-ME is developed for use in the Netherlands, it contains some Dutch text. To improve the clarity of the screenshots that are part of Figure 2 and other figures, any Dutch text has been translated to English.



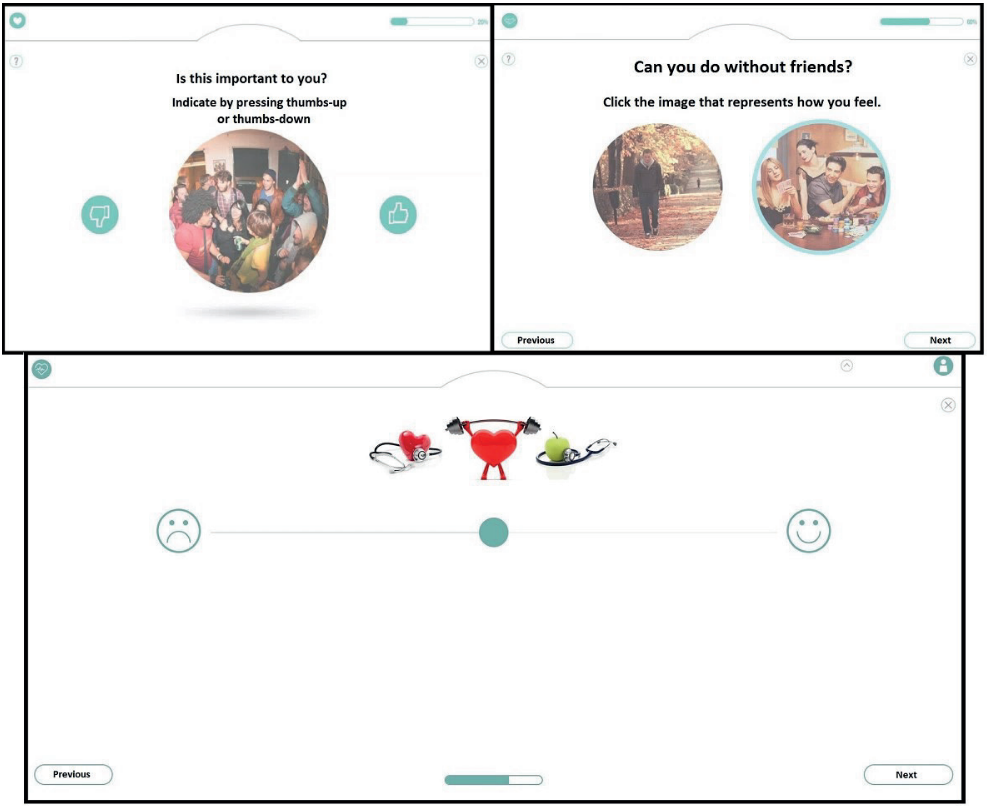
Social relations

People differ in their need for friendship. Do you have a good friend? (someone who knows a lot about you)

Is friendship important for you?

Figure 2. Four mechanisms for selecting additional modules. In the top-left mechanism, users rate the importance of every domain individually. In the top right corner, the same mechanism is displayed for every domain at the same time. In the bottom left panel, every domain is rated by giving it one to three stars. In the bottom right panel, the icons on the left and right have to be swiped or dragged to one of the two circles.

Participants indicated a strong preference for the option in which icons had to be swiped (see the bottom-right panel in Figure 2). In addition, multiple forms of interaction for use in the items of the additional modules of the QoL-ME were tested. Figure 3 provides an overview of three interaction mechanisms. Because participants indicated a preference for the VAS, a VAS was used in the prototype. The majority of participants had little to no difficulty with the touchscreen, even though some participants initially described themselves as computer illiterate and reported never having used a touchscreen before. Some participants did indicate that it would be a good idea to also enable the use of keyboard and mouse to operate the QoL-ME.



Is this important to you?

Indicate by pressing thumbs-up or thumbs-down

Can you do without friends?

Click the image that represents how you feel.

Figure 3. Three possible mechanisms for interaction in the items of the additional modules.

Secondly, initial versions of the QoL-ME allowed participants to select the order in which they wanted to progress through the app. Participants had the opportunity to choose one of four menu items (see Figure 4).

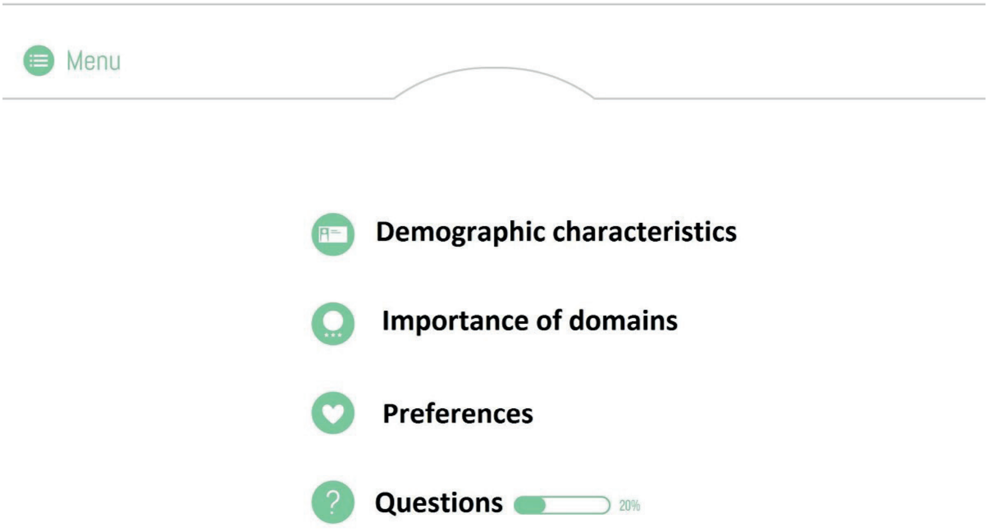
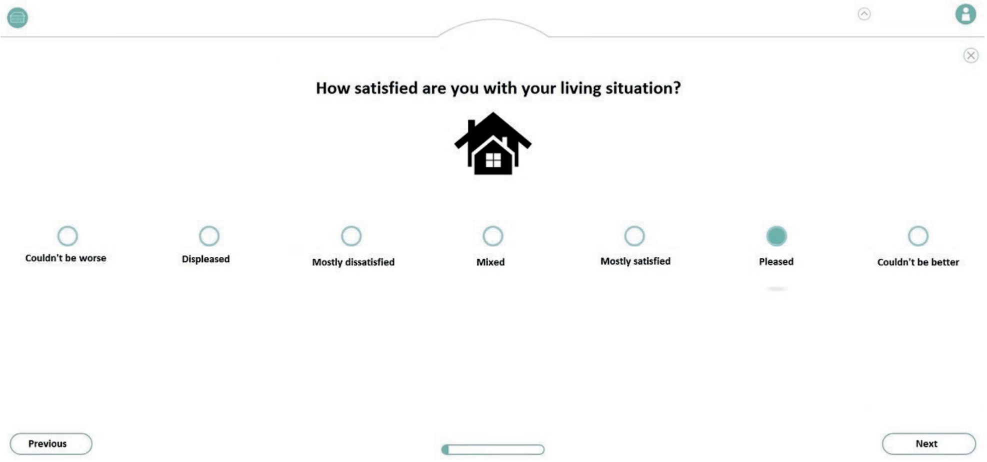


Figure 4. Earlier versions of the QoL-ME required users to select one of four menu options.

Most of the participants in the design stage were unsure which of the four options to select and preferred a linear navigational structure, which was adopted in later versions of the QoL-ME. The QoL-ME requires participants to navigate the app explicitly by selecting buttons at the bottom of the screen (see Figure 5). Participants saw this as a valuable feature, as it allowed them to correct possible mistakes before progressing to the next item or part of the app, and because it introduces predictability. In addition, participants indicated a preference for large navigation buttons with a fixed location.

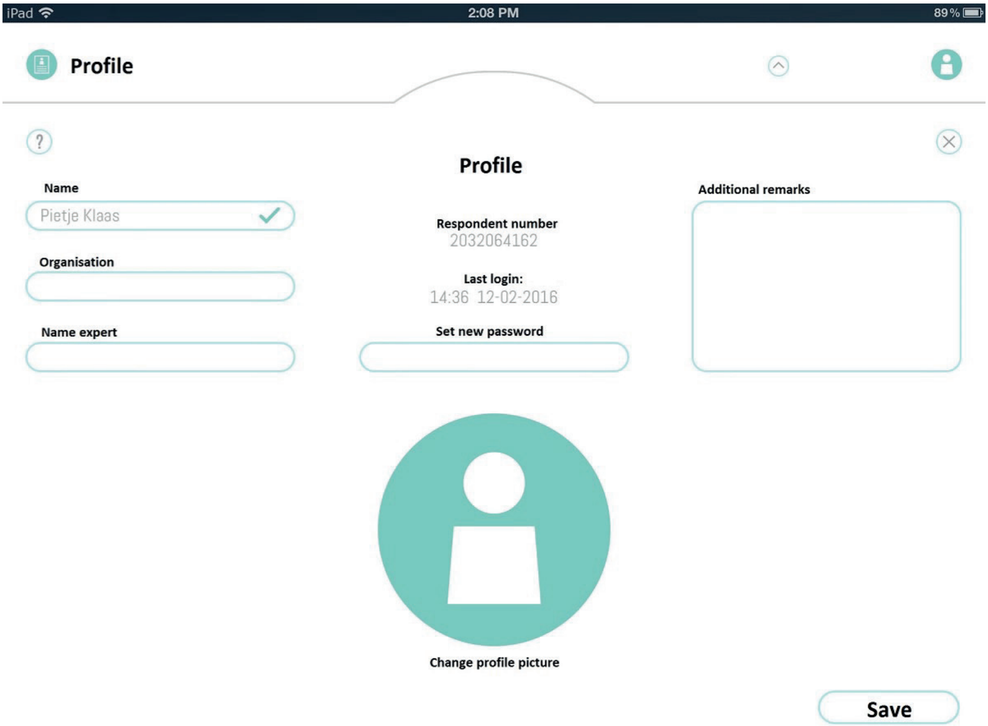

How satisfied are you with your living situation?

○ Couldn't be worse ○ Displeased ○ Mostly dissatisfied ○ Mixed ○ Mostly satisfied ● Pleased ○ Couldn't be better

Figure 5. Users are required to navigate explicitly by selecting one of the two buttons at the bottom left and bottom right of the screen.

Third, possibilities for the personalization of the QoL-ME were explored. Versions of the QoL-ME that were tested in this stage allowed participants to create a user profile (see Figure 6) and to select one of several colors for the layout of the app (see Figure 7). Participants, however, were not enthusiastic about these features, and they were dropped in later versions of the QoL-ME.

Fourth, throughout the design stage, participants had a fondness for the calm and clean layout of the QoL-ME (see Multimedia Appendices 2 and 3). Several participants noted that the layout of the QoL-ME made it look professional and added to its credibility and trustworthiness. Two participants, however, found the QoL-ME's appearance to be a little dull. In addition, participants preferred large fonts and sufficient contrast between text and background.



Name
Pietje Klaas

Organisation

Name expert

Respondent number
2032064162

Last login:
14:36 12-02-2016

Set new password

Additional remarks

Figure 6. Early versions of the QoL-ME included the possibility to create a user profile.

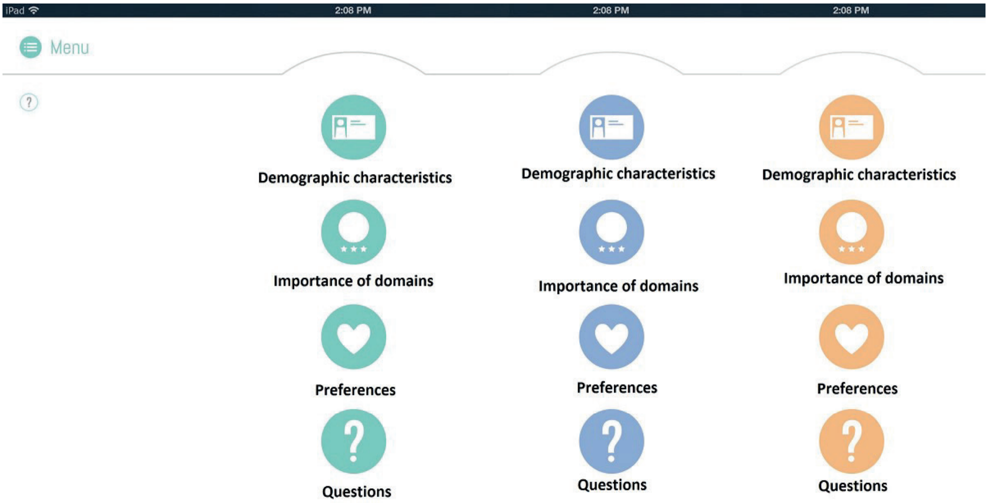


Figure 7. Earlier versions of the QoL-ME allowed users to customize the colors of the QoL-ME.

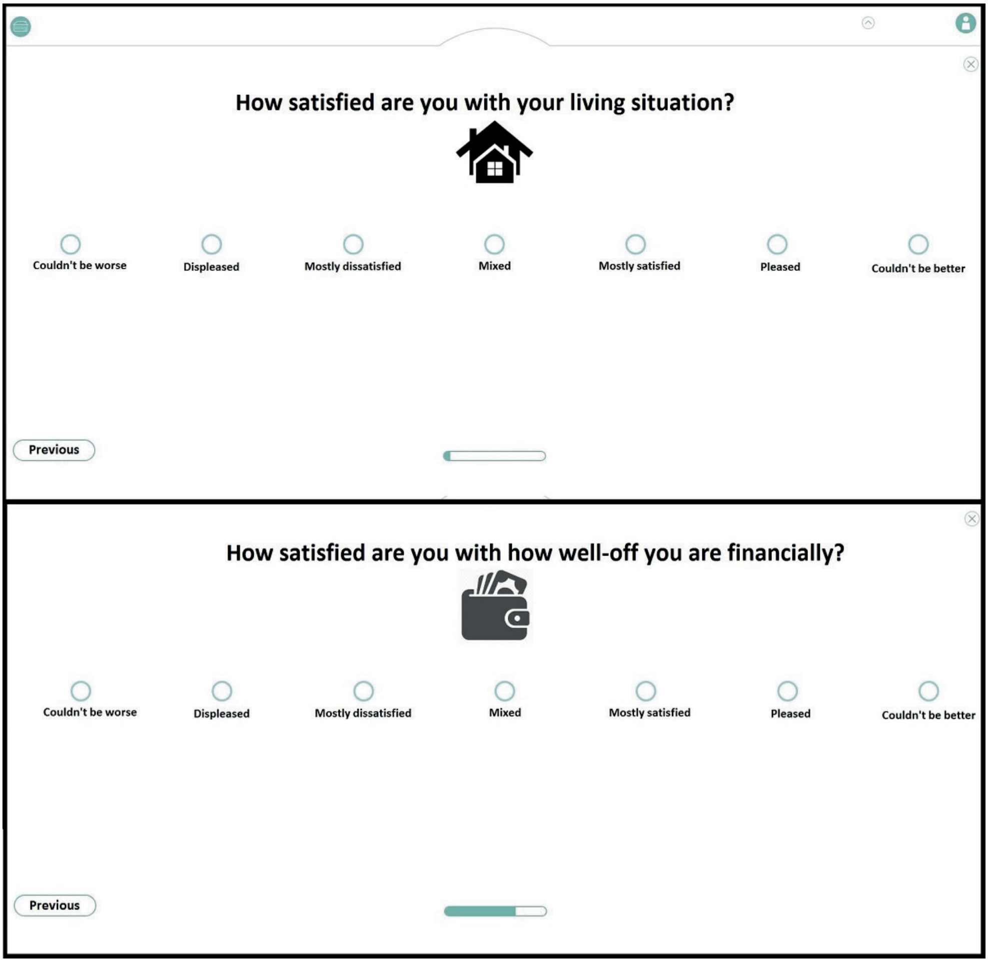
The average SUS score was 76.8 (SD = 14.9, median = 76.3), and scores ranged between 35 and 97.5. According to the classification reported by Bangor and Kortum [50], a SUS score of 76.8 indicates good to excellent usability.

After filling out the SUS, participants were invited to share any additional feedback. Most of the participants in the usability stage did not have any additional feedback and found the QoL-ME to be easy to use, as reflected by their SUS scores. Some participants wanted more explanation on how to select the content of the additional modules of the QoL-ME. Others had difficulty placing the VAS exactly at the halfway point. These minor remarks were taken into consideration and some slight modifications to the prototype were made, resulting in the QoL-ME that is described in the following section.

The final QoL-ME

The following section contains a brief walkthrough of the QoL-ME. An accompanying video is provided in Multimedia Appendix 2. After logging into the QoL-ME app using their e-mail address and a personalized password, users arrive at the home screen, which includes a brief explanation of the goal and structure of the app. Users have the opportunity to view a short video tutorial in which the structure and operating mechanisms of the QoL-ME are explained (see Multimedia Appendix 2). After pressing the *start* button on the homepage, users arrive at the core version of the QoL-ME. To determine which of the two core versions is applicable to the user, users are first requested to indicate whether they consider themselves as being homeless or not.

An affirmative answer will lead the user to the core version for people who are homeless. Alternatively, users are invited to fill out the core version for people with psychiatric problems. Having selected the appropriate core version, users arrive at an explanation of the core version. Examples of two items of the core version are presented in Figure 8.



How satisfied are you with your living situation?

How satisfied are you with how well-off you are financially?

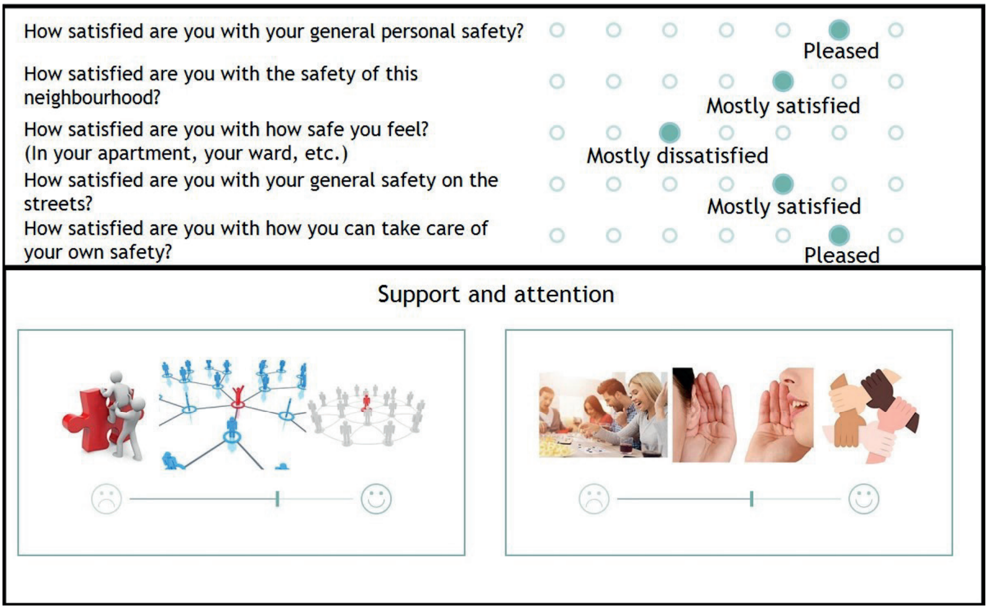
Figure 8. Examples of two items of the QoL-ME's core version.

Having completed the core version, users are asked to indicate which domains of the additional modules are important to them. A screenshot of the mechanism used to select add-on modules is available in Figure 9. To ensure that the correct domains have been selected, users are asked to confirm their choice (see Figure 9).

Next, users answer questions corresponding to their selection of additional modules. Figure 9 provides examples of two visual items of the additional modules. Once all questions have been answered, users have the option to review their answers on the results page (see Figure 10).

Did you choose the following domains? If yes, click 'Continue'. If not, click 'Edit'.
Support and attention
Social relations
Happiness and love
Lifestyle

Figure 9. Four screenshots depicting the additional modules of the QoL-ME. The top-left panel displays the mechanism for selecting additional modules. Respondents are invited to drag eight icons, corresponding to the eight modules, to either a circle that says 'important' or a circle that says 'not important'. The top-right panel shows how respondents are asked to confirm their choice of additional modules. The two remaining panels provide examples of items of the additional modules.



How satisfied are you with your general personal safety?	○ ○ ○ ○ ○ ● ○	Pleased
How satisfied are you with the safety of this neighbourhood?	○ ○ ○ ○ ● ○ ○	Mostly satisfied
How satisfied are you with how safe you feel? (In your apartment, your ward, etc.)	○ ○ ● ○ ○ ○ ○	Mostly dissatisfied
How satisfied are you with your general safety on the streets?	○ ○ ○ ○ ● ○ ○	Mostly satisfied
How satisfied are you with how you can take care of your own safety?	○ ○ ○ ○ ○ ● ○	Pleased

Figure 10. Results section of the QoL-ME. The top panel displays how the results of the core version are displayed, whilst the bottom panel demonstrates the results of the additional modules.

Discussion

This study pertains to the co-creative development of the QoL-ME: an innovative, personalized and visual QoL assessment app. A diverse group of people with severe mental health problems contributed to every iteration of the development. The feedback regarding the design and functionality of the QoL-ME that was provided by participants played an essential and central role in the development. The usability evaluation using the SUS revealed good to excellent usability of the QoL-ME.

The feedback gathered during the development of the QoL-ME can be split into three categories: 1) feedback that corresponds to previous design recommendations [21; 28; 31], 2) feedback that deviates from these recommendations, and 3) findings specific to the QoL-ME and its function as a visual QoL assessment app. First, some of the feedback received in the design stage corresponds to existing recommendations reported by Rotondi and colleagues [28] as part of their FEDM, and by Bernard and colleagues [21] in their review of factors that facilitate the web use of people with mental disorders. The majority of participants had little difficulty operating the touchscreen. Some participants, however, recommended enabling the use of keyboard and mouse. These findings correspond to the results by Bernard and colleagues [21], who recommend providing multiple, alternative ways to operate a technology. Moreover, the fixed position of the navigation buttons made using the QoL-ME predictable and clear, in line with recommendations included in the FEDM [28]. In addition, participants were positive regarding the appearance of the QoL-ME and experienced it as calming, pleasant and professional. Furthermore, participants stressed the importance of using sufficient contrasts between important elements and the background of the apps, and of using large fonts. These findings regarding the layout, font size and contrasts of the QoL-ME confirm existing recommendations [21; 28].

Second, some feedback deviated from the design guidelines found in the literature. One of the main recommendations of the FEDM covers the navigational structure of a digital technology. The FEDM advocates a shallow hierarchical structure, whilst participants in this study strongly preferred a linear structure, as it removed the need for making navigational choices. Furthermore, the FEDM promotes scrolling down a page for additional content over paging: having to go to another page for additional content. In this study, however, participants indicated a clear preference for paging over scrolling. The fact that the FEDM primarily targets websites, whilst the QoL-ME is a (web) app, may explain this deviation. General guidelines that target smartphone applications specifically do recommend minimizing navigational choices and advise against scrolling [57]. An alternative explanation for the deviating findings lies in the increasing importance and usage of digital technologies, which may cause shifts in user preferences. In addition, Bernard and colleagues [21] identified the personalisation of the appearance of a digital technology, including color and font size, as a facilitating factor. In this study, participants did not welcome the possibilities for personalisation included in earlier versions of the QoL-ME. Possibly, the personalisation of the appearance of the QoL-ME was seen as a distraction as it was unrelated to the function of the QoL-ME.

Third, two preferences indicated by participants are specific to the functionalities of the QoL-ME and are therefore unrelated to existing design recommendations. First, participants preferred the use of VAS scales over the Likert scale to answer the items of the additional modules. This finding confirms earlier research [58]. Second, participants preferred a mechanism that involved swiping or dragging icons for the selection of the additional modules. Both mechanisms were tested on a touchscreen device, which may have enhanced their popularity. Prior research confirms the accessibility of touchscreen-based interaction [59; 60].

Usability evaluations of the QoL-ME using the SUS reveal good to excellent usability. The average SUS score of 76.8 obtained in this study is similar to SUS scores gathered in usability evaluations of comparable applications. Kooistra and colleagues [61] evaluated the usability of a blended cognitive behavioral therapy for people with depression and found an average SUS score of 73.2. Fiorillo and colleagues [62], moreover, obtained an average SUS score of 81.8 when evaluating the usability of a web-based acceptance and commitment therapy intervention for people with trauma-related psychological difficulties. In addition, Kobak and colleagues [63] reported an average SUS score of 83.5 in their evaluation of computerized cognitive behavior therapy for people with obsessive-compulsive disorder.

Strengths and limitations

The diversity of the study population is an important strength. Participants from diverse age groups and care backgrounds shared their insights regarding the QoL-ME. This diverse sample ensures that the QoL-ME appeals to a large and diverse group of potential users and may enhance the generalizability of the results to people with severe mental health problems. The strong emphasis on collaboration with people with severe mental health problems can be seen as another strength [37]. People with severe mental health problems were heavily involved in the development of the QoL-ME, and their feedback, tips and insights strongly influenced the direction of the development.

Apart from these strengths, several limitations ought to be taken into account when interpreting the results of this study. First, the sample was not selected randomly, but by a combination of convenience sampling and stratified sampling. This sampling strategy may negatively affect the generalizability of the results. At the same time, the aforementioned diversity of the sample indicates that the negative consequences of the sampling strategy are minimal. Second, the results may be biased by a selection effect. It is likely that clients who were interested in this study had at least some affinity and experience with digital technology and apps. If this is the case, potential issues in the design of the QoL-ME may not have been uncovered. A number of participants, however, described themselves as digital illiterates, and some even indicated never having used apps or touchscreen devices before. This anecdotal evidence appears to indicate that no major selection effect occurred. Nevertheless, participants' previous experience with digital technologies was not investigated systematically and therefore no firm conclusion can be drawn. Third, the group of participants who evaluated the usability of the QoL-ME using the SUS was rather small. As a study by Tullis and Stentson [64] revealed, however, a sample of 12-14 participants is sufficient to obtain reliable results using the SUS. A fourth limitation concerns the dearth of available information regarding the background of participants. In this study, however, we strove to include a broad group of participants, so that the QoL-ME suits a sample of people with severe mental health problems with diverse vulnerabilities and problems. Therefore, no conclusions regarding the appropriateness of the QoL-ME for groups with specific cultural backgrounds, psychopathology, or socioeconomic status can be drawn on the basis of this study. Further research will have to reveal whether the co-creative development has resulted in an application that is suitable for specific groups.

Conclusion

The co-creative development of the QoL-ME resulted in an innovative, personalized and visual app for QoL assessment. Overall, participants had little difficulty operating the QoL-ME and were positive regarding its usability. Participants indicated a preference for paging over scrolling, linear navigation, a clean and minimalist layout, and the use of touchscreen functionality in various modes of interaction. Further research is needed to evaluate both the validity and reliability of the QoL-ME. In addition, it is important to investigate the usefulness of the QoL-ME for both clients and care professionals in practice. Moreover, for the QoL-ME to be of use in clinical practice, its sensitivity to change in QoL ought to be examined.

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Chapter 5

Psychometric properties of the QoL-ME: a visual and personalized quality of life assessment app for people with severe mental health problems

This chapter has been submitted and is currently under review as: Buitenweg, D. C., Van de Mheen, D., Van Oers, H. A., & Van Nieuwenhuizen, Ch. (submitted). Psychometric properties of the QoL-ME: a visual and personalized quality of life assessment app for people with severe mental health problems

Abstract

Background: Assessment of Quality of Life (QoL) in people with severe mental health problems may benefit from improved personalization and accessibility. Therefore, an innovative, digital, visual and personalized QoL assessment app for people with severe mental health problems was recently developed: the QoL-ME. The aim of this study was to evaluate the psychometric quality of the QoL-ME by assessing its reliability, validity and responsiveness.

Methods: To examine the reliability of the QoL-ME, the internal consistency of its subscales was assessed using Cronbach's Alpha. Correlations between the QoL-ME and MANSA were computed to appraise the construct validity of the QoL-ME. External responsiveness was evaluated by correlating difference scores on the QoL-ME and the MANSA.

Results: Cronbach's Alpha of the subscales of the QoL-ME ranged between .5 and .84. In accordance with expectations, the language-based core version of the QoL-ME correlated strongly (r = between .55 and .76) with the MANSA, whilst the picture-based additional modules of the QoL-ME correlated moderately (r = .3) with the MANSA. Difference scores between MANSA and QoL-ME were not significantly correlated.

Conclusions: The QoL-ME has adequate psychometric properties. In comparison with similar pictorial instruments, both the QoL-ME's reliability and validity can be considered as strong. The results indicate that the responsiveness of the QoL-ME is insufficient and additional research is needed to evaluate and potentially modify the instrument to improve its responsiveness.

Introduction

Quality of life (QoL) is an essential patient-reported outcome in mental health services [1-3]. Subsequently, a number of instruments to assess the QoL of people with severe mental health problems have been developed [3; 4]. These instruments, such as the Lancashire Quality of Life Profile (LQoLP; [5]) and the Manchester Short Assessment of Quality of Life (MANSA; [6]), communicate using language and generally assess QoL on the basis of a fixed set of life domains, such as 'Social relations', 'Living situation' or 'Finances' [5; 7]. Respondents are required to respond to a statement or question by selecting one of multiple Likert options. This conventional approach to QoL assessment faces three important challenges. First, recent research reemphasizes the subjective nature of QoL, as the concept is shaped by individual values and priorities [8; 9]. Respecting this subjective aspect of QoL requires a more personalized assessment. Second, existing QoL instruments depend on verbal, language-based communication. Research indicates that this language-based approach may not be optimal for every individual with severe mental health problems [10-12]. Visual communication may provide a suitable alternative to language-based methods due to ease of processing and intuitiveness [13-15]. Third, given the continuing digitalization of society and mental healthcare [16; 17] it is vital to explore the potential of digital applications in QoL assessment. Examples of characteristics of digital applications that may benefit QoL assessment include their flexibility [18; 19] and multimedia compatibility [20].

In response to these challenges in QoL measurement, a new digital QoL assessment app was recently developed: the QoL-ME [21]. The QoL-ME is a digital QoL assessment app that utilizes a personalized and visual assessment approach. The app consists of two main components: a core version and additional modules. The core version involves a fixed set of universal QoL domains that every respondent is required to answer questions about. The additional modules give respondents the possibility to select any combination of eight modules and they only answer questions about the modules of their choice [21].

The QoL-ME was developed co-creatively with patients [21]. A usability evaluation, that was part of the development, revealed good to excellent usability scores [21]. Participating patients were enthusiastic regarding the visual approach employed in the QoL-ME and welcomed the opportunity to select QoL domains based on their personal relevance [21]. No conclusion regarding the utility of the QoL-ME can be drawn, however, without an evaluation of its psychometric quality. A psychometric evaluation of the QoL-ME is of special importance in light of the visual assessment approach employed in the QoL-ME. This approach does not depend on respondents' language proficiency and is more intuitive [22]. At the same time, visual information also tends to be more ambiguous than verbal information [23; 24]. This ambiguity may have consequences for the validity and reliability of the QoL-ME. In addition, insight into the responsiveness of the QoL-ME is needed. A responsive QoL instrument reflects true changes or differences in QoL [25; 26]. Sufficient reliability, validity, and responsiveness are essential qualities if the QoL-ME is to be of use in the context of scientific research and clinical practice.

Therefore, the aim of this study is to investigate the psychometric quality of the QoL-ME. To this end, the reliability, construct validity and responsiveness of the QoL-ME are investigated.

Methods

Participants

In this study, three populations of people with severe mental health problems were included: 1) people with severe psychiatric problems, 2) people treated in forensic psychiatry and 3) people who are homeless. These groups may have difficulty with traditional language-based QoL assessment due to experiencing fewer educational opportunities [27-29], co-occurring intellectual disabilities [29-31], and compromising psychiatric symptoms [11; 32].

Six societal organizations collaborated in a consortium to facilitate this study, including a multimodal day treatment center for multi-problem young adults, a hospital for forensic psychiatry, a mental health institution, a day center for people who are homeless and two research institutions focusing on lifestyle, homelessness and addiction. A group of 121 participants was recruited with the help of the consortium.

Design

To assess the reliability, validity and responsiveness of the QoL-ME, a quantitative longitudinal design was used. Participants were asked to fill out the QoL-ME every month during six months, leading to a maximum of seven measurements. The intermediate assessments served to investigate respondents’ QoL-trajectories, which lies outside the scope of this article. Therefore, only the results gathered at the first measurement and final measurement will be discussed. During the first measurement (t0), participants also filled out the MANSA [34] and were asked a number of demographic questions. During the last measurement, participants filled out the MANSA again. For practical reasons, roughly a third of participants (n = 39), who were included later in the study, had their final assessment after four months instead of six months. A one-way ANOVA was used to assess whether having a final assessment after four months or six months had a significant effect on scores on both the QoL-ME and the MANSA at the first (2 ANOVA’s) and final (2 ANOVA’s) measurement. None of the four analyses returned a significant result. All final measurements were therefore taken together and will henceforth be called ‘tfinal’.

Measures

The QoL-ME

Previous studies revealed a difference in universal QoL domains between (forensic) psychiatric patients on the one hand and people who are homeless on the other hand. Therefore, the QoL-ME contains two core versions [21; 33; 34]. The content of both core versions and the additional modules is described in next paragraphs.

The first core version targets people with (forensic) psychiatric problems and includes three domains of the LQoLP [5; 7]: 'Living situation', 'Safety', and 'Finances'. A recent study indicates the universality of these three domains [35], based on their high univariate entropies. Both 'Living situation' and 'Finances' are assessed using four items, whilst the domain 'Safety' contains five items. The first core version therefore contains 13 items. Examples of items included 'How satisfied are you with the amount of money you make?' and 'How satisfied are you with your general personal safety?'. The 7-point Likert scale used to assess these items ranges from 'cannot be worse' (1) to 'cannot be better' (7) and is identical to the scale used in the LQoLP [5; 7].

The second core version targets homeless people and covers two domains regarding meaning in life, which is especially important for homeless people [33; 34]. The second core version contains the Dutch version of the Meaning in Life Questionnaire (MLQ; [36]), a 10-item measure that assesses both the presence of meaning in one's life and the search for meaning in life [36]. Examples of MLQ items include 'My life has a clear sense of purpose', and 'I am searching for meaning in my life'. The MLQ also uses a seven-point Likert scale, ranging from 'completely disagree' (1) to 'completely agree' (7).

The additional modules serve to ensure the personalization of the QoL-ME. The QoL-ME contains eight additional modules, all of which correspond to a domain of QoL: 1) Support and Attention, 2) Social Contacts, 3) Happiness and Love, 4) Relaxation and Harmony, 5) Leisure, 6) Lifestyle, 7) Finances, and 8) Health and Living. Users are free to select any combination of these eight modules. The eight QoL domains were identified in a visual concept mapping study of the QoL of people with severe mental health problems [37]. Domains are assessed using two to four visual items. Every visual item contains three pictures that together depict an aspect of QoL. Users respond to these items using a Visual Analogue Scale (VAS scale) with visual anchors. VAS scores range between 0 and 100.

This structure, involving both a core version and additional modules, makes the QoL-ME a flexible QoL assessment tool. The core version is useful in contexts where group-level data are of interest, such as comparisons of the QoL of different client populations. The additional modules are especially suitable for use in individual care planning. An introductory video of the QoL-ME and a video impression can be found in Additional files 1 and 2.

The MANSA

The MANSA is a shorter and slightly altered version of the LQoLP. The MANSA was developed by Priebe and colleagues [6]. Van Nieuwenhuizen and colleagues [5; 38] developed an authorized Dutch version of the MANSA. The Dutch MANSA consists of 16 items, of which 12 assess the subjective QoL of respondents. The remaining four items measure objective circumstances. The objective items cover a respondents objective circumstances (‘In the past week have you visited with a friend?’), whilst the subjective items involve respondents’ satisfaction with several domains of life (‘How satisfied are you with how well-off you are financially?’). The psychometric properties of the (Dutch version of the) MANSA were investigated extensively in multiple studies [38]. In these studies, the reliability of the MANSA (Cronbach’s alpha) ranged between .75 and .84. Convergent validity between the LQoLP and the MANSA ranged between .65 and .97 [38].

Demographics/background variables

In addition to the QoL-ME and the MANSA, participants were asked to fill out a number of basic demographic questions on their gender, age, cultural background, and employment status.

Procedure

Participants contributed either in person, or on-line, depending on whether participants required personal assistance. Contacts at the consortium institutions approached potential participants using flyers and an information letter. Once participants indicated their interest in contributing to this study, they received an e-mail containing additional information on the study, and a detailed outline of what was expected of them. Moreover, the e-mail contained a link to the QoL-ME and to Qualtrics; an online survey program used to administer the MANSA and the demographic questions. Once participants had filled out the online questionnaires, they received a €10 gift voucher by post. Alternatively, an appointment between researcher and participant was scheduled. During that appointment, the researcher provided additional information regarding the study, and outlined what was expected of the participant. Next, participants filled out the demographic items, the MANSA and the QoL-ME. Once all the questionnaires were filled out, participants received a €10 gift voucher. For the second to sixth measurement, participants received a request to fill out the QoL-ME via email or text message. The procedure for the last measurement was similar, but involved both the QoL-ME and the MANSA. Upon completing the last assessment, all participants received an additional €20 gift voucher.

Statistical analysis

Total scores on the MANSA were computed using the method described by Van Nieuwenhuizen and colleagues [38]. To calculate a total score for the QoL-ME, mean scores were computed for every domain included in the core version and additional modules selected by respondents. As the core version has a 7-point Likert scale and the additional modules use a 0-100 VAS scale, all scores on the additional modules were transformed with the following formula: new score = (VAS score / 100) * 7). Then, the mean of all the domain scores was calculated to arrive at a total score.

To assess the reliability of the QoL-ME, the internal consistency of the subscales of the QoL-ME was evaluated using Cronbach's Alpha. Based on the size of Cronbach's Alpha, international consistency is seen as 'excellent' ($\alpha \geq .9$), 'good' ($.9 > \alpha \geq .8$), 'acceptable' ($.8 > \alpha \geq .7$), 'questionable' ($.7 > \alpha \geq .6$), 'poor' ($.6 > \alpha \geq .5$) or 'unacceptable' ($0.5 > \alpha$) [39]. Construct validity of the QoL-ME was evaluated based on the size of the correlation between scores on the QoL-ME and the MANSA at t0. As they target the same construct using language-based methods, the correlation between the core version for people with psychiatric problems of the QoL-ME and the MANSA was expected to be strong (>0.5; [40]). Note: As the core version for homeless people was not based on the LQoLP but on the MLQ, we could not test the internal validity of this core version. The correlation between the QoL-ME's additional modules and the MANSA was expected to be medium sized (>0.3 and <0.5; [40]). To further examine the validity of the visual assessment approach employed in the additional modules, correlations were computed for pairs of items of the additional modules and their corresponding MANSA items. Lacking fully objective criteria, this was done for items of the additional modules that have a direct parallel MANSA item. Therefore, correlations were computed for 6 pairs of items, which are provided in Table 5. Due to non-normally distributed data, correlations were computed using Spearman's Rho. These correlations were also expected to be of medium size (>0.3 and <0.5). As for the responsiveness, the QoL-ME's external responsiveness is especially of interest [41]. External responsiveness is assessed by relating change on the measure of interest to change on an established measure. In this study, external responsiveness was assessed by correlating change scores (tFinal – t0) on the QoL-ME with change scores on the MANSA [41]. No guidelines for interpreting the size of the correlation between difference scores exist. According to Husted and colleagues [41], an instrument may be considered responsive when the correlation between difference scores approaches 1 [41]. Therefore, the responsiveness of the QoL-ME will be considered 'good' ($r \geq .7$), 'sufficient' ($0.5 \geq r$ 0.7) or 'insufficient' ($r < 0.5$).

Results

Participants

A total of 121 participants agreed to contribute to this study and filled out the demographic items, the QoL-ME and the MANSA at the first measurement (t0). Seventy-two participants (59.5 %) filled out the core version for (forensic) psychiatric patients. The group that filled out the core version for people who are homeless included 49 participants (40.5 %). Participants' age ranged between 17 and 66 with an average of 39.6 (SD = 14.9). A little over 70 percent of participants was male and 42.1 percent had a Dutch cultural background. Additional demographic characteristics are provided in Table 1. Eighty-one participants contributed to the final measurement. Statistical analyses revealed that individuals in the group of responders (those that completed a final assessment) were on average 10,6 years older than individuals in the group of non-responders, which was a significant difference (n=40): T(117) = 3.72, p < .01. The groups did not differ significantly on other demographic characteristics including sex, cultural background, educational level or occupational status.

Table 1. Participants' demographic characteristics (N = 121).

Average age (SD)	**39.6 (14.9)**
Range	17-66
Males (%)	85 (70.2)
Cultural background	
Dutch (%)	51 (42.1)
Western (%)	5 (4.1)
Non-western (%)	65 (53.7)
Level of education^x	
Basic (%)	42 (34.2)
Intermediate (%)	65 (54.1)
Higher (%)	6 (5)
Unknown (%)	8 (6.7)
Occupational status	
Paid employment/Volunteer work (%)	50 (41.3)
Unemployed (%)	71 (58.7)

x = categorized based on the standard education classification (SOI -2016) of the Dutch CBS.

QoL-ME

Average scores on the domains of both core versions of the QoL-ME can be found in Table 2. Table 3 indicates how frequently the eight additional modules were selected at t0. Frequencies ranged between 97 (80.2 %) for the modules *Social relations* and *Lifestyle* and 111 (91.7 %) for the modules *Relaxation and harmony* and *Health and living*. Mean scores at t0 of the items of the additional modules of the QoL-ME are provided in Additional file 3. Mean module scores are displayed in Table 3.

Table 2. Scores on domains of the core versions of the QoL-ME at t0 (N = 121).

Core version homeless people (n = 49)	
Searching for meaning	4.67 (1.18)
Presence of meaning	5.39 (0.99)
Core version (forensic) psychiatric patients (n = 72)	
Living situation	5.02 (1.09)
Safety	5.15 (0.93)
Finances	3.95 (1.06)

Table 3. Overview of the number of participants that selected the eight additional modules of the QoL-ME and mean scores at t0 (N = 121).

Additional module	# selections	Percentage of participants	Mean score (SD)
Support and attention	101	83.5	74.1 (21.9)
Social relations	97	80.2	73.16 (22.3)
Happiness and love	105	86.8	74.1 (22.2)
Relaxation and harmony	111	91.7	77.34 (18.2)
Leisure	103	85.1	72 (19.8)
Lifestyle	97	80.2	76 (20.9)
Finances	105	86.8	62.72 (26.7)
Health and living	111	91.7	70 (23.5)

MANSA

The average total score on the MANSA at t0 was 4.52 (SD = 0.86). Analysis revealed a good internal consistency for the MANSA in this sample: Cronbach’s Alpha = .84.

Reliability

The internal consistency of the three domains of the core version for people with (forensic) psychiatric problems was α = .74. (Finances), .76 (Living situation) and .83 (Safety). The internal consistency of the MLQ in this sample was α = .74. The internal consistency of the eight additional modules of the QoL-ME, computed using Cronbach’s alpha, is provided in Table 4. Alpha’s ranged between 0.50 (domain Leisure) and 0.84 (Domain Happiness and love).

Table 4. Overview of the internal consistency of the eight additional modules of the QoL-ME.

Support and attention	α = .69 (n = 101)
Social relations	α = .78 (n = 97)
Happiness and love	α = .84 (n = 105)
Relaxation and harmony	α = .76 (n = 111)
Leisure	α = .50 (n = 103)
Lifestyle	α = .69 (n = 97)
Finances	α = .70 (n = 105)
Health and living	α = .63 (n = 111)

Validity

Correlations between the three domains of the QoL-ME core version for people with (forensic) psychiatric problems and their corresponding MANSA-domains were $r = .55$ (Living situation), $r = .62$ (Safety) and $r = .76$ (Finances). All correlations were significant ($p < 0.001$). Mean total scores for the MANSA and the additional modules of the QoL-ME correlated at $r = .30$, $p < 0.001$. The correlations between the six pairs of QoL-ME and MANSA items are provided in Table 5. Correlations ranged between .15 (Finances) and .39 (Living situation).

Table 5. Correlations between six pairs of items of the additional modules of the QoL-ME and corresponding MANSA items.

Item QoL-ME[1]	Item MANSA	Correlation (n)
Support and attention item 1	Friendships	.29* (96)
Social relations item 3	Family relations	.23* (93)
Leisure item 1	Leisure	.19 (100)
Finances item 1	Finances	.15 (101)
Health and living item 1	Living situation	.39* (64)
Health and living item 2	Physical health	.36* (109)

1 = the content of the items of the additional modules of the QoL-ME are provided in Additional file 3.
* = significant correlation at p < .05

Responsiveness

An overview of the mean scores on MANSA and QoL-ME at the first and last measurement is displayed in Table 6. The Pearson correlation between change scores (tFinal – t0) on the QoL-ME and MANSA was r(81) = -.095, *p = 0.4.*

Table 6. Mean total scores for the QoL-ME and MANSA at t0 and tFinal.

	T0 (n = 81)	tFinal (n = 81)	Δ scores	Correlation Δ scores
QoL-ME (SD)	4.85 (.91)	4.73 (.94)	-.12 (.48)	-.095, p = 0.4
MANSA (SD)	3.78 (.66)	3.96 (.6)	.17 (.37)	

Discussion

In this study, the psychometric properties of the QoL-ME were assessed. The results show satisfactory reliability for most of the subscales of the core version and additional modules of the QoL-ME. In addition, the QoL-ME has good construct validity. The external responsiveness of the QoL-ME, however, is poor.

Regarding the reliability of the QoL-ME, one of the additional modules has poor internal consistency (Leisure; $.6 > \alpha \geq .5$). Furthermore, four modules have questionable internal consistency (Support and attention, Lifestyle, Finances and Health and living; .7 >

α ≥ .6). The internal consistency of the four remaining modules and of both core versions is acceptable to good (.9 > α ≥ .7). Whilst these Alpha's are slightly lower than those of other QoL instruments [5; 38], they hold up well when compared to similar multidimensional pictorial assessment scales. Engell and colleagues [42], for example, reported the results of a psychometric evaluation of a pictorial version of the Aachen Quality of Life Inventory (AQLI) targeting people with aphasia [42]. The psychometric quality of the pictorial AQLI was evaluated by comparing results on the pictorial AQLI with scores on the regular AQLI that was filled out by the partners of a group of 24 patients. The results revealed notably lower reliability on some of the domains of the pictorial AQLI compared to the conventional AQLI that are very comparable to the QoL-ME [42]. Second, Reid and colleagues [43] described the development and evaluation of a pictorial motivation scale (PMS) targeting adolescents and adults with an intellectual disability. The PMS involves four subscales, whose Alpha's ranged between .64 and .88 [43]. Moreover, the items of both the pictorial AQLI and the PMS involve both a picture and a verbal statement [42; 43], while the items of the additional modules of the QoL-ME consist solely of pictures.

The content of the QoL-ME was derived from a visual concept mapping study into the meaning of QoL for people with severe mental health problems [37]. The use of concept mapping as the basis for measurement development is a dependable way to establish content validity [44]. Two prior expectations regarding the validity of the QoL-ME were confirmed by the results. First, the domains of the core version for (forensic) psychiatric patients of the QoL-ME correlated highly ($r = .55 - .76$) with the corresponding models of the MANSA. Second, scores on the language-based MANSA and the additional modules of the QoL-ME revealed a correlation of medium size (r = .3). Correlations between single items of the additional modules of the QoL-ME and corresponding MANSA items were of a similar magnitude, ranging between .15 and .39. These results are in accordance with the study of Engell and colleagues [42] in which they found correlations between the pictorial and language-based versions of the AQLI ranging between -.01 and .75, but most correlations varied around .3 [42].

Further, the results reveal substandard external responsiveness of the QoL-ME. Scores on the MANSA increased slightly whilst scores on the QoL-ME decreased. An explanation for the inadequate responsiveness of the QoL-ME may be provided by the literature on subjective well-being. In subjective well-being literature, a distinction between an affective and a cognitive component has been firmly established [45-47]. Research revealed that the two components of subjective well-being are determined by distinct variables and mechanisms [47]. The pictorial approach to QoL assessment as employed in the additional modules of the QoL-ME may tap into the affective component of subjective well-being and QoL, whilst the language-based MANSA may draw on the cognitive component.

Strengths and limitations

In this study, the psychometric quality of the QoL-ME was assessed in a diverse sample including respondents from various cultural backgrounds and age groups, which is an important strength.

Still, the results of this study should be regarded in light of four limitations. The first limitation concerns the convenience sampling method employed in this research. The resulting sample may not be representative for the target population, which may limit the generalizability of the results. Still, the aforementioned diversity in the sample indicate that the negative consequences of the employed sampling strategy are minimal. Second, analyses revealed that respondents who completed a final assessment were significantly older than respondents who dropped out of the study before their final assessment. Therefore, the findings related to the responsiveness of the QoL-ME may not be generalizable to younger age groups. However, we do not think this is a serious threat, because the results regarding the responsiveness of the QoL-ME are still inconclusive. The third limitation relates to the absence of information on the occurrence of treatment interventions or life events known to influence the QoL of respondents during the study period. It is therefore unclear whether changes in the QoL of respondents are caused by treatment interventions, life events, inadequacies in the assessment instruments, or other causes. The fourth limitation concerns the use of the MANSA as a gold standard for evaluating the validity and responsiveness of the QoL-ME. The MANSA is a credible and valid QoL assessment instrument, but it is not personalized and primarily language-based. It is unclear to what degree the differences between the QoL-ME and the MANSA have affected the results.

Future research

The results of this study provide strong evidence for the suitability of the QoL-ME as an accessible alternative to existing language-based QoL instruments for people with severe mental health problems. At the same time, the multiple innovative characteristics of the QoL-ME, such as its flexible structure and visual approach to QoL assessment, offer a wide range of starting points for future research. First, future research may further investigate how the constituents of QoL may be optimally visualized, which may strengthen the psychometric quality of visual instruments such as the QoL-ME. Second, future research may investigate to what degree the visual assessment approach employed in the QoL-ME does indeed tap into the affective rather than cognitive component of QoL and what this means for the psychometric quality of the QoL-ME. Third, more research into the responsiveness of the QoL-ME that involves the clinical characteristics of respondents is needed to draw a more definitive conclusion regarding the suitability of the QoL-ME in clinical practice.

Conclusion

This psychometric evaluation revealed adequate reliability and validity of the QoL-ME. Albeit slightly lower than the psychometric properties of conventional, language-based QoL instruments, in light of the psychometrics of similar pictorial instruments, both the QoL-ME's reliability and validity can be considered strong. Overall, the QoL-ME displays adequate reliability and validity that is promising regarding the feasibility of its visual assessment approach. The responsiveness of the QoL-ME, however, is insufficient and additional research is required to evaluate and potentially modify the instrument to improve its responsiveness.

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Chapter 6

What’s in it for me? Qualitative evaluation of the QoL-ME, a visual and personalized quality of life assessment App for people with severe mental health problems

This chapter has been accepted for publication as:

Buitenweg, D., van de Mheen, H., Grund, J. P. C., van Oers, J. A. M., & van Nieuwenhuizen, Ch. (Accepted/In press). What’s in it for me? Qualitative evaluation of the QoL-ME, a visual and personalized quality of life assessment app for people with severe mental health problems. *JMIR Mental Health. https://doi.org/10.2196/19593*

Abstract

Background: The QoL-ME is a digital, visual and personalized QoL assessment App for people with severe mental health problems. Research reveals that e-mental health Apps such as the QoL-ME frequently suffer from low engagement and fall short of expectations regarding their impact on patients' daily lives. Studies often indicate that e-mental health Apps ought to respect the needs and preferences of end-users to achieve optimal user-engagement.

Objective: The aim of this study was to explore the experiences of users regarding the usability and functionality of the QoL-ME and whether the App is actionable and beneficial for patients.

Methods: Eight end-users who gained experience using the QoL-ME contributed to semi-structured interviews. An interview guide was used to direct the interviews. All interviews were audio recorded and transcribed verbatim. Transcriptions were analysed and coded thematically.

Results: Analysis revealed three main themes 1) Obtained benefit, 2) Actionability and 3) Characteristics of the QoL-ME. The first theme reveals that the QoL-ME was beneficial for the majority of respondents, primarily by prompting them to reflect on their QoL. The current version of the QoL-ME is not yet actionable for respondents. The actionability of the QoL-ME may be improved by enabling respondents to view the development of their scores over time and by supplying practical advice for QoL improvement. Overall, participants had positive experiences with the usability, design and content of the QoL-ME.

Conclusions: The QoL-ME can be beneficial to users as it provides them with insight into their QoL and elicits reflection. Incorporating more functionalities that facilitate self-management, such as advice and strategies for improving lacking areas, will likely make the App more actionable. Patients positively regarded the usability, design and content of the QoL-ME.

Introduction

Quality of Life (QoL) assessment in people with severe mental health problems faces several challenges. First, respondents may not have had the opportunity to develop the abilities necessary to engage in traditional, language-based QoL assessment [1-3]. Alternatively, comorbid intellectual disabilities [3-5] or psychopathology [6-8] may compromise the validity of QoL results. Second, in mental health QoL is understood as an inherently subjective concept that is shaped by individuals' values and preferences [9-11]. Research underlines this notion, [12-14] which calls for the further personalisation of QoL measurement. Third, QoL assessment instruments may promote patient empowerment by providing patients with insight in their QoL scores, which is an important prerequisite for shared-decision making [15, 16]. Both patient empowerment and shared-decision making have become important goals in mental health services [17-19]. To meet these three challenges, an innovative, personalized and visual QoL assessment App was developed: the QoL-ME [20]. The QoL-ME consists of a core version that can be supplemented with additional modules. The core version involves a mandatory set of three universal QoL domains. In addition, respondents can choose from eight additional modules. Every module involves a domain of QoL that respondents may select if it is important for their QoL. Respondents only answer questions on their selection of additional modules. After filling out the QoL-ME, respondents receive direct feedback from the App in the form of an overview of their answers. The QoL-ME was developed co-creatively in close collaboration with patients, family members and care professionals [20, 21].

Both research and practice reveal that e-mental health Apps such as the QoL-ME frequently suffer from low engagement and fall short of expectations regarding their impact on the daily lives of patients. [22-26]. Researchers have therefore investigated what factors enable e-mental health Apps to bridge the gap from development to high engagement and practical use by patients [25, 27, 28]. Generally, these studies often indicate that e-mental health Apps such as the QoL-ME ought to respect the needs and preferences of patients to achieve optimal user-engagement [25, 27-29]. Regarding the QoL-ME, two specific factors are of special importance. First, it is essential that the QoL-ME is actionable. The QoL-ME is actionable if provides a useful base for practical action for patients [25]. Examples of practical action include patients altering their sleep schedule after using an app that has sleep tracking functionality [30] or opting not to engage in a romantic relationship based on the results of a self-management App [31]. Second, use of the QoL-ME ought to be beneficial to patients. The QoL-ME should effectively address an issue patients care about so that they derive a tangible benefit from utilizing the App [32].

End users played a vital role in the development of the QoL-ME. In the context of this development, participants rated the usability of the App as "very high" [20]. It is unknown, however, whether the intensive user-involvement and positive rating of the usability of the QoL-ME translates to an instrument that is of use for patients in a real-life setting.

In light of the discrepancy between the potential of e-mental health Application and their lack of impact on patients' daily lives, it is crucial to investigate the experiences of patients who used the QoL-ME. In addition, it is of special importance to examine to what degree the QoL-ME is actionable and beneficial to its users. The aim of this study was to explore the experiences of users regarding the usability and functionality of the QoL-ME and whether the App is actionable and beneficial for patients. To this end, participants who had used the QoL-ME were interviewed about their experiences with several aspects of the QoL-ME including its usability, functionality and beneficiality.

Methods

Participants

This study targeted three specific populations of people with severe mental health problems: 1) people with psychiatric problems, 2) people treated in forensic psychiatry and 3) people who are homeless. Homeless individuals were included in this study because of the high prevalence of severe mental health problems in this group [3, 33, 34]. These groups may have difficulties with traditional language-based QoL assessment due to experiencing fewer educational opportunities [1-3], co-occurring intellectual disabilities [3-5] and compromising psychopathology [6, 7]. A consortium consisting of six societal institutions was formed to facilitate this study and the broader research project. These institutions include a multimodal day treatment centre for multi-problem young adults, a hospital for forensic psychiatry, a mental health institution, a day centre for people who are homeless and two research institutions focusing on lifestyle, homelessness and addiction. Participants were recruited with the help of the consortium partners.

The research population consisted of individuals who had gained experience with the QoL-ME in the context of a psychometric evaluation of the App. In this psychometric evaluation, respondents were invited to use the QoL-ME monthly for a period of six months. A specific inclusion criterion of at least five uses of the QoL-ME was employed. This criterion ensures that patients had sufficient experience with the QoL-ME to be able to contribute valuable information. The aim was to include enough participants to reach saturation in the sample, defined as a lack of new information in the final two interviews [36].

Ethical approval was obtained from the Ethics Committee of the Tilburg School of Behavioural and Social Sciences at Tilburg University (EC-2015.44). Informed consent was obtained from each participant. All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

The QoL-ME

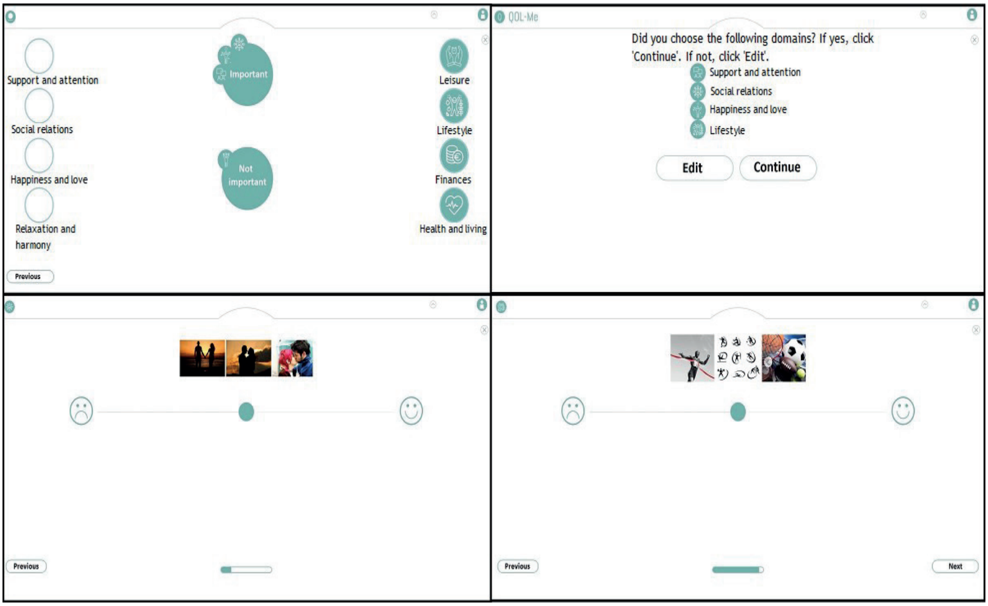
A group of 59 patients contributed to the development of the QoL-ME. The iterative development comprised six iterations divided over three stages. In the first stage, patients were invited to share their ideas regarding the design and functionality of the QoL-ME. In the second stage, initial designs and wireframes were developed into a fully functioning prototype of the QoL-ME. This process was guided by the feedback and ideas of patients. The prototype was subjected to a usability evaluation in the final stage [20].

The QoL-ME encompasses two separate core versions. The first core version targets people with psychiatric problems and people treated in forensic psychiatry and includes three domains of the Lancashire Quality of Life Profile (LQoLP; [11]): ‘safety’, ‘living situation’ and ‘finances’. A recent study indicates that these three LQoLP domains are universal [12]. The LQoLP uses a 7-point Likert scale, ranging from ‘cannot be worse’ (1) to ‘cannot be better’ (7). The second core version is tailored to people who are homeless and comprises the Dutch version of the Meaning in Life Questionnaire (MLQ), a 10-item measure that assesses both the presence of meaning in one’s life, and the search for meaning in life [37]. Research indicates that having meaning in life is especially important for people who are homeless [38, 39]. The MLQ also uses a seven-point Likert scale, ranging from ‘completely disagree’ (1) to ‘completely agree’ (7).

The additional modules serve to ensure the personalization of the QoL-ME. The following eight domains of QoL are included: (1) Support and Attention, (2) Social Contacts, (3) Happiness and Love, (4) Relaxation and Harmony, (5) Leisure, (6) Lifestyle, (7) Finances and (8) Health and Living. These domains were identified in a visual concept mapping study of the QoL of people with severe mental health problems [21]. Domains are assessed using two to four visual items. Every visual item contains three pictures that together denote an aspect of QoL. Users respond to these items using a Visual Analogue Scale (VAS scale) with visual anchors. Figure 1 depicts how respondents select additional modules and provides two examples of items of the additional modules.

When filling out the QoL-ME, users first indicate which of the two core versions is appropriate for them and respond to the items of that core version. Next, they select a combination of the eight additional modules based on their importance. Upon completing the visual items of the additional modules, users are provided with an overview of their answers.

A thorough description of the development of the QoL-ME, including additional visual material, is provided elsewhere [20].



Did you choose the following domains? If yes, click 'Continue'. If not, click 'Edit'.

Support and attention
Social relations
Happiness and love
Lifestyle

Figure 1. Four screenshots depicting the additional modules of the QoL-ME. The top-left panel displays how respondents select additional modules. Respondents are invited to drag eight icons, corresponding to the eight modules, to a circle that says 'important' or a circle that says 'not important'. The top-right panel shows how respondents are asked to confirm their choice of additional modules. The two bottom panels provide examples of items of the additional modules.

Approach

A qualitative research approach was employed to explore participants' experiences with the QoL-ME. Specifically, individual semi-structured interviews were utilized as they allowed participants to elaborate on their experiences, and allowed the researcher to clarify on any confusing or unclear questions when necessary. In addition, the context of individual interviews enabled referring back to the QoL-ME to make questions more tangible. The use of semi-structured interviews combined a guiding structure with providing participants freedom to expand on their answers.

Content of the interview

An interview guide was used to guide the interviews conducted in this study. Four sources of information were consulted to inform this interview guide (See Table 1). First, insights regarding patients' needs and preferences concerning the QoL-ME gained during the development of the QoL-ME were fed back into the interview guide. Second, the Health Information Technology Acceptance Model (HITAM) was consulted [40]. The HITAM describes consumers' behavioral intentions towards the use of health technology. Third, relevant information was extracted from two questionnaires designed to evaluate mobile (health)

Apps 1) the Mobile App Rating Scale (MARS; [41]) and 2) the App Chronic Disease Checklist (ACDC; [42]). Fourth, the scientific literature was examined and information regarding patients' needs and preferences regarding mobile mental health Apps was extracted [25, 32, 43, 44]. The 18 identified topics were grouped into five overarching themes (see Table 1) and each theme was introduced using a short prime.

Table 1. Overview of the interview guide used in this study. The guide includes the different factors queried in this study, their origin, and the questions used to explore them.

Topic	Question	Source(s)
Deriving Value		
Beneficial	Did using the QoL-ME benefit you? And if so, how? If not, what changes can we make for you to derive benefit from using the QoL-ME?	Development, HITAM, Torous 2018
Actionable	Did your use of the QoL-ME result in actions? If yes, which actions?	
Content and results		
Number of questions	What do you think about the number of questions in the QoL-ME?	Development
Match questions and respondents	To what degree did the questions of the QoL-ME match your world and experiences?	
Feedback	At the end of the QoL-ME, you can review your answers. What do you think about that?	Development, ACDC
Comparing results	Would you welcome the possibility to compare your own results with others and why?	Development
Stimulation / motivation	What do you think about the possibility to stimulate the use of an App such as the QoL-ME through push messages or other mechanisms?	Development, ACDC
Usability		
General usability	What do you think about the QoL-ME's usability? Are there any changes we can make to improve its usability? If yes, which changes?	Development, HITAM, ACDC, 2016 Bernard, Torous 2018
Structure	Does the QoL-ME have a clear structure according to you? Why/why not?	Development, ACDC, MARS
Intuitive design	Did you have to learn or practice before using the QoL-ME? If yes, what did you have to learn or practice?	ACDC, MARS
Appearance	What do you think about the appearance of the QoL-ME?	MARS
Performance	Did you run into any problems using the QoL-ME on your phone/tablet/laptop/computer? If yes, which problems?	ACDC, MARS
Barriers	Were you unable to use the App for any reason? If yes, what reasons?	HITAM

Topic	Question	Source(s)
Personalization		
Personalized content	What did you think about selecting your own topics in the QoL-ME?	Development, ACDC, MARS
Personalized Appearance	During the development of the QoL-ME, some participants indicated a preference for customizing the appearance of the QoL-ME. What do you think about that?	Development, ACDC, MARS, Torous 2016
Trust		
Privacy / data security	Do you think that your data is safe and confidential in the QoL-ME? Why?	Development, ACDC, Satinsky 2018
Transparency	Do you know which parties get to see your data and what they do with them?	Development, Torous 2016
Professional credibility	What do you think about the credibility of the QoL-ME?	ACDC, MARS

Data analysis

A deductive, or theoretical [45], analysis approach was employed, starting from a specific predefined research question. All interviews were audio recorded. The recordings were transcribed verbatim and transcripts were coded thematically utilizing the six-step method as outlined by Braun and Clarke [45] in order to capture user experience themes. Initial themes were continuously refined and reflected on using a deductive approach. In the First Step, the researchers familiarized themselves with the data through checking and verifying the accuracy of the transcripts. The Second Step involved the selection of an initial set of codes and themes based on the first three interviews. Codes are used to label and organize qualitative data. Codes with similar content are clustered into overarching themes. The coding was performed using ATLAS ti version 8. The two researchers compared their initial codes to ensure consistency throughout the coding process. Once the initial set of codes was confirmed, the researchers independently coded all of the interviews using the initial set. This set was modified or added to if necessary. Once all the interviews had been coded and the researchers reached consensus regarding the coding of the transcribed interviews, the Third Step involved clustering of the codes into overarching themes. Themes were identified based on recurring codes. In Step Four, the researchers discussed the themes and modified them when required to reach consensus on their content and labelling. Step Five encompassed the interpretation and naming of the emerging themes. The results of the six-step analysis method were reported in Step Six [45].

Procedure

Participants who contributed to the quantitative evaluation of the QoL-ME [35] were invited to participate in the interview. Participants who met the inclusion criteria were contacted via e-mail, via care professionals at the consortium institutions, or via telephone if possible. Participants, who expressed interest in contributing, were provided with additional information on the qualitative study. Once a participant agreed to contribute, the researcher

(DB) and participant scheduled an appointment for an interview. Interviews were held at the institution that supported the participant, or at a neutral location such as a café. Prior to the interview, the researcher provided a detailed explanation of the study and of what was expected of the participant. Moreover, the researcher explained that there were no right or wrong answers and that it was important that participants freely shared their opinions. Next, the researcher and participant went through the QoL-ME together to ensure that all participants had a refreshed understanding of the QoL-ME. The interview guide as displayed in Table 1 steered the interview, while the interviewer elaborated on topics when necessary. Upon completing the interview, the interviewer explained how the gathered data would be analyzed and how this aided the study. Participants were given room to ask any further questions. The interview ended when all questions were addressed whereupon the participant received a gift voucher. The duration of the interviews varied between 17 and 42 minutes and the average duration was 31 minutes.

Results

Participants

A group of 19 patients contributed to at least five assessments in the psychometric evaluation of the QoL-ME. Of these 19 patients, ten patients initially agreed to contribute to an interview. The nine patients who declined reported a lack of time and/or interest as their reason for declining to participate in the interviews. Of the ten patients who initially agreed, one patient could not be reached anymore and another was too busy to schedule an appointment. Therefore, eight individuals with severe mental health problems participated in this study. The aim of continuing inclusion until saturation was not entirely met, because the number of experienced users that agreed to participate in the interviews was relatively low. Participants' demographic characteristics are provided in Table 2. Five participants were male, the mean age of participants was 34 (SD = 12) and five of the eight participants had a Dutch cultural background. All participants had gained experience using the QoL-ME by contributing to the psychometric evaluation of the QoL-ME [35]. On average, participants had filled out the QoL-ME 6 times (range: 5-7) over a period of between four and six months. Six of eight participants reported using the QoL-ME on their personal smartphone device and the remaining two participants used their personal computer. Participants primarily used the QoL-ME at home, whilst some reported using the QoL-ME at their care institution.

Table 2. Demographic characteristics of the eight participants.

Participant	Age	Gender	Cultural background	Level of education	Occupational status
1	18	Male	Dutch	Basic	Paid employment
2	41	Male	Turkish	Basic	Volunteer work
3	39	Female	Dutch Antilles	Basic	Education
4	33	Male	Dutch	Basic	Unemployed
5	43	Female	Dutch	Basic	Volunteer work
6	27	Female	Dutch	Intermediate	Unemployed
7	52	Male	Dutch	Intermediate	Volunteer work
8	19	Male	Indonesian	Basic	Unemployed

Main findings

The following three themes were identified based on analysis of the interviews: 1) Obtained benefit, 2) Actionability and 3) Characteristics of the QoL-ME. An overview of the codes and themes is provided in Multimedia Appendix 1. This appendix includes both an overview in table-form and a graphic depiction of the network of codes and themes. As the first two themes pertain to the two concepts (beneficial and actionable) that were of special interest in this study, these themes will be discussed in more detail.

Obtained benefit

According to six of the eight interviewees, using the QoL-ME was beneficial to them. All six of these participants mentioned that using the QoL-ME made them more aware of their level of satisfaction on the life domains incorporated in the QoL-ME.

> *[Well, because of the questions that are asked, you start to think about what you do and don't have. In principle, I am actually satisfied with everything. But you are going to look at how you are doing. In your relationships, your family and your finances.] - Participant 6*

For some participants, being confronted with their dissatisfaction on some domains drove them to look for ways to improve their situation.

> *[The questions about income and whether you were satisfied with how much money you can spend made me think. When I have a job later on, I have more room for big expenses. So I started thinking about that. Yeah, that's it, yes.] – Participant 7*

For other participants, the QoL-ME facilitated the realization that they were happier than they thought they were.

> *[Ehmm. I started to think more consciously about how happy I actually was. And I turned out to be happier than I actually thought.] – Participant 8*

The two participants for whom the QoL-ME was not beneficial mentioned having sufficient insight already into how satisfied they were with their lives as the main reason for this lack of benefit:

> *[No, no the questions that were asked, I already had some kind of insight in them. In those areas. So no I didn't really get anything out of it.] – Participant 5*

Both participants did feel that the QoL-ME would be more beneficial to them if they lacked this insight:

> *[I: And if you hadn't known how you were doing in life? P: Yes, if you don't have that then you can discuss it with someone: oh, this is not going well so maybe I should do something with that. So then it would help.] - Participant 1*

Actionability

For three participants, the QoL-ME proved to provide a useful base for taking actions in their daily lives. One participant mentioned that using the QoL-ME assisted her in the maintaining of social relationships.

> *[Well, for example I had not seen someone for a long time and I thought: let me call them. I tried to make contact. And you are also busy with your own life, I know, but I did think about that.] – Participant 3*

Another participant spoke of being more careful in public transport as a consequence of filling out the 'Safety' domain:

> *[I: And based on that, have you done something, changed something to what you normally do? For example in the area of personal safety? P: Yes, subconsciously I did, because if I don't feel safe and I don't have to leave, then I stay inside. And for example if I travel by public transport and I see something strange then I get off. You start thinking more about these things.] - Participant 2*

None of the participants reported discussing their QoL-ME results with others, but two participants acknowledged the possibility:

> *[Then you have it right in front of you: things are not going so well. And then you can discuss that with someone. Okay, how are we going to improve this?] - Participant 1*

Five participants reported not having taken any concrete action, based on their experiences with the QoL-ME. Two participants indicated that incorporating the option to compare current results with previous results would improve the actionability of the QoL-ME.

> *[P: what seems interesting to me is to see if your answers change over the different measurement moments. I: Why is that interesting to you? P: To see if it changes or if I am consistent. Because every day is different. I: Yes, and if you could see that change, how would that affect how the App benefits you? P: When I see that I am very satisfied with a certain topic one day and not at all the next, then I start to think 'hmm, what is the reason for that?' Where does that difference come from? And then it is also easier to do something with it.] - Participant 4*

Regarding the potential negative effects of confronting users of the QoL-ME with a decrease in their QoL scores in the absence of care professionals, none of the participants expected this to be a problem.

> *[Yes for some people you wouldn't want to see that of course. But I feel like ... it's how you feel at the time. The situation may still be the same, but the way you deal with it may be different. You can feel different every day.] – Participant 3*

Some participants provided tips for improving the clarity of the results section, which would also improve the actionability of the QoL-ME but is discussed under the third theme. One participant recommended including advice for how to improve low scores in the QoL-ME to improve its actionability. He used a food diary App as an example. Users register what they eat on a daily basis and the App generates an advice based on user input.

> *[P: Yes, okay, so it really is for you… yes maybe you can generate an advice at the end of such a test. We see from your answers that you score negative on these topics and maybe you can think about that. Something like that. I: Is that also a way to get more benefit from it? P: Sure, I think so. That is ultimately what you want, a system that thinks along with you. I have an example, a silly example maybe, but I have an App from the nutrition center. This keeps track of exactly what you eat, and there is also advice. We see that you eat too much salt and too many unhealthy products. And then you are really triggered like I have to fall within the margins of that App. Or something like a pedometer, things like that.] - Participant 4*

Characteristics of the QoL-ME

Overall, participants welcomed the opportunity to view their results upon completing the QoL-ME. Three participants provided specific advice for improving the clarity of the results section and thereby increasing the actionability of the QoL-ME:

> *[I: And the results you get to see at the end, did you think they are clearly displayed? P: Ehm, I think in the second part, that you could add something like a number or something, I think. I: Add a number or replace something with a number? P: Add a number. So that you can see more clearly what it is .. or a percentage or something I am not sure. At least something that reflects it more clearly.] - Participant 1*

Seven participants appreciated the possibility to personalize the content of the QoL-ME. The one participant who disagreed, indicated that he found all domains important and therefore preferred a version in which no choices had to be made. Participants were divided regarding the option to personalize the appearance of the QoL-ME. Four participants welcomed this functionality, but the other participants thought it added too little value.

Several participants commented on the content of the QoL-ME. One participant thought that the items on the financial situation of respondents were too direct and advised an alternative formulation. Four participants commented on the images used in the additional modules of the QoL-ME. One participant recommended using pictures that are more diverse. Three participants reported that some of the images used were unclear to them. They advised including a written description of the content of the item using a word or a short sentence for clarification.

None of the participants had trouble with the duration of filling out and the number of questions. Three participants did miss a clear ending message and they advised including this. One participant had issues with the low contrast between foreground and background elements due to her visual handicap. Seven participants thought the QoL-ME looked professional, primarily due to the uncluttered and simple layout.

No participant reported having insight in which persons and parties had access to their data. Still, six participants trusted the security of their data. The inclusion of a disclaimer containing information regarding data access and use was a welcome addition for seven participants.

In general, all participants were very positive regarding the design and usability of the QoL-ME. Participants appreciated the clear structure of the App and favored the navigational system.

Discussion

This study explored the experiences of users regarding the usability and functionality of the QoL-ME and whether the App is actionable and beneficial for patients. As it is important that an e-mental health tool such as the QoL-ME is both beneficial and actionable to its users, special attention was paid to these concepts. The interviews revealed that using the QoL-ME is beneficial to most users, primarily by pushing them to consider their satisfaction with various life domains. The QoL-ME did not prove to be actionable for most respondents. In addition, respondents were positive about the design and usability of the QoL-ME, but also had some tangible tips and advice for improvement.

The main way in which the QoL-ME was beneficial to users was through providing insight and facilitating reflection. Some respondents indicated that their use of the QoL-ME made them realize that they were more satisfied with their lives than expected. This result echoes findings by Morton and colleagues [31] in their evaluation of a QoL self-monitoring tool for people with bipolar disorder. Respondents also indicated that they were sometimes surprised by how high their scores were, which lead to the insight that 'things were not so bad'. Two participants indicated that they already had sufficient insight into their own QoL and therefore derived no extra benefit from using the QoL-ME. This finding echoes results found by Berry and colleagues [46], who investigated views on using digital self-management tools among people with severe mental health problems. A number of participants who contributed to this qualitative interview study indicated that they were sufficiently self-aware already and expected little benefit from using digital self-management tools [46].

Participants provided three useful suggestions for making the QoL-ME more actionable. First, half of the participants proposed to include numerical indicators for users' satisfaction scores for every item or domain. The results section of the current version of the QoL-ME does not include numbers but only shows a bar that is partly filled based on underlying scores. The Personal Health Information Self-Quantification System model [47] outlines how self-quantification is of vital importance for the self-management of health. In the model, self-quantification is described as the step in which an individuals' goal (having a good QoL) is transformed into objectively measured units [47]. Results by Morton and colleagues [31] confirm the importance of quantification, as respondents indicated that it was the quantification of their QoL that enabled self-management. A second important suggestion to make the QoL-ME more actionable, raised by two participants, was to incorporate practical advice for improving users' satisfaction on certain life domains. The tool evaluated by Morton and colleagues [31] was integrated in a larger digital self-management platform that included practical advice and strategies for self-management. The results section of the tool provided direct links to these strategies, a feature that participants were very enthusiastic about [31]. Expanding the QoL-ME to include similar functionality will likely make the App more actionable for users. The third suggestion pertains to enable users to consult the development of their QoL scores over time. Every participant saw this as a welcome addition. This finding is in accordance with findings by Morton and colleagues [31] and by Berry and colleagues [46]. These three suggestions may be used to strongly improve how beneficial and actionable an assessment tool such as the QoL-ME is to patients.

Several participants acknowledged the possibility of discussing the results of the QoL-ME with other individuals such as a family member or professional caregiver. The fact that none of them did so may be an indication of social isolation, which has frequently been reported in this population [1-3]. Moving towards self-management, future versions of the QoL-ME may actively encourage users to share their results and include practical suggestions for decreasing social isolation.

Participants were unanimously positive regarding the QoL-ME's usability. They found the application easy to use, appreciated its linear structure and prized the calm and clean layout. These results confirm what was found during the usability evaluation that made up the last part of the development of the QoL-ME [20] and serve as additional corroboration of the design recommendations [43, 48] consulted during the Apps' development. Several respondents preferred combining the visual material used in the additional modules with a word or short sentence to denote the content of its item. Comparable pictorial assessment instruments, such as the pictorial version of the Aachen Quality of Life Interview [49] and the pictorial motivation scale in physical activity [50] also combine both visual and verbal content. Respondents had very limited insight into which persons and parties had access to their data. This did not deter them from engaging with the QoL-ME. This may be because respondents used the QoL-ME in the context of a scientific study, or because participating did not require respondents to share any personal information.

The results draw attention to several ways in which the QoL-ME may be modified so that it is more beneficial for patients. Future research may further investigate what images used in the QoL-ME are unclear and identify alternative images. Moreover, the results section may be updated to display the development of results over time. In addition, following the example by Morton and colleagues [31], the QoL-ME may be integrated into a larger self-management platform for people with severe mental health problems.

Strengths and limitations

This study provides an important contribution to the field of e-mental health App development. The qualitative methodology provided patients with the opportunity to share their opinions regarding the usability and functionality of the QoL-ME and to what degree the App is beneficial and actionable to them. The results draw attention to the fact that patients require functionalities that target their needs. Specifically, patients require functionality targeting self-management. In addition, the content of the interview was partially derived from existing frameworks that have proven to be effective for evaluating health Apps [51].

Still, the results do need to be interpreted in light of three limitations involving the sample of participants who contributed to this study. The first limitation pertains to the size of the convenience sample used in this study. The eligible research population, based on the criterion of having completed at least five measurements, was small. Still, the results provide important insights into user experiences and in the extent to which the QoL-ME is beneficial and actionable for users. Once a larger group of patients starts using the QoL-ME, additional research will have to reveal whether the current results hold up in this larger population. Analyses revealed that saturation, defined as a lack of new information in the final interviews, was not fully attained in the sample. The final two interviews did contain new information, but these were not substantial insights and no changes to the codes or themes were made based on these interviews.

The context in which participants gained experience with the QoL-ME forms a second limitation. Participants were aware that they used the QoL-ME in the context of a scientific study in which the psychometric quality of the QoL-ME was evaluated. Moreover, participants were incentivized to use the QoL-ME and to participate in the interviews. Therefore, their use of the QoL-ME may not represent use in a real-life setting and their responses in the interviews may have been biased. To counter possible bias due to the incentives, the researcher indicated that respondents were allowed to freely give their opinions before the interviews started. Future research may investigate to what degree the current results hold up when patients' who used the QoL-ME on their own accord are interviewed.

The third limitation pertains to the absence of data on participants' medical background, such as psychiatric diagnoses or symptom severity. Still, all participants received care from the consortium institutions and we can therefore be certain that they are part of the QoL-MEs' target population. Future research may investigate whether individuals with specific symptoms or diagnoses have differing experiences using the QoL-ME.

Conclusions

The QoL-ME can be beneficial to users as it provides them with helpful insight into their QoL. Including added functionality in support of self-management, such as advice and potential strategies for improving QoL domains App users are dissatisfied with will likely make the QoL-ME app more actionable. Overall, the interviewed patients positively regarded the usability, functionality and contents of the QoL-ME.

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Chapter 7

Summary and general discussion

Introduction

The importance of adequate outcome measures capable of capturing the effects of psychiatric treatment and mental healthcare is indisputable [1-4]. One of these outcomes that is considered of special importance in mental health services is Quality of Life (QoL) [5-9]. The assessment of QoL, however, still offers room for optimization in three specific areas. First, the inherent subjective nature of QoL - re-emphasized by research [10-12] - conflicts with a measurement approach in which respondents are required to answer questions on a fixed set of life domains such as *Family relations, Finances, Physical health*, and *Safety [9; 13; 14]*. This calls for personalization of QoL assessment instruments. Second, an assessment approach that circumvents language may be more accessible to groups of patients, such as people with severe mental health problems, who may not have the necessary skills to engage in language-based QoL assessment [15-17] or have a comorbid intellectual disability [18; 19]. Third, a QoL assessment instrument is needed that serves the needs of patients, professional caregivers, researchers and policy makers [20]. Digital applications (apps) offer novel possibilities such as flexibility [21-23] and multimedia integration [24; 25] and a QoL assessment app may therefore have the required characteristics to facilitate improvement in these three areas.

The current study revolved around the development and evaluation of a digital, personalized and accessible QoL instrument for people with severe mental health problems: the QoL-ME. The QoL-ME has three main goals: 1) increasing the personalization of QoL assessment, 2) providing an alternative to language-based QoL assessment, and 3) providing patients, professional caregivers, researchers and policy makers with a practically valuable instrument. The QoL-ME targets three populations of people with severe mental health problems: 1) people with severe psychiatric problems, 2) people treated in forensic psychiatry and 3) people who are homeless.

This final chapter provides a summary of the main results of this thesis. These results will subsequently be synthesized and discussed. In addition, the strengths and limitations of this thesis will be considered, as well as implications for clinical practice and policy. In addition, potential avenues for future research will be discussed and finally, a main conclusion will be drawn.

Summary of the main results

The QoL-ME was developed and evaluated in five subsequent studies. The QoL-ME consists of two main components: a core version and additional modules. The core version contains mandatory QoL domains on which all respondents answer questions. Respondents are then free to select any combination of additional modules based on their personal preferences. The identification of the content of the core version of the QoL-ME is described in **Chapter 2**. A large dataset of 1277 patients who had been interviewed with the Dutch version of the Lancashire Quality of Life Profile (LQoLP) was analyzed using Latent Class Analysis (LCA). Three subgroups of respondents with distinguishable profiles of scores on the ten domains of the LQoLP were identified. On the basis of sociodemographic variables, health-related variables and measures of well-being, the three classes were labelled ‘Socially isolated individuals with unmet care needs’ (Class 1), ‘Individuals with an overall good QoL having a meaning in life’ (Class 2), and ‘individuals with a good overall QoL but lacking a meaning in life and struggling with affect’ (Class 3). To assess how well the three profiles could be distinguished on the different LQoLP-domains, univariate entropy was computed for all domains. Three domains had relatively low univariate entropies, indicating that the included population cannot easily be separated in classes on these domains: (1) Living situation, (2) Safety, and (3) Finances. Therefore, these three domains were incorporated in the core version of the QoL-ME.

Chapter 3 covered a visual concept mapping exercise to identify the content of the QoL-MEs’ additional modules. A group of fifty patients, care professionals and family members provided 160 pictures of what they thought were important aspects of QoL for people with severe mental health problems. A new group of 17 participants, care professionals and family members then sorted the pictures individually - based on the life domain that was depicted according to them. The sorting solutions were quantified by converting them into Binary Symmetric Similarity Matrices (BSSMs). The number of rows and columns of these matrices correspond to the total number of pictures and every cell indicates whether a pair of pictures is placed into the same group (1) or not (0). The 17 BSSMs were aggregated into a total BSSM, which was decomposed using Principal Component Analysis (PCA). The 160 pictures were plotted in a two-dimensional space using the first two dimensions of the PCA as x- and y-coordinates. The pictures were subsequently clustered using hierarchical cluster analysis. After comparing concept maps with differing cluster solutions, a concept map with eight clusters was determined to best fit the data. The eight clusters were interpreted and labelled (1) Support and attention, (2) Social relations, (3) Happiness and love, (4) Relaxation and harmony, (5) Leisure, (6) Lifestyle, (7) Finances, and (8) Health and living. The content of the additional modules of the QoL-ME corresponds to the eight visual clusters of the concept map.

The results of the studies described in the second and third chapters formed the basis of the development of the QoL-ME which is described in **Chapter 4**. A total of 59 patients contributed to the development that covered six iterations. In the brainstorm stage, that made up the first iteration, ten participants reflected on their experiences using smartphone apps and provided ideas for the QoL-ME. Several initial designs and interaction mechanisms were created based on the ideas gathered in the brainstorm stage, combined with knowledge and guidelines derived from the scientific literature on the design and user interaction for people with mental health problems. These designs were tested and refined in the second to fourth iterations that formed the design stage. A group of 25 patients contributed to the design stage. A first prototype of the QoL-ME was developed between the fourth and fifth iteration. Twenty-four participants contributed by testing the prototype and giving their feedback in the usability stage that involved the final two iterations. In addition, all participants filled out the System Usability Scale (SUS). SUS scores revealed good to excellent usability. Participants valued the QoL-ME's linear structure, calm and consistent layout and intuitive touch-screen-based interaction. The development of the QoL-ME resulted in the QoL-ME itself.

Chapter 5 and Chapter 6 involved the evaluation of the QoL-ME. **Chapter 5** details a quantitative assessment of the psychometric quality of the QoL-ME. Specifically, the reliability, validity, and responsiveness of the QoL-ME were evaluated in a longitudinal design. Internal consistency was used to assess the reliability of the additional modules of the QoL-ME and revealed poor ($.5 < \alpha \leq .6$) internal consistency for the Leisure module, questionable ($.6 < \alpha \leq .7$) internal consistencies for the modules Support and Attention, Lifestyle, Finances, and Health and living, and acceptable to good ($.7 < \alpha \leq .9$) internal consistency for the modules Social relations, Happiness and Love and Relaxation and harmony. The construct validity of the QoL-ME was assessed by computing the correlation between scores on the QoL-ME and the MANSA. The correlations between the domains of the core version of the QoL-ME and their corresponding MANSA domains were strong and ranged between $r = .55$ and $r = .76$. A medium-sized correlation was found between the language-based MANSA and the pictorial additional modules of the QoL-ME ($r = .3$). Correlations between single items of the additional modules of the QoL-ME and corresponding MANSA items were of a similar magnitude, ranging between .15 and .39. The responsiveness of the QoL-ME was assessed by correlating difference scores on the QoL-ME and MANSA. This correlation was small and insignificant. Based on these results, the reliability and validity of the QoL-ME are adequate. The responsiveness of the QoL-ME, however, proved to be insufficient and further research is required to evaluate and potentially modify the instrument to improve its responsiveness.

The degree in which the QoL-ME matched the values and preferences of patients was explored qualitatively in **Chapter 6**. In this study, the extent to which the QoL-ME was beneficial and actionable for users was of special interest. Eight participants contributed to semi-structured interviews. An interview guide was constructed to guide the interviews. The content of this guide was derived from the scientific literature and from our experiences during the development of the QoL-ME. A deductive analysis approach and thematic analysis were used to identify themes in the qualitative data. Analysis of the transcribed interviews revealed three themes: 1) Obtained benefit, 2) Actionability and 3) Characteristics of the QoL-ME. The interviews revealed that using the QoL-ME is beneficial to most users, primarily by stimulating them to consider and contemplate their situation on various life domains. The direct actionability of the QoL-ME was not very high for most respondents, as only a few respondents had taken practical action based on their use of the QoL-ME. Respondents did have some tangible tips and advice for improving the actionability of the QoL-ME, for example by providing suggestions for self-management or enabling respondents to view the development of their scores over time. Regarding the characteristics of the QoL-ME, in general, all participants were very positive regarding the design and usability of the QoL-ME. Participants appreciated the clear structure of the app and favored the navigational system.

Discussion of the main results

The mail goal of this thesis was to develop the QoL-ME: a digital QoL assessment app for people with severe mental health problems. In this section, the results are synthesized and discussed in light of the three main goals of the QoL-ME: 1) increasing the personalization of QoL assessment, 2) providing an alternative to language-based QoL assessment, and 3) providing patients, professional caregivers, researchers and policy makers with a practically valuable instrument. In addition, two important aspects of the development of e-mental health apps will be discussed: 1) co-creation and 2) usability. Finally, some conceptual implications regarding QoL are considered.

Personalization

The first main goal of the QoL-ME was to improve the personalization of QoL assessment for people with severe mental health problems through the flexibility offered by e-mental health apps. In the QoL-ME, personalization is achieved through the additional modules. Respondents are free to select any combination of eight modules that corresponds to their personal priorities and values. Throughout the development of the QoL-ME that is described in Chapter 4, participants were very positive regarding the personalization of QoL assessment in the QoL-ME. The results of the qualitative evaluation (Chapter 6) confirm this notion, as six of eight participants welcomed the ability to select personally relevant QoL domains. In the scheme developed by Dijkers [26], the approach to personalization employed in the QoL-ME may be referred to as ‘investigator nominates, subject selects’, as respondents are required to select a number of additional modules that were previously nominated by stakeholders during the development of the QoL-ME. Other instruments, such as the Patient Generated Index [27; 28], the Schedule for the Evaluation of Individual Quality of Life [29; 30] and the Schedule for the Evaluation of Individual Quality of Life- Direct Weighting [31; 32] pursue personalization of QoL assessment by enabling respondents to nominate their own QoL domains. Personalization by asking respondents to nominate their own domains, however, is cognitively demanding [26] and was therefore not adopted in the QoL-ME. In addition, QoL assessment based solely on patient-nominated domains interferes with another important goal of QoL assessment: comparing group-level data to inform scientific research or policy decisions [26].

Not all participants made use of the opportunity to personalize their QoL assessment. Two of eight interviewees questioned the benefit of the selection procedure as they found all the domains of the additional modules to be important (Chapter 6). In addition, the quantitative evaluation of the QoL-ME (Chapter 5) revealed that the majority of respondents (sixty-seven percent) chose seven or eight additional modules. In terms of Cummins’ proposed theory of QoL [33], the domains of the additional modules may be too close to ‘life as a whole’ and therefore relevant for the majority of respondents. The inclusion of domains or aspects that only apply to a subgroup of respondents may enable a more differentiated assessment. There is likely to be a limit, however, to the amount of domains that can be included in the QoL-ME until its usability starts to suffer. Future research may examine how many domains respondents are willing to select from until the procedure becomes too cumbersome to complete. In addition, the domains of the additional modules may be moved to the core version if the percentage of respondents that selects them exceeds a certain limit, such as 90 percent.

Pictorial assessment

The second main goal of the QoL-ME was to provide an accessible and intuitive alternative to conventional, language-based QoL assessment instruments. This is achieved by employing a pictorial assessment approach, especially in the additional modules. The items of the additional modules denote their content using a set of three pictures derived from the visual concept map. No verbal information is provided and respondents indicate their level of satisfaction by dragging or swiping a button on a horizontal scale. During the development of the QoL-ME, covered in Chapter 4, respondents did not report substantial difficulties with the pictorial assessment approach, a finding that is confirmed by the usability scores. In the qualitative evaluation (Chapter 6), however, three participants reported problems with interpreting the visual content of the QoL-ME. Two participants indicated that items belonging to the modules ‘Leisure’ and ‘Lifestyle’ were not clear to them. These were the domains with the lowest internal consistency (Chapter 5), which confirms their questionable functioning. Two characteristics of the QoL-ME may be responsible for the vagueness of some of the visual content off the QoL-ME. First, the additional modules of the QoL-ME involve no guiding text whatsoever. Other pictorial assessment instruments, which have primarily been developed for use among young children [34-36], people with Intellectual Disabilities (ID; [37; 38]), and people with aphasia [39; 40], do combine pictures and text. Three participants in the qualitative evaluation recommended using both verbal and visual information to increase the clarity of the items. Future research should investigate whether the clarity of the QoL-ME improves when verbal cues are used to accompany the visual content of the items of the additional modules of the QoL-ME. A second characteristic of the QoL-ME that may cause unclarity is found in the origin of the visual material used in pictorial scales. In the QoL-ME, this visual material was selected directly by a group of patients, family members and professional caregivers as detailed in Chapter 3. In all of the other scales, content was initially verbal and visual material was specifically developed to visualize this verbal content within the context of a pictorial assessment instrument [36; 37; 39]. In a sense, the procedure adopted in the QoL-ME represents a 'purer' approach as patients directly selected the content of the QoL-ME. At the same time, respondents who supplied visual material were unaware that the material was to be used in a visual QoL assessment instrument. This may have negative consequences for the psychometric properties of the QoL-ME. Future research will have to clarify whether the psychometric quality of the QoL-ME improves if unclear visual material is replaced with material specifically developed for use in pictorial QoL assessment.

The content of the visual concept map, that was constructed in Chapter 3 and formed the basis of the additional modules of the QoL-ME, is comparable to the results of verbal explorations of QoL among people with severe mental health problems. At the same time, the results relating to the responsiveness of the QoL-ME described in Chapter 5 suggest that the QoL-ME taps into different mechanisms than conventional, language-based methods. In the literature on subjective well-being, a distinction is made between cognitive and affective mechanisms that both determine an individuals' subjective well-being [41-43]. The notion that the pictorial QoL-ME taps more strongly into affective than cognitive mechanisms may be tested by associating scores on the QoL-ME with both ratings of affect and scores on a cognitive evaluation of QoL.

Practical value for stakeholders

The third main goal of the QoL-ME was to provide patients, clinicians, researchers and policy makers with an instrument that is of practical value for them.

The degree in which the QoL-ME is beneficial and actionable to patients was investigated in the qualitative evaluation of the QoL-ME (Chapter 6). The interviews revealed that the QoL-ME likely requires additional functionality aimed at self-management before it is truly of benefit to patients. Examples of this functionality include the quantification of results, the opportunity to compare results over time and practical advice to improve domains that respondents are unsatisfied about. Expanding the QoL-ME with functionalities aimed to support self-management may result in an instrument that optimally benefits all stakeholders involved. The QoL self-management tool developed by Morton and colleagues [44] provides an excellent example. The tool is embedded within a larger online environment that includes tips and strategies for self-management. Upon completing the self-management tool, users reach a summary of their results that includes links to this environment.

The additional modules of the QoL-ME provide clinicians with an overview of QoL scores that were personally selected by patients. In theory, this makes the QoL-ME a very useful tool for the planning and monitoring of treatment. The responsiveness of the QoL-ME (Chapter 5), however, proved to be inadequate when the MANSA is used as a gold standard. Additional research is required to further examine the responsiveness of the QoL-ME and to assess whether the QoL-ME is of use in clinical practice.

The core version of the QoL-ME is especially useful for policy makers and scientific researchers as it contains mandatory QoL domains that are of most interest when comparing group-level data. Moreover, the quantitative evaluation of the QoL-ME in Chapter 5 revealed that its reliability and validity are sufficient. No firm conclusion regarding the utility of the QoL-ME for policy can be drawn, however, without additional research into this matter. Qualitative methods, such as focus groups or interviews with policy makers, may be used to investigate to what degree the QoL-ME caters to the needs of policy makers.

In general, digitalized scientific assessment instruments such as the QoL-ME enable the combination of personalized and accessible assessment with functionalities directed at self-management. Such an instrument will benefit patients as it provides them with insight into their QoL and strategies for self-management. Clinicians may benefit by receiving a personalized picture of the QoL of patients. Scientific researchers and policy makers may benefit from higher data quality and completion rates as patients are likely to be more intrinsically motivated to engage in QoL assessment.

Co-creative development

The development of the QoL-ME was strongly guided by a co-creative philosophy. Patients supplied the content of the additional modules of the QoL-ME and were heavily involved in the iterative development process. In addition, patients provided ideas regarding the appearance and functionality of the QoL-ME, tested initial designs and participated in a usability evaluation. Based on the literature, it was expected that this heavy user involvement in the development of the QoL-ME enhanced the app's utility [45]. In this section, the degree in which the co-creative development philosophy contributed to a QoL-ME that 1) has strong usability [46-48] and 2) is both beneficial and actionable for patients [45] is discussed.

First, the usability evaluation that comprised the final iterations of the development of the QoL-ME, revealed good to excellent usability (Chapter 4). Overall, this result was confirmed in the qualitative evaluation of the QoL-ME as detailed in Chapter 6. A number of respondents, however, found some of the visual material used in the additional modules hard to interpret or unclear. This notion is reflected by the questionable to poor reliability of some of the additional modules found in Chapter 5. It is surprising that none of the participants to the development of the QoL-ME reported these problems. This may be explained by the different contexts in which the participants to the development on the one hand and evaluation on the other hand used the QoL-ME. During the development, participants who tested the app were explicitly informed that their answers to the items of the QoL-ME were not recorded. This may have made it less important for them to have a clear grasp of the meaning of the visual material. In the quantitative evaluation, participants used the app in a real-life context and knew that their answers were recorded which is likely to have made it more important for them to fully understand what was denoted by the images.

Second, the qualitative evaluation revealed that the QoL-ME was beneficial to most patients but not yet actionable. These issues were not encountered during the development of the QoL-ME. Again, the difference in contexts between development and evaluation is a likely explanation for this discrepancy.

These results emphasize the importance of both real-life testing and qualitative data collection during the development of an e-mental health app, which is in accordance with recent literature [47; 49; 50].

Usability

Based on insights from the scientific literature and the feedback received during the development, most of the design and usability of the QoL-ME is aimed at reducing users' cognitive effort [51; 52]. The development of the QoL-ME (Chapter 4) was informed by design recommendations by Bernard and colleagues [53] and by Rotondi and colleagues [51; 52]. The results obtained in the remainder of the development of the QoL-ME and during its qualitative evaluation confirmed the legitimacy of these recommendations. Low cognitive effort is achieved in the QoL-ME in three ways. First, the QoL-ME's structure is linear and sequential. It is divided into three parts (core version, selecting add-on modules and answering add-on modules) and has a clear beginning and ending. Users can only move one screen forward or backward using the navigational buttons. Second, the layout of the QoL-ME is consistent regarding the placement of repeating elements such as navigation buttons, response options and item content. In addition, the QoL-ME is consistent in its use of colors and backgrounds. Third, the layout of the QoL-ME is as clean and simple as possible. It contains no superficial elements that are unrelated to the primary goal of the app. The low cognitive effort design philosophy resulted in strong usability scores in the final stage of the QoL-ME's development and very positive feedback during the qualitative assessment. These results validate findings previously reported in the scientific literature [51-53] and enhance the credibility of these recommendations and guidelines.

In addition to strong usability, the low cognitive effort philosophy also benefitted the perceived credibility of the QoL-ME. Participants reported that the clean and calm layout made the app appear credible and professional (Chapter 6). A credible and professional appearance has been found to benefit the acceptability of e-mental health apps [46; 54; 55]. Based on our results, we advise researchers or designers engaging in the design and development of a (web)-application for people with severe mental health problems to employ the guidelines by Bernard and colleagues [53] and by Rotondi and colleagues [51; 52] wherever possible.

Conceptual implications

Over the past three decades, the lack of theory/model development regarding the concept of QoL has frequently been described as an important gap in the field of QoL research [8; 33; 56]. The development of a conceptual model or theory of QoL was not an explicit goal of this study. Still, the results of this thesis might contribute to what is known regarding the concept of QoL. Specifically, the results confirm two fundamental and widely accepted notions on QoL: 1) the concept's multidimensionality and 2) the subjective nature of the concept, meaning that its constituents vary based on individual values and preferences.

Multidimensionality

The results of the concept mapping study covered in Chapter 3 strongly speak for the multidimensional nature of QoL. Individual participants supplied a wide range of visual material depicting important aspects of QoL. Processing of this visual material according to the concept mapping methodology resulted in a concept map that included multiple distinct clusters of images with homogeneous content. The clusters correspond to distinct dimensions of QoL. These results regarding the multidimensionality of QoL are in accordance with findings by Connell and colleagues [13; 57] and Van Nieuwenhuizen [9; 58].

Subjective nature of the concept

Additional evidence for the subjective nature of QoL is provided by the concept mapping study, as well as the quantitative evaluation of the QoL-ME (Chapter 5). When asked to supply visual material depicting important aspects of QoL, participants provided a diverse variety of images. In addition, the quantitative evaluation of the QoL-ME revealed that different respondents selected distinct combinations of additional modules. Both results attest to the subjective nature of QoL. Based on the results of this thesis, QoL may be defined as the product of an individuals' satisfaction with the domains of life that are important to them. This definition corresponds to the 'Satisfaction with specific domains' approach as described by Moons and colleagues [6]. This approach is also employed in other QoL instruments for people with severe mental health problems, such as the LQoLP [9; 59] and the MANSA [14; 60].

Strengths and limitations of this study

The co-creative philosophy that underpinned every step of the development of the QoL-ME is an important strength of this thesis. Patients, care professionals and family members played a vital role in determining the content of the QoL-ME, the development of the design and functionalities of the QoL-ME and in its evaluation. The involvement of patients in the development of outcome measures is crucial [61-63] and research has revealed that outcome measures that were not developed together with patients may lack important topics or contain content that is not relevant for patients [62; 64]. In addition, user involvement in the development of e-mental health apps and other digital tools for use in mental health services has been found to be indispensable [45; 65; 66]. The innovative characteristics of the QoL-ME may be seen as another strength: both the QoL-ME's unique structure, consisting of a core version and additional modules, and the pictorial approach to QoL assessment are novel. As such, the results of this thesis pave the way for various avenues of future research, which are discussed later in this chapter.

In addition to these strengths, some limitations ought to be considered when interpreting the results of this thesis. First, all participants who contributed to the development of the QoL-ME were recruited via convenience sampling. Consequently, the sample may be biased towards people with severe mental health problems who are research- or tech-enthusiasts. This may have amplified the results pertaining to usability and the QoL-ME may be less favorably received by others who have less or no experience with technologies such as smartphones, tablets and apps.

Second, patients, care professionals and family members contributed to the visual concept mapping study in which the content of the additional modules was determined. In the co-creative development of the QoL-ME itself, however, only patients contributed substantially and the contribution of other stakeholders was considerably smaller. Research has identified professional caregivers as an especially important party to involve in the development of e-mental health apps [47; 67] and important insights may have therefore been missed in the development of the QoL-ME. This development was, however, also guided by an ethical and philosophical analysis that included the perspective of care professionals [68]. In this way, values important for care professionals were in fact considered during the development.

A third limitation pertains to a possible downside of the co-creative development process. This type of development is difficult to capture in a fixed protocol, as patients make important decisions. Replication of the current study is therefore hindered. This potential disadvantage, however, is outweighed by the advantages of co-creation.

Implications for clinical practice and policy

The results of this thesis carry important implications for clinical practice. Three implications are discussed in this section. The first implication pertains to the use of QoL assessment instruments in clinical practice. Participants who contributed to the qualitative evaluation (Chapter 6) of the QoL-ME positively welcomed the opportunity to select personally relevant QoL domains. In addition, the quantitative evaluation (Chapter 5) revealed that 60 percent of all participants opted to not select one or more domains. These results indicate that QoL assessment using an instrument with fixed content is likely to contain domains that are irrelevant for a substantial part of respondents. Assessment instruments that employ some form of personalization are to be preferred and if not, clinicians should be aware that the instrument used might not optimally reflect what is important for the QoL of individual patients. The second implication is related to the importance of using outcome measures that have been developed together with the target population. The content of the QoL-ME was developed together with patients, care professionals and family members. In the evaluation of the QoL-ME, respondents indicated that the QoL-ME covered all aspects of QoL that are important to them. This finding confirms earlier research which concluded that instruments that were developed in collaboration with the target population are more likely to contain important and relevant topics [61; 63]. Third, the results of this thesis imply that e-mental health apps can be very intuitive and easy to use, especially when developed in co-creation with end-users. This holds true for patients who are relatively inexperienced in using digital tools. Moreover, e-mental health apps offer new possibilities, such as the inclusion of audio and video, which may further enhance their usability and effectiveness.

In addition to practical implications, the results of this thesis also carry two significant implications for policy regarding resource allocation in (mental) healthcare and public health. These implications concern the personalization and accessibility of QoL assessment instruments. First, it is important for policy makers to consider groups of patients for whom conventional language-based QoL instruments are inaccessible. The results of this study reveal that a pictorial QoL instrument is a welcome alternative for many individuals with severe mental health problems. Accessible instruments such as the QoL-

ME provide these individuals with a means to engage in QoL assessment and ensures that their QoL is rightfully considered in policy. Second, QoL instruments that are not sufficiently personalized require respondents to respond to domains that are not relevant for them. Consequently, policy will partly be based on data of questionable validity. The core version of the QoL-ME provides users policy makers with a minimal set of domains that have proven to be most informative when aggregating data.

Suggestions for future research

This research project may be characterized as an educated 'leap of faith' in the sense that the QoL-ME combines several new and innovative characteristics, such as visualization and personalization. The project resulted in important new insights, but also serves as a basis for multiple possible new lines of research. In the following sections, six important opportunities for future research are discussed.

First, the results of both the qualitative and quantitative evaluations of the QoL-ME offer several opportunities for improving the current version of the QoL-ME. Most of these suggestions have been mentioned above and will be repeated briefly. These opportunities include 1) enabling respondents to compare their current scores with previous scores, 2) providing advise on how to improve QoL on domains where respondents score low, possibly by integrating the QoL-ME within a larger on-line self-management framework, 3) improving the usability of the QoL-ME by replacing unclear pictures or by adding verbal information, and 4) investigating if and how many additional modules may be added before the selection procedure starts to become too cumbersome.

Second, it is vital to investigate the responsiveness of the QoL-ME. Potential modifications that may benefit the responsiveness of the QoL-ME are replacing pictures that patients find difficult to interpret and altering the VAS-scale used in the additional modules to include incremental markers.

Third, the pictorial approach to QoL assessment employed in the QoL-ME was chosen as a supposed accessible and more intuitive alternative to verbal instruments. It is uncertain, however, to what extent the visual assessment approach actually is more intuitive and to what extent it taps into different mechanisms than traditional QoL assessment tools. As mentioned before, the literature on subjective well-being distinguishes between a cognitive and an emotive component of subjective well-being. We hypothesized that the pictorial additional modules of the QoL-ME address this emotive component. Future research that tests this hypothesis may utilize methodology employed in the field of subjective well-being research.

Fourth, In Chapter 5, the construct validity and external responsiveness of the QoL-ME were evaluated through a comparison with the MANSA. The MANSA is a credible and psychometrically sound QoL instrument, but it is also not personalized and language-based. It is therefore difficult to pinpoint whether the results of Chapter 5 truly reflect the QoL-MEs' psychometric quality. The aforementioned differences between the QoL-ME and the MANSA may have partly influenced the results. Future research may investigate to what degree this has happened and, if necessary, how the psychometric quality of the QoL-ME may be optimally assessed.

Fifth, other populations exist for whom conventional, language-based approaches to QoL assessment may not be an optimal fit, such as people with autism or people with dementia. The pictorial approach to QoL assessment employed in the QoL-ME may provide a welcome alternative for these populations and future research may reveal whether this is the case.

Sixth, it is important to investigate whether using the QoL-ME increases the QoL of patients. Several mechanisms may be responsible for a possible increase. Patients themselves, for example may use the insights provided by the QoL-ME to look for their own solutions to improve their QoL, especially if additional self-management functionality is added to the QoL-ME. In addition, the QoL-ME may be more useful for guiding and adjusting individual treatment than existing instruments. Future research may compare the QoL of patients who use the QoL-ME with patients who used an alternative QoL assessment instrument.

Conclusions

This thesis concerns a digital, visual and personalized QoL assessment instrument for people with severe mental health problems: the QoL-ME. The inclusive concept mapping method resulted in a visual representation of QoL that corresponds to existing conceptualizations of QoL and was used as a basis for the content of the QoL-ME. The co-creative development led to an app that is both accessible and usable. Psychometric evaluation of the QoL-ME reveals slightly lower reliability than conventional, language-based QoL instruments. In light of the psychometrics of similar pictorial instruments, however, both the QoL-ME's reliability and validity can be considered strong. Overall, the QoL-ME displays adequate reliability and validity that is promising regarding the feasibility of its visual assessment approach. The responsiveness of the QoL-ME, however, is insufficient and additional research is required to evaluate and potentially modify the instrument to improve its responsiveness. The QoL-ME is beneficial to users as it provides them with insight into their QoL and elicits reflection. Incorporating more functionalities that facilitate self-management, such as advice and strategies for improving lacking areas will likely make the app more actionable. Most of the additional characteristics of the QoL-ME, including its usability, design and content, match the needs and preferences of users. The results provide several starting points for future research regarding optimization of visual instruments, employing the pictorial QoL assessment approach within other populations and to what degree the pictorial assessment approach taps into cognitive or affective mechanisms.

The QoL-ME allows the voices of people with severe mental health problems who are marginalized in society to be heard in QoL assessment, which may ultimately result in the improvement of their own QoL.

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Nederlandse Samenvatting

Kwaliteit van leven is een essentiële uitkomstmaat in de zorg en begeleiding van mensen met ernstige geestelijke gezondheidsproblemen. Door de jaren heen zijn daarom diverse meetinstrumenten voor kwaliteit van leven ontwikkeld. Deze instrumenten maken het mogelijk om kwaliteit van leven steeds nauwkeuriger in kaart te brengen. Tegelijkertijd zijn er drie belangrijke mogelijkheden voor verbetering. Ten eerste laat onderzoek zien dat kwaliteit van leven betekenis krijgt op basis van individuele voorkeuren en prioriteiten. Om die reden is het essentieel dat kwaliteit van leven op een gepersonaliseerde manier wordt gemeten. Ten tweede gebruiken bestaande meetmethoden voor kwaliteit van leven vaak (ingewikkelde) taal. Deze op taal gebaseerde aanpak is minder goed toegankelijk voor een deel van de mensen met ernstige geestelijke gezondheidsproblemen. Er is daarom vraag naar een instrument dat minder afhankelijk is van verbale communicatie. Ten derde is het belangrijk dat een kwaliteit van leven instrument multi-inzetbaar is en bruikbaar voor cliënten, zorgprofessionals, onderzoekers en beleidsmakers.

Digitale instrumenten zijn bij uitstek flexibel en bieden mogelijkheden voor alternatieve vormen van communicatie. Dit proefschrift is daarom gericht op de ontwikkeling van een digitaal, gepersonaliseerd en visueel meetinstrument voor kwaliteit van leven: de QoL-ME.

De QoL-ME bestaat uit een kernversie en aanvullende modules. De kernversie bevat een beperkt aantal domeinen van kwaliteit van leven die het meest geschikt zijn om groepen te vergelijken. De kernversie wordt aangevuld met een selectie van aanvullende modules. Respondenten selecteren zelf welke modules voor hen belangrijk zijn en beantwoorden vervolgens alleen vragen over de door hen gekozen modules. De QoL-ME is ontwikkeld voor drie specifieke groepen van mensen met ernstige geestelijke gezondheidsproblemen: (1) mensen met ernstige psychiatrische aandoeningen, (2) mensen die worden behandeld in de forensische psychiatrie en (3) dak- of thuislozen.

In de studie van **Hoofdstuk 2** is de inhoud van de kernversie van de QoL-ME met behulp van een secundaire data-analyse bepaald. Eerst is een database (N= 1277) van eerder met de Lancashire Quality of Life Profile (LQoLP) verzamelde gegevens samengesteld. De LQoLP is een gestructureerd interview dat tien domeinen van kwaliteit van leven bevat. De samengestelde database is in de eerste stap van de analyse geanalyseerd met behulp van een Latente Klasse Analyse (LCA). Met LCA zijn de 1277 respondenten opgedeeld in subgroepen (of: klassen) met een vergelijkbaar antwoordprofiel op de tien domeinen van de LQoLP. De analyse liet drie duidelijk onderscheidbare klassen zien. Op basis van sociodemografische achtergrondkenmerken en informatie over de gezondheid en het welbevinden van respondenten zijn de drie klassen gekarakteriseerd in de tweede stap van de analyse. De eerste klasse is ‘Sociaal geïsoleerde personen met onvoldane zorgbehoeften’ genoemd, de tweede klasse bestond uit ‘Personen met een goede algemene kwaliteit van leven en zingeving’, en de derde klasse is ‘Personen met een goede algemene kwaliteit van leven die worstelen met zingeving en stemmingsproblematiek’. De drie klassen laten zien dat kwaliteit van leven een heterogeen en subjectief concept is. De klassen kunnen daarnaast bijdragen aan de interpretatie van kwaliteit van leven-scores. In de derde stap van de analyse is voor elk van de tien domeinen van de LQoLP met univariate entropy bekeken hoe duidelijk het onderscheid tussen de drie klassen was op dat domein. Een duidelijk onderscheid tussen de klassen op een domein betekent dat de scores op dat domein sterk samenhangen met individuele kenmerken. De drie domeinen Woonsituatie, Veiligheid en Financiën hadden een substantieel lagere univariate entropy dan de andere zeven domeinen. Dit betekent dat deze domeinen het minst samenhangen met individuele kenmerken. Ze zijn daarmee juist het meest geschikt om groepen te vergelijken. De domeinen Woonsituatie, Veiligheid en Financiën vormen samen de inhoud van de kernversie van de QoL-ME.

In **Hoofdstuk 3** stond de inhoud van de aanvullende modules van de QoL-ME centraal. Met een aanpassing van de concept mapping methodiek is een visuele weergave van kwaliteit van leven uitgewerkt. Concept mapping is een gestructureerde methode om abstracte concepten, zoals kwaliteit van leven, in kaart te brengen. Een groep van vijftig cliënten, zorgprofessionals en familieleden leverde 160 unieke beelden van aspecten van kwaliteit van leven aan. Deze beelden zijn door 17 andere cliënten, zorgprofessionals en familieleden gegroepeerd. De 17 groeperingen zijn daarna vertaald naar Binary Symmetric Similarity Matrices (BSSM). Elke BSSM bevatte 160 rijen en kolommen, overeenkomend met het aantal beelden. De cellen van de BSSM geven aan of de deelnemer een paar beelden wel (1) of niet (0) in bij elkaar heeft gegroepeerd. De 17 BSSMs zijn gecombineerd in een totale BSSM met waarden tussen 0 en 17. De totale BSSM is geanalyseerd met een Principale Componenten Analyse (PCA). De 160 beelden zijn geplot in een tweedimensionaal assenstelsel op basis van de eerste twee dimensies van de PCA. Met een hiërarchische clusteranalyse zijn de beelden opgedeeld in acht clusters. Samen met deelnemers zijn de clusters geïnterpreteerd en als volgt gelabeld: (1) Aandacht en ondersteuning, (2) Sociale relaties, (3) Geluk en liefde, (4) Rust en balans, (5) Vrije tijd, (6) Leefstijl, (7) Financiën en (8) Gezondheid en wonen. Een vergelijking liet zien dat de acht clusters overeenkomen met de resultaten van verbale conceptualisaties van kwaliteit van leven. De acht visuele clusters vormen de inhoud van de aanvullende modules van de QoL-ME.

De resultaten van de studies van Hoofdstuk 2 en Hoofdstuk 3 vormden de basis van de ontwikkeling van de QoL-ME die is beschreven in **Hoofdstuk 4.** Een groep van 59 cliënten heeft deelgenomen aan de zes iteraties en drie fases van het ontwikkelproces. De eerste iteratie vormde de brainstorm fase. In deze eerste fase hebben tien deelnemers op hun ervaringen met apps gereflecteerd. De deelnemers hebben daarnaast ideeën aangedragen voor de vormgeving en functionaliteit van de QoL-ME. Deze ideeën, gecombineerd met inzichten uit de wetenschappelijke literatuur, zijn vertaald naar ontwerpen. In de tweede, derde en vierde iteratie (2^{e} fase: de Design fase) zijn de ontwerpen bijgeschaafd en uitgewerkt op basis van de feedback van 25 deelnemers. De Design fase heeft in een eerste prototype van de QoL-ME geresulteerd. Dit prototype is in de Usability fase (fase 3, iteratie 5 en iteratie 6) onderzocht en waar nodig aangepast. Vierentwintig deelnemers hebben de gebruiksvriendelijkheid van het prototype beoordeeld door de System Usability Scale (SUS) in te vullen. De SUS-scores lieten een goede tot uitstekende gebruiksvriendelijkheid zien. Deelnemers waren erg positief over de lineaire structuur, de rustige en consistente lay-out en de intuïtieve touchscreen interactie. De studie van Hoofdstuk 4 resulteerde in de uiteindelijke versie van de QoL-ME.

De betrouwbaarheid, validiteit en responsiviteit van de QoL-ME is in de studie van **Hoofdstuk 5** in een longitudinaal design onderzocht. Op het eerste meetmoment hebben 121 deelnemers de QoL-ME, de Manchester Short Assessment of quality of life (MANSA) en vragen over hun achtergrond ingevuld. Na vier tot zes maanden hebben 81 deelnemers de QoL-ME en de MANSA nogmaals ingevuld. Om de betrouwbaarheid van de QoL-ME te evalueren, is de interne consistentie met Cronbach's Alpha in kaart gebracht. De drie domeinen van de kernversie lieten een acceptabel tot goede (α = .74 - .83) interne consistentie zien. De interne consistentie van de aanvullende modules varieerde. De interne consistentie van de module Vrije tijd was matig (α= .50). De modules Gezondheid en wonen, Aandacht en ondersteuning en Leefstijl hadden een redelijke interne consistentie ($.6 \leq \alpha < .7$). De interne consistentie van de modules Sociale relaties, Rust en balans en Financiën was acceptabel ($.7 > \alpha < .8$) en de module Geluk en liefde had een goede interne consistentie (α = .84). Met correlaties tussen de QoL-ME en MANSA is de convergente validiteit van de QoL-ME onderzocht. De correlaties tussen de drie domeinen van de kernversie en hun corresponderende MANSA-items (r = .55, .62 en .76) lieten zien dat de convergente validiteit van de kernversie voldoende tot goed was. De convergente validiteit van de aanvullende modules van de QoL-ME is berekend met de correlatie tussen de aanvullende modules en de MANSA. Deze correlatie was naar verwachting van gemiddelde grootte (r = .3). Correlaties tussen individuele items van de aanvullende modules en overeenkomende MANSA-items (r = .15-.39) hebben deze bevinding bevestigd. De externe responsiviteit van de QoL-ME is beoordeeld op basis van de correlatie tussen de verschilscores op de QoL-ME en de MANSA. Deze correlatie (r = -0.1) liet zien dat de responsiviteit van de QoL-ME onvoldoende is. De resultaten van dit hoofdstuk laten zien dat de betrouwbaarheid en convergente validiteit van de QoL-ME redelijk goed zijn. Zeker in vergelijking met andere visuele meetinstrumenten. De externe responsiviteit van de QoL-ME is voor verbetering vatbaar en vraagt om vervolgonderzoek.

In de studie van **Hoofdstuk 6** zijn de ervaringen met de QoL-ME van deelnemers met kwalitatieve interviews onderzocht. In de interviews stond centraal of de QoL-ME toegevoegde waarde heeft en/of een geschikte basis voor actie vormt. De acht interviews zijn verbatim uitgeschreven en vervolgens thematisch geanalyseerd. In de analyse zijn drie thema's naar voren gekomen: (1) Verkregen voordeel, (2) Bruikbaarheid en (3) Eigenschappen van de QoL-ME. De QoL-ME heeft de meeste deelnemers voordeel opgeleverd omdat de applicatie hen aan het denken heeft gezet over hun kwaliteit van leven. Voor de meeste deelnemers is de QoL-ME echter nog niet bruikbaar genoeg. Deelnemers hebben twee belangrijke suggesties gedaan om de bruikbaarheid van de QoL-ME te vergroten. Ten eerste maken aanvullende functionaliteiten op het gebied van zelfmanagement de QoL-ME waarschijnlijk nog beter bruikbaar. Ten tweede adviseerden deelnemers om gebruikers het verloop van hun scores te laten inzien. De deelnemers waren positief over de lay-out, structuur en gebruiksvriendelijkheid van de QoL-ME. Bovendien waren de meeste deelnemers positief over de visuele aanvullende modules van de QoL-ME. Toch waren er deelnemers voor wie een aantal van de beelden niet duidelijk of passend waren, met name op de modules Leefstijl en Vrije tijd. Deze studie laat zien dat deelnemers over het algemeen positieve ervaringen hebben met de QoL-ME. De resultaten van deze studie bieden daarnaast belangrijke aanknopingspunten om de bruikbaarheid van de QoL-ME te vergroten.

Het eerste gedeelte van **Hoofdstuk 7** bevat een synthese en discussie van de belangrijkste resultaten van dit proefschrift. De drie doelen van de QoL-ME (1) personalisatie, (2) visualisatie en (3) flexibiliteit kwamen als eerst aan bod. De conceptuele implicaties en de gebruiksvriendelijkheid van de QoL-ME zijn daarna besproken.

De QoL-ME geeft gebruikers de gelegenheid om zelf belangrijke aanvullende modules te kiezen. Tijdens de ontwikkeling en evaluatie van de QoL-ME zijn de meeste deelnemers positief over deze vorm van personalisatie geweest. Toch kwam in de interviews van Hoofdstuk 6 naar voren dat twee deelnemers het kiezen van de modules overbodig vonden. In de kwantitatieve evaluatie van de QoL-ME (Hoofdstuk 5) heeft bovendien 67 procent van de deelnemers voor zeven of acht modules gekozen. Mogelijk zijn de acht aanvullende modules nog te algemeen en daarom relevant voor de meerderheid van de gebruikers. Dit zou betekenen dat aanvullende, specifiekere domeinen nodig zijn voor nog meer differentiatie.

De visuele benadering maakt de QoL-ME laagdrempelig en ook goed te gebruiken voor personen die moeite hebben met verbale meetmethoden. Het gebruik van beelden is over het algemeen erg positief ontvangen in de ontwikkeling van de QoL-ME. In de kwalitatieve evaluatie bleek echter dat deelnemers een aantal beelden onduidelijk en/of niet passend vond. Dit waren met name beelden van de domeinen Vrije tijd en leefstijl. Deze domeinen lieten tevens de laagste interne consistentie zien. Deelnemers aan de kwalitatieve evaluatie van de QoL-ME hebben geadviseerd om de beelden te combineren met woorden, zoals in andere visuele meetinstrumenten.

De QoL-ME is ontwikkeld om bruikbaar te zijn voor cliënten, zorgprofessionals, onderzoekers en beleidsmakers. In de kwalitatieve evaluatie is gebleken dat de QoL-ME voor cliënten functionaliteit op het gebied van zelfmanagement mist om optimaal praktisch bruikbaar te zijn. De QoL-ME is in principe ook bruikbaar voor de andere groepen, maar dat is in dit onderzoek niet specifiek onderzocht.

De resultaten van dit proefschrift hebben een aantal conceptuele implicaties voor kwaliteit van leven. De resultaten bevestigen ten eerste dat kwaliteit van leven een subjectief begrip is dat invulling krijgt op basis van individuele voorkeuren en prioriteiten. In de concept mapping studie hebben diverse deelnemers sterk uiteenlopende afbeeldingen aangeleverd. In de kwantitatieve evaluatie hebben de meeste deelnemers bovendien voor een verschillende combinatie van aanvullende modules gekozen. Ten tweede bevestigen de resultaten van dit proefschrift dat kwaliteit van leven een multidimensionaal concept is. In de studie van hoofdstuk 3 is een visuele concept map uitgewerkt met acht homogene clusters die duidelijk van elkaar te onderscheiden zijn.

De resultaten van dit proefschrift bevestigen de bestaande richtlijnen op het gebied van de gebruiksvriendelijkheid van digitale applicaties voor mensen met psychiatrische problemen. Ontwikkelaars die een gebruiksvriendelijke applicatie willen ontwikkelen doen er daarom goed aan om deze richtlijnen tijdens de ontwikkeling in acht te nemen.

In het tweede gedeelte van hoofdstuk 7 kwamen de sterke punten en beperkingen, implicaties voor de praktijk, mogelijkheden voor vervolgonderzoek en een algemene conclusie aan bod.

De co-creatieve werkwijze en het innovatieve karakter van het onderzoek zijn belangrijke sterke punten. Tegelijkertijd is er ook een aantal belangrijke beperkingen. Ten eerste is in geen enkel van de studies een gerandomiseerde steekproef gebruikt. Ten tweede komt het perspectief van cliënten duidelijk naar voren, maar dat van andere stakeholders en stuk minder. Ten derde is het cocreatieve ontwikkelproces niet gestructureerd en kan daarom niet gemakkelijk gerepliceerd worden.

De resultaten hebben belangrijke implicaties voor het meten van kwaliteit van leven in behandeling, onderzoek of beleid. Bij vragenlijsten met een vaste inhoud is het onvermijdelijk dat sommige respondenten vragen moeten beantwoorden over onderwerpen die voor hen niet relevant zijn. Dankzij de flexibiliteit van digitale tools kunnen vragenlijsten gemakkelijker worden gepersonaliseerd. Het is daarnaast essentieel om de doelgroep te betrekken bij de ontwikkeling van een (digitaal) wetenschappelijk meetinstrument. Dat geldt zowel voor de inhoud als voor de vormgeving en gebruiksvriendelijkheid van het instrument.

De resultaten bieden diverse aanknopingspunten voor vervolgonderzoek. Deelnemers hebben concrete mogelijkheden aangedragen om de QoL-ME verder te ontwikkelen. Bijvoorbeeld door het verloop van scores inzichtelijk te maken of door praktische adviezen te geven voor de verbetering van lage scores. Een andere interessante mogelijkheid voor vervolgonderzoek is om de visuele meetbenadering te extrapoleren naar andere doelgroepen, zoals mensen met autisme of dementie. Vervolgonderzoek zou zich ook kunnen richten op de vraag of gebruik van de QoL-ME uiteindelijk leidt tot een betere kwaliteit van leven van cliënten.

De QoL-ME vormt het belangrijkste resultaat van dit proefschrift. De studies laten zien dat de QoL-ME gebruiksvriendelijk is en psychometrisch adequaat. Wel is er ruimte voor verbetering op het gebied van de responsiviteit van de QoL-ME en de praktische bruikbaarheid voor cliënten. Dit proefschrift laat zien dat het perspectief van cliënten onmisbaar is en centraal moet staan bij de ontwikkeling van wetenschappelijke meetinstrumenten. De QoL-ME geeft mensen met ernstige geestelijke gezondheidsproblemen de gelegenheid om ook hun stem te laten horen in hun streven naar een betere kwaliteit van leven.

Dankwoord

Wat is het prachtig om mijn zegeningen te mogen tellen en dankbaar te mogen zijn! En dat is ook niet meer dan terecht, want zonder de bijdrage, aandacht en ondersteuning van vele collega's, deelnemers en anderen was dit proefschrift nooit tot stand gekomen.

Allereerst wil ik alle deelnemers aan dit onderzoek ontzettend bedanken voor hun bijdrage. Zonder hen was het natuurlijk niets geworden. Heel veel dank aan alle deelnemers die beelden hebben aangedragen, geïnterpreteerd en gesorteerd, die hebben nagedacht over de QoL-ME, de applicatie hebben getest en de eindversie hebben gebruikt.

Mijn promotieteam is natuurlijk ook onmisbaar geweest. Chijs, Dike en Hans, wat heb ik het getroffen met jullie als promotoren. De afgelopen jaren heb ik ontzettend veel van jullie mogen leren. Onze overleggen waren niet alleen effectief, maar ook erg gezellig. Chijs, ik wil je bedanken voor het vertrouwen en voor de gelegenheid dit mooie project uit te mogen voeren. Jouw kennis, creativiteit en leiding zijn onmisbaar geweest in dit promotieonderzoek. Ik ben dankbaar dat ik uit jouw ruime ervaring heb mogen putten. Ook waardeer ik je kunde, veelzijdigheid, en gevoel voor humor. Dike, ik ben dankbaar voor jouw deskundige adviezen. In eerste instantie op afstand vanuit Rotterdam, later als departementsvoorzitter van Tranzo. Als voorzitter bleef je benaderbaar en ik ben er erg dankbaar voor dat je klaar stond om tijdelijk bij te springen wanneer dat nodig was. Hans, je was misschien het meest 'op afstand' betrokken, maar was perfect op de hoogte van de stand van zaken van het project en bewaakte de grote lijnen. Ik ben dankbaar voor je scherpe adviezen en je vriendelijkheid.

Ivo en Ilja, jullie zijn nauw betrokken geweest bij dit promotieonderzoek en verdienen daarom een speciaal woord van dank. Ivo, ik kijk met veel plezier terug op onze samenwerking als promovendus en post-doc. Ik vond het fijn om met jou van gedachten te kunnen wisselen over ons project en over de dingen die ons bezig hielden. Na de afronding van jouw postdoc heb ik je doordachte observaties en opmerkingen gemist.

Ilja, bedankt dat ik altijd bij je binnen kon en kan lopen. Dank voor je onmisbare adviezen en je methodologische expertise waar ik regelmatig gebruik van mocht maken. Ik vind het fijn om onze samenwerking na mijn promotieonderzoek voort te kunnen zetten.

Mijn promotieonderzoek heb ik op twee werkplekken mogen uitvoeren. Dat brengt vele voordelen met zich mee. Denk bijvoorbeeld aan een dubbel kerstpakket en twee keer zoveel etentjes. Maar bovenal heb ik genoten van een dubbele hoeveelheid gezelligheid met collega's. Bij Tranzo, mijn eerste werkplek, heb ik genoten van de prettige en open sfeer. Dat het Tranzo lukt om een ontspannen en ongedwongen atmosfeer te combineren met hoogstaand en maatschappelijk zeer relevant onderzoek is bewonderenswaardig. Dank aan Sanne Giesbers, Leonieke, Noud, Loraine, Marloes, Tess, Wendy, Miel, Joost, Charlotte, Lieke, Jacqueline, Henk, Vincent, Sanne de Laat, Peter, Nienke, Tineke, Vera, Jogé, Evelien, Liselore, en alle andere Tranzuelen.

De leden van mijn promovendigroepje, Emma, Wendy, Marloes en Sanne wil ik speciaal bedanken. Ik vond het mooi om elkaars artikelen van opbouwende feedback te voorzien.

De Onderzoeksgroep Forensische Geestelijke Gezondheidszorg van GGzE is mijn tweede werkplek geweest. En die deed qua gezelligheid niet onder voor de eerste. Lisette, ik vind het erg fijn al een jaar of zes jouw kamergenoot te mogen zijn. Meddy, Marilyn, Emma, Rebecca, Romy, Renee, Wendy, Jacqueline, Ed, Diana, Alexa, Jeroen, Janna en Anne wil ik daarnaast bedanken voor de gezelligheid en de goede samenwerking. En ik ben blij dat ik die samenwerking met een aantal van jullie mag voortzetten.

Zonder de consortiuminstellingen had dit onderzoek nooit kunnen plaatsvinden. Ik dank Arne Popma, Theo Doreleijers, Floor Bevaart en Toine Bakermans van AW De Nieuwe Kans, Joan van Horn en Mara Eisenberg van de Waag, Hans Wijnands en Janneke van Loo van De Regenbooggroep, Barbara van Straaten en Cas Barendregt, van het IVO, alle collega's van GGzE en Jean-Paul Grund en Dick de Bruin van het voormalig CVO. Helaas heeft Dick geen getuige van de afronding van dit proefschrift mogen zijn. Ik ben dankbaar dat ik je heb mogen kennen.

Naast de consortiuminstellingen hebben Jos Henderson van Reakt locatie Soeda, Jolien van Everdingen van Reakt Den Haag Platinaweg, Annemarie de Zwart van Stichting Ontmoeting, Kimberley Kortekaas en Dieuwertje Vermeulen van LIMOR en Aranka van der Velden van Corridor bijgedragen. Bedankt daarvoor.

De geweldige (werk)colleges van Ignace Hooge hebben mijn interesse in wetenschappelijk onderzoek aangewakkerd. De les dat 'een ontwerper zichzelf vaak niet als voorbeeld voor gebruikers kan stellen' is tijdens dit onderzoek goed van pas gekomen. Bjorn Vlaskamp, van jouw begeleiding tijdens mijn stage en afstuderen heb ik veel geleerd. De afgelopen jaren heb ik je lessen regelmatig kunnen toepassen tijdens mijn promotieonderzoek. Dank dat ik zoveel van je heb mogen leren.

Zoals de deelnemers aan mijn promotieonderzoek al aangaven, is vrije tijd belangrijk voor een goede kwaliteit van leven. Die vrije tijd heb ik regelmatig fietsend doorgebracht. Peter, Freek, Coen, Stefan en Joel, dank dat jullie je de afgelopen jaren met regelmaat door mij uit het wiel hebben laten beuken. Natuurlijk ben ik daarnaast ook dankbaar dat jullie mijn vrienden zijn.

Veel deelnemers hebben met diverse afbeeldingen van gezinnen onderstreept hoe belangrijk familie is voor hun kwaliteit van leven. Daar kan ik mij absoluut bij aansluiten. Ik ben dankbaar voor het warme gezin waarin ik mocht opgroeien en de goede banden die er nu nog zijn. De leuke vakanties, verjaardagen en andere bezoekjes hebben mij de nodige ontspanning en gezelligheid gebracht. Mama en papa, bedankt voor alle mogelijkheden die jullie mij hebben gegeven, voor het besef dat jullie altijd voor mij klaar staan en dat jullie laten weten trots op mij te zijn. Naomi, Daan, Tirsa, Chiel, Sarah en Raham, Selah, Jarah en Isaya, wat ben ik blij dat jullie mijn familie zijn.

Lieve Nina, ik ben ontzettend blij en dankbaar dat ik jou heb leren kennen. Ik ben je dankbaar voor de steun tijdens de afronding van dit promotieonderzoek. Ik vond het ontzettend leuk de behaalde mijlpalen samen te kunnen vieren en zie enorm uit naar wat de toekomst ons zal brengen!

Deo Gratias

David Buitenweg
September 2020

About the author

David Buitenweg was born on the 2nd of May 1990 in Nieuwegein (the Netherlands). He completed his secondary education in 2008 at the Cals College in Nieuwegein. David obtained a bachelor's degree in cognitive neuropsychology and a master's degree in applied cognitive psychology, both at Utrecht University. During this time, he developed an interest in scientific research and in the design of digital tools. In 2014, David started as a PhD-student at Tranzo, scientific center for care and wellbeing, at Tilburg University. During his time as a PhD-student, he was posted at the research group Forensic Mental Health of GGzE. In June of 2019, David started working as a senior researcher at the research group Forensic Mental Health. There, he is involved in several research projects on (digital tools for) recovery in adolescents and adults with severe mental health problems.

Over de auteur

David Buitenweg werd geboren op 2 mei 1990 te Nieuwegein, Nederland. In 2008 slaagde hij voor zijn vwo-opleiding aan het Cals College te Nieuwegein. David behaalde een bachelordiploma in de cognitieve neuropsychologie en een masterdiploma in de toegepaste cognitieve psychologie aan de Universiteit Utrecht. In deze periode ontwikkelde hij interesse in wetenschappelijk onderzoek en in het ontwerp van digitale toepassingen. In 2014 begon hij aan zijn promotieonderzoek bij Tranzo, wetenschappelijk centrum voor zorg en welzijn van Tilburg University. Tijdens zijn promotieonerzoek was hij gedetacheerd bij de onderzoeksgroep Forensische Geestelijke Gezondheidszorg van GGzE. Momenteel werkt hij als senior wetenschappelijk medewerker bij de onderzoeksgroep Forensische Geestelijke Gezondheidszorg. Hij houdt zich bezig met onderzoeksprojecten rond (digitale tools voor) herstel van adolescenten en volwassenen met ernstige mentale gezondheidsproblemen.

Vorige

Volgende