Received: 2 February 2018 | Revised: 22 March 2018 | Accepted: 9 April 2018

DOI: 10.1002/mpr.1721

ORIGINAL ARTICLE

WILEY

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

David C. Buitenweg[1,2] | Ilja L. Bongers[1,2] | Dike van de Mheen[1,3] | Hans A.M. van Oers[1,4] | Chijs Van Nieuwenhuizen[1,2]

[1] Tranzo Scientific Centre for Care and Welfare, Tilburg University, Tilburg, the Netherlands

[2] Centre for Child and Adolescent Psychiatry, GGzE Institute for Mental Health Care, Eindhoven, the Netherlands

[3] IVO Addiction Research Institute, Erasmus Medical Centre, Rotterdam, the Netherlands

[4] National Institute for Public Health and the Environment, Bilthoven, the Netherlands

Correspondence
David C. Buitenweg, Tranzo Scientific Centre for Care and Welfare, Tilburg University, PO BOX 90153, 5000 LE Tilburg, the Netherlands.
Email: d.c.buitenweg@tilburguniversity.edu

Funding information
Netherlands Organisation for Scientific Research, Grant/Award Number: 319-20-005

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 8 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.

KEYWORDS

concept mapping, people with severe mental health problems, quality of life, visual method

1 | INTRODUCTION

Current quality of life (QoL)-related research focuses on improving our ability to measure QoL in a number of ways. First, researchers have developed and translated QoL scales (Modabbernia et al., 2016; Nasiri-Amiri, Tehrani, Simbar, Montazeri, & Mohammadpour, 2016; Wu et al., 2016). Second, Rasch models and item response theory are often used to assess the psychometric properties of QoL scales (Bjorner & Bech, 2016; Wassef et al., 2016). Third, the rise of computerised adaptive testing (Cella, Gershon, Lai, & Choi, 2007; Gershon et al., 2012) has provoked an increase in computerised adaptive testing-related work, including the development of item banks (Greco et al., 2016; Tulsky et al., 2015). Finally, the accuracy of QoL measurement in different groups in the form of measurement invariance (Costa et al., 2015; Stevanovic & Jafari, 2015), and over time in the form of response shift (Sprangers & Schwartz, 1999; Verdam, Oort, & Sprangers,

2016), 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 conceptualisation 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 utilising this format include the Medical Outcomes Study SF-36 and related measures (McHorney, Ware Jr, & Raczek, 1993), the EQ-5D and its numerous adaptations (Herdman et al., 2011), and the MANSA (Priebe, Huxley, Knight, & Evans, 1999). Development of scales such as these often involves a conceptualisation of QoL (Aubeeluck, Buchanan, & Stupple, 2012; Caputo, 2014; Pandian et al., 2014), in which participants are commonly asked to verbalise what QoL means to them in interviews or focus groups. These language-based approaches, both for the measurement and conceptualisation 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 marginalised position in society. Examples of this marginalised position include fewer social support from family (Fazel, Geddes, & Kushel, 2014; Tyler & Schmitz, 2013), an increased risk of suffering from a substance abuse disorder (Mercier & Picard, 2011; Swendsen et al., 2010; Van Straaten et al., 2014), and being criminally victimised more frequently compared with the general population (Deck & Platt, 2015; Kamperman et al., 2014). Furthermore, people with severe mental health problems often have fewer educational opportunities (Mercier & Picard, 2011; Schindler & Kientz, 2013; Van Straaten et al., 2014) and occupational success compared with the general population (Boardman, Grove, Perkins, & Shepherd, 2003; Heuchemer & Josephsson, 2006; Marshall & Lysaght, 2016).

Several empirical studies support the notion that people with severe mental health problems have difficulties engaging in conventional QoL assessment. Evidence gathered by Reininghaus, McCabe, Burns, Croudace, and Priebe (2012) suggests that the validity of a QoL measure for psychiatric patients may be compromised due to psychopathology. A study by Ogden and Lo (2012) 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 (Winn, 1991), and little to no requirement of analytical decomposition (Unnava & Burnkrant, 1991). 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 (2010), for example, investigated neighbourhood 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 (Haque & Rosas, 2010). Other examples include the use of visual communication to enhance the health literacy of people with limited reading proficiency (Houts, Doak, Doak, & Loscalzo, 2006; Kreps & Sparks, 2008), the use of pictures in a functional communication system for children with autism (Bondy & Frost, 2011; Howlin, Magiati, & Charman, 2009), and Photovoice, a form of participatory action research in which participants use photography to express their point of view (Cabassa, Nicasio, & Whitley, 2013; Mizock, Russinova, & Shani, 2014; Seitz & Strack, 2016). These examples strongly indicate that a visual approach to the conceptualisation 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 utilising 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.

2 | METHOD

2.1 | 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: (a) people with psychiatric problems, (b) people treated in forensic psychiatry, and (c) people who are homeless. In addition to patients' own perspectives on QoL, the perspectives of family members and care professionals were also explored. These nonpatient 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 (Lehman, 1996; Van Nieuwenhuizen, Schene, Koeter, & Huxley, 2001). 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 multimodal day treatment centre for multi-problem young adults, a day centre for people who are homeless, and two research institutions that concentrate on lifestyle, homelessness, and addiction.

2.2 | 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 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/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

2.3 | 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 conceptualisation of complex multidimensional concepts (Trochim, 1989; Trochim & Kane, 2005), based exclusively on participants' input. It has been used in fields such as mental health (Windsor & Murugan, 2012) and patient-reported outcomes (Hammarlund, Nilsson, & Hagell, 2012). 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 (Boltz, Capezuti, & Shabbat, 2010), or development of a measure (Armstrong & Steffen, 2009), or an intervention (Snider, Kirst, Abubakar, Ahmad, & Nathens, 2010).

To suit the aim of the current study, a visual modification of the method described by Trochim (1989) was used. The following four steps, derived from Trochim's method, are discussed below: (a) gathering statements, (b) structuring and prioritising statements, (c) statistical analysis, and (d) 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 2. 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 (2012) 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 interpret 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.

2.4 | 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 (Connell, Brazier, O'Cathain, Lloyd-Jones, & Paisley, 2012; Connell, O'Cathain, & Brazier, 2014). In a review of 13 qualitative studies pertaining to the meaning of QoL for people with severe psychiatric problems, Connell et al. (2012) 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 (Connell et al., 2014). This combined approach of a comprehensive literature review, supplemented by an empirical study, lends authority to the results by Connell et al. (2012, 2014) and ensures that their work is a credible standard for comparison.

2.5 | 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 (R Development Core Team, 2016).

3 | RESULTS

3.1 | Participants

Eighty-two 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-seven percent of them were male; their mean age was 41.8 (*SD* = 17.6)

3.2 | Concept mapping

One hundred sixty-seven visual statements were collected in the first step. Seven of these were duplicates, leading to 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.

R-squared revealed that the first two PCA components explained 84.3% of the variance of the aggregated BSSM. Hierarchical cluster analysis was used to compute six concept maps, containing seven 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 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 1 Number of participants from each subgroup per step of the concept mapping procedure

	Participants (*N*)	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

	Participants (*N*)	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)

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

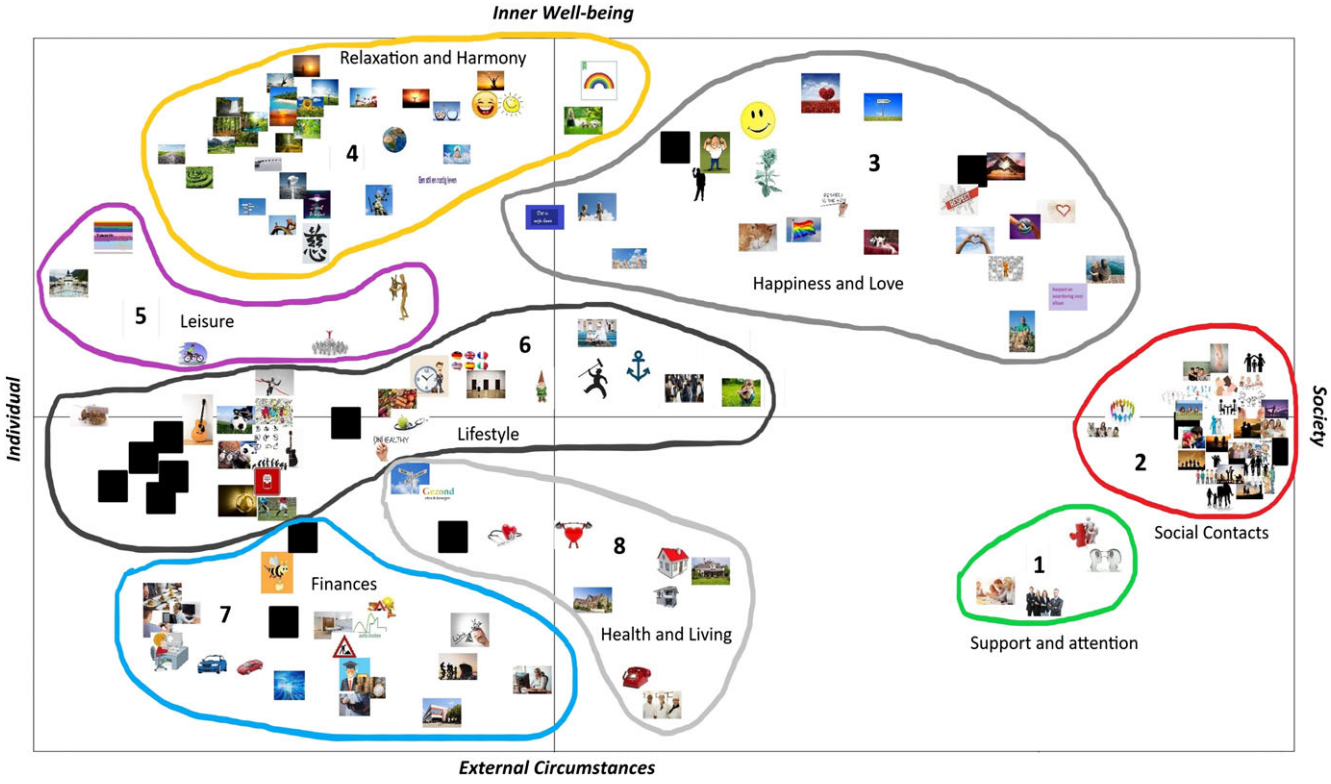

FIGURE 2 The final concept map, including interpretations for the eight clusters and two dimensions. The horizontal axis ranges from "Individual" to "Society," whereas the vertical axis ranges from "Inner well-being" to "External circumstances." Fourteen visual statements were replaced with black squares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

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

Cluster no.	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 Number of statements contributed to the eight clusters per participant group

Cluster name (no. of unique statements[a])	No. of statements patients (%)	No. of statements care professionals (%)	No. 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 (42)	12 (36)	7 (21)
Leisure (5)	1 (20)	4 (80)	0 (0)
Lifestyle (30)	14 (47)	14 (47)	2 (7)
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)

[a]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*.

3.3 | Validation of the visual clusters

In Table 5, a comparison of the eight visual clusters and the main themes and subthemes identified by Connell et al. (2012, 2014) is provided. Every visual cluster has a counterpart in the main themes 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 labour, 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 et al. (2012, 2014)

Current cluster	Corresponding subtheme(s) identified by Connell et al. (2012, 2014)	Corresponding main theme(s) identified by Connell et al. (2012, 2014)
Support and Attention	Support Acceptance and Understanding	Belonging Belonging
Social Contacts	Belonging Good relationships Love, Care, and Affection Company/Camaraderie	Belonging Belonging Belonging Belonging
Happiness and Love	Love, Care, and 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 and Enjoyable Activities Physical Well-being Routine and 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

4 | 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. Utilising 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 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 (De Maeyer, Van Nieuwenhuizen, Bongers, Broekaert, & Vanderplasschen, 2013; Dijkers, 2003; Ratcliffe et al., 2017), as different individuals supplied a tremendous variety of statements in response to the same question. Second, the present results underline the multidimensionality of QoL, (Revicki, Kleinman, & Cella, 2014; Van Nieuwenhuizen, 2006), 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 (Connell et al., 2014; Prigent, Simon, Durand-Zaleski, Leboyer, & Chevreul, 2014; Van Nieuwenhuizen et al., 2001).

Virtually, all of the aspects of QoL portrayed by the visual statements correspond to one or more subthemes identified by Connell et al. (2012, 2014). The statements depicting houses, part of the cluster *Health and Living*, form the single exception, as Connell and colleagues 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 (SMI), Kyle and Dunn (2008) reviewed nine articles in which the effect of housing interventions on QoL in people with SMI was investigated. The results seem to indicate a positive connection between improved housing and QoL. Further, Nelson et al. (2007) 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 SMI (Prigent et al., 2014; Van Nieuwenhuizen et al., 2001). 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 (2009) and Rose (2014), visual research methods may elicit information that language-based methods, such as surveys or interviews, cannot. The visual research method utilised in this study did not identify aspects of QoL beyond those reported in the literature (Connell et al., 2012; Prigent et al., 2014; Van Nieuwenhuizen et al., 2001).

4.1 | Strengths and limitations

The visual approach to the conceptualisation 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 (2012). 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 verbalised 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 (Koć-Januchta, Höffler, Thoma, Prechtl, & Leutner,

2017) to gain insight into whether participants mentally represent information in a visual or verbal way.

5 | 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 conceptualisations 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.

ACKNOWLEDGEMENTS

This work is part of the research programme "Quality of Life and Health," project number 319-20-005, which is financed by the Netherlands Organisation for Scientific Research (NWO).

DECLARATION OF INTEREST STATEMENT

The authors declare that they have no conflict of interest.

ORCID

David C. Buitenweg http://orcid.org/0000-0002-8593-1722

REFERENCES

Armstrong, N. P., & Steffen, J. J. (2009). The Recovery Promotion Fidelity Scale: Assessing the organizational promotion of recovery. *Community Mental Health Journal*, *45*, 163–170. https://doi.org/10.1007/s10597-008-9176-1

Aubeeluck, A. V., Buchanan, H., & Stupple, E. J. N. (2012). 'All the burden on all the carers': Exploring quality of life with family caregivers of Huntington's disease patients. *Quality of Life Research*, *21*, 1425–1435. https://doi.org/10.1007/s11136-011-0062-x

Bagnoli, A. (2009). Beyond the standard interview: The use of graphic elicitation and arts-based methods. *Qualitative Research*, *9*, 547–570.

Bjorner, J. B., & Bech, P. (2016). Modern psychometric approaches to analysis of scales for health-related quality of life. In *Beyond assessment of quality of life in schizophrenia* (pp. 103–120). Cham, Switzerland: Springer International Publishing.

Boardman, J., Grove, B., Perkins, R., & Shepherd, G. (2003). Work and employment for people with psychiatric disabilities. *British Journal of Psychiatry*, *182*, 467–468.

Boltz, M., Capezuti, E., & Shabbat, N. (2010). Building a framework for a geriatric acute care model. *Leadership in Health Services*, *23*, 334–360.

Bondy, A., & Frost, L. (2011). *A picture's worth: PECS and other visual communication strategies in autism*. Bethesda, MD: Woodbine House.

Cabassa, L. J., Nicasio, A., & Whitley, R. (2013). Picturing recovery: A photovoice exploration of recovery dimensions among people with serious mental illness. *Psychiatric Services*, *64*, 837–842. https://doi.org/10.1176/appi.ps.201200503

Caputo, A. (2014). Exploring quality of life in Italian patients with rare disease: A computer-aided content analysis of illness stories. *Psychology, Health & Medicine*, *19*, 211–221. https://doi.org/10.1080/13548506.2013.793372

Cella, D., Gershon, R., Lai, J. S., & Choi, S. (2007). The future of outcomes measurement: Item banking, tailored short-forms, and computerized adaptive assessment. *Quality of Life Research*, *16*(Suppl 1), 133–141. https://doi.org/10.1007/s11136-007-9204-6

Connell, J., Brazier, J., O'Cathain, A., Lloyd-Jones, M., & Paisley, S. (2012). Quality of life of people with mental health problems: A synthesis of qualitative research. *Health and Quality of Life Outcomes*, *10*, 138.

Connell, J., O'Cathain, A., & Brazier, J. (2014). Measuring quality of life in mental health: Are we asking the right questions? *Social Science & Medicine*, *120*, 12–20. https://doi.org/10.1016/j.socscimed.2014.08.026

Costa, D. S., Aaronson, N. K., Fayers, P. M., Pallant, J. F., Velikova, G., & King, M. T. (2015). Testing the measurement invariance of the EORTC QLQ-C30 across primary cancer sites using multi-group confirmatory factor analysis. *Quality of Life Research*, *24*, 125–133. https://doi.org/10.1007/s11136-014-0799-0

De Maeyer, J., Van Nieuwenhuizen, Ch., Bongers, I. L., Broekaert, E., & Vanderplasschen, W. (2013). Profiles of quality of life in opiate-dependent individuals after starting methadone treatment: A latent class analysis. *International Journal of Drug Policy*, *24*, 342–350.

Deck, S. M., & Platt, P. A. (2015). Homelessness is traumatic: Abuse, victimization, and trauma histories of homeless men. *Journal of Aggression, Maltreatment & Trauma*, *24*, 1022–1043.

R Development Core Team (2016). *R: A language and environment for statistical computing*. Vienna, Austria: R Foundation for Statistical Computing.

Dijkers, M. P. (2003). Individualization in quality of life measurement: Instruments and approaches. *Archives of Physical Medicine and Rehabilitation*, *84*, S3–S14.

Fazel, S., Geddes, J. R., & Kushel, M. (2014). The health of homeless people in high-income countries: Descriptive epidemiology, health consequences, and clinical and policy recommendations. *Lancet*, *384*, 1529–1540. https://doi.org/10.1016/S0140-6736(14)61132-6

Gershon, R. C., Lai, J. S., Bode, R., Choi, S., Moy, C., Bleck, T., … Cella, D. (2012). Neuro-QOL: Quality of life item banks for adults with neurological disorders: Item development and calibrations based upon clinical and general population testing. *Quality of Life Research*, *21*, 475–486. https://doi.org/10.1007/s11136-011-9958-8

Greco, C. M., Yu, L., Johnston, K. L., Dodds, N. E., Morone, N. E., Glick, R. M., … Pilkonis, P. A. (2016). Measuring nonspecific factors in treatment: Item banks that assess the healthcare experience and attitudes from the patient's perspective. *Quaity of Life Research*, *25*, 1625–1634. https://doi.org/10.1007/s11136-015-1178-1

Hammarlund, C. S., Nilsson, M. H., & Hagell, P. (2012). Measuring outcomes in Parkinson's disease: A multi-perspective concept mapping study. *Quality of Life Research*, *21*, 453–463. https://doi.org/10.1007/s11136-011-9995-3

Haque, N., & Rosas, S. (2010). Concept mapping of photovoices: Sequencing and integrating methods to understand immigrants' perceptions of neighborhood influences on health. *Family & Community Health*, *33*, 193–206.

Herdman, M., Gudex, C., Lloyd, A., Janssen, M., Kind, P., Parkin, D., … Badia, X. (2011). Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Quality of Life Research*, *20*, 1727–1736. https://doi.org/10.1007/s11136-011-9903-x

Heuchemer, B., & Josephsson, S. (2006). Leaving homelessness and addiction: Narratives of an occupational transition. *Scandinavian Journal of Occupational Therapy*, *13*, 160–169.

Houts, P. S., Doak, C. C., Doak, L. G., & Loscalzo, M. J. (2006). The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence. *Patient Education and Counseling*, *61*, 173–190.

Howlin, P., Magiati, I., & Charman, T. (2009). Systematic review of early intensive behavioral interventions for children with autism. *American Journal on Intellectual and Developmental Disabilities*, *114*, 23–41.

Kamperman, A. M., Henrichs, J., Bogaerts, S., Lesaffre, E. M., Wierdsma, A. I., Ghauharali, R. R., … Theunissen, J. R. (2014). Criminal victimisation in people with severe mental illness: A multi-site prevalence and incidence survey in the Netherlands. *PLoS One*, *9*, e91029.

Koć-Januchta, M., Höffler, T., Thoma, G. B., Prechtl, H., & Leutner, D. (2017). Visualizers versus verbalizers: Effects of cognitive style on

learning with texts and pictures–An eye-tracking study. *Computers in Human Behavior*, *68*, 170–179.

Kreps, G. L., & Sparks, L. (2008). Meeting the health literacy needs of immigrant populations. *Patient Education and Counseling*, *71*, 328–332.

Kyle, T., & Dunn, J. R. (2008). Effects of housing circumstances on health, quality of life and healthcare use for people with severe mental illness: A review. *Health & Social Care in the Community*, *16*, 1–15.

Lehman, A. F. (1996). Measures of quality of life among persons with severe and persistent mental disorders. *Social Psychiatry and Psychiatric Epidemiology*, *31*, 78–88.

Marshall, C. A., & Lysaght, R. (2016). The experience of occupational transition from homelessness to becoming housed. *American Journal of Occupational Therapy*, *70*(Suppl. 1], 7011505089), 1. https://doi.org/10.5014/ajot.2016.70S1-RP301B

McHorney, C. A., Ware, J. E. Jr., & Raczek, A. E. (1993). The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Medical Care*, *31*, 247–263.

Mercier, C., & Picard, S. (2011). Intellectual disability and homelessness. *Journal of Intellectual Disability Research*, *55*, 441–449. https://doi.org/10.1111/j.1365-2788.2010.01366.x

Mizock, L., Russinova, Z., & Shani, R. (2014). New roads paved on losses: Photovoice perspectives about recovery from mental illness. *Qualitative Health Research*, *24*, 1481–1491. https://doi.org/10.1177/1049732314548686

Modabbernia, A., Yaghoubidoust, M., Lin, C. Y., Fridlund, B., Michalak, E. E., Murray, G., & Pakpour, A. H. (2016). Quality of life in Iranian patients with bipolar disorder: A psychometric study of the Persian Brief Quality of Life in Bipolar Disorder (QoL.BD). *Quality of Life Research*, *25*, 1835–1844. https://doi.org/10.1007/s11136-015-1223-0

Nasiri-Amiri, F., Tehrani, F. R., Simbar, M., Montazeri, A., & Mohammadpour, R. A. (2016). Health-related quality of life questionnaire for polycystic ovary syndrome (PCOSQ-50): Development and psychometric properties. *Quality of Life Research*, *25*, 1791–1801. https://doi.org/10.1007/s11136-016-1232-7

Nelson, G., Sylvestre, J., Aubry, T., George, L., & Trainor, J. (2007). Housing choice and control, housing quality, and control over professional support as contributors to the subjective quality of life and community adaptation of people with severe mental illness. *Administration and Policy in Mental Health and Mental Health Services Research*, *34*, 89–100.

Ogden, J., & Lo, J. (2012). How meaningful are data from Likert scales? An evaluation of how ratings are made and the role of the response shift in the socially disadvantaged. *Journal of Health Psychology*, *17*, 350–361. https://doi.org/10.1177/1359105311417192

Pandian, V., Bose, S., Miller, C., Schiavi, A., Feller-Kopman, D., Bhatti, N., & Mirski, M. (2014). Exploring quality of life in critically ill tracheostomy patients: A pilot study. *ORL-Head and Neck Nursing*, *32*(6–8), 10–13.

Priebe, S., Huxley, P., Knight, S., & Evans, S. (1999). Application and results of the Manchester Short Assessment of Quality of Life (MANSA). *International Journal of Social Psychiatry*, *45*, 7–12.

Prigent, A., Simon, S., Durand-Zaleski, I., Leboyer, M., & Chevreul, K. (2014). Quality of life instruments used in mental health research: Properties and utilization. *Psychiatry Research*, *215*, 1–8. https://doi.org/10.1016/j.psychres.2013.10.023

Ratcliffe, J., Lancsar, E., Flint, T., Kaambwa, B., Walker, R., Lewin, G., … Cameron, I. D. (2017). Does one size fit all? Assessing the preferences of older and younger people for attributes of quality of life. *Quality of Life Research*, *26*, 299–309.

Reininghaus, U., McCabe, R., Burns, T., Croudace, T., & Priebe, S. (2012). The validity of subjective quality of life measures in psychotic patients with severe psychopathology and cognitive deficits: An item response model analysis. *Quality of Life Research*, *21*, 237–246. https://doi.org/10.1007/s11136-011-9936-1

Revicki, D. A., Kleinman, L., & Cella, D. (2014). A history of health-related quality of life outcomes in psychiatry. *Dialogues in Clinical Neuroscience*, *16*, 127.

Rosas, S. R., & Kane, M. (2012). Quality and rigor of the concept mapping methodology: A pooled study analysis. *Evaluation and Program Planning*, *35*, 236–245.

Rose, G. (2014). On the relation between 'visual research methods' and contemporary visual culture. *The Sociological Review*, *62*, 24–46.

Schindler, V. P., & Kientz, M. (2013). Supports and barriers to higher education and employment for individuals diagnosed with mental illness. *Journal of Vocational Rehabilitation*, *39*, 29–41.

Seitz, C. M., & Strack, R. W. (2016). Conducting public health photovoice projects with those who are homeless: A review of the literature. *Journal of Social Distress and the Homeless*, *25*, 33–40.

Snider, C. E., Kirst, M., Abubakar, S., Ahmad, F., & Nathens, A. B. (2010). Community-based participatory research: Development of an emergency department–based youth violence intervention using concept mapping. *Academic Emergency Medicine*, *17*, 877–885.

Sprangers, M. A. G., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science & Medicine*, *48*, 1507–1515. https://doi.org/10.1016/S0277-9536(99)00045-3

Stevanovic, D., & Jafari, P. (2015). A cross-cultural study to assess measurement invariance of the KIDSCREEN-27 questionnaire across Serbian and Iranian children and adolescents. *Quality of Life Research*, *24*, 223–230. https://doi.org/10.1007/s11136-014-0754-0

Swendsen, J., Conway, K. P., Degenhardt, L., Glantz, M., Jin, R., Merikangas, K. R., … Kessler, R. C. (2010). Mental disorders as risk factors for substance use, abuse and dependence: Results from the 10-year follow-up of the National Comorbidity Survey. *Addiction*, *105*, 1117–1128. https://doi.org/10.1111/j.1360-0443.2010.02902.x

Trochim, W. (1989). An introduction to concept mapping for planning and evaluation. *Evaluation and Program Planning*, *12*, 1–16. https://doi.org/10.1016/0149-7189(89)90016-5

Trochim, W., & Kane, M. (2005). Concept mapping: An introduction to structured conceptualization in health care. *International Journal for Quality in Health Care*, *17*, 187–191. https://doi.org/10.1093/intqhc/mzi038

Tulsky, D. S., Kisala, P. A., Lai, J. S., Carlozzi, N., Hammel, J., & Heinemann, A. W. (2015). Developing an item bank to measure economic quality of life for individuals with disabilities. *Archives of Physical Medicine and Rehabilitation*, *96*, 604–613. https://doi.org/10.1016/j.apmr.2014.02.030

Tyler, K. A., & Schmitz, R. M. (2013). Family histories and multiple transitions among homeless young adults: Pathways to homelessness. *Children and Youth Services Review*, *35*, 1719–1726. https://doi.org/10.1016/j.childyouth.2013.07.014

Unnava, H., & Burnkrant, R. (1991). An imagery-processing view of the role of pictures in print advertisements. *Journal of Marketing Research*, *28*, 226–231. https://doi.org/10.2307/3172811

Van Nieuwenhuizen, Ch. (2006). Measuring quality of life in mental disorders. In H. Katschnig, H. Freeman, & N. Sartorius (Eds.), *Quality of life in mental disorders* (pp. 85–90). Hoboken, New Jersey: John Wiley & Sons Ltd.

Van Nieuwenhuizen, Ch., Schene, A. H., Koeter, M. W. J., & Huxley, P. J. (2001). The Lancashire quality of life profile: Modification and psychometric evaluation. *Social Psychiatry and Psychiatric Epidemiology*, *36*, 36–44. https://doi.org/10.1007/s001270050288

Van Straaten, B., Schrijvers, C. T. M., Van der Laan, J., Boersma, S. N., Rodenburg, G., Wolf, J. R. L. M., & Van de Mheen, D. (2014). Intellectual disability among Dutch homeless people: Prevalence and related psychosocial problems. *PLoS One*, *9*, 9. http://doi.org/ARTNe8611210.1371/journal.pone.0086112.

Verdam, M. G. E., Oort, F. J., & Sprangers, M. A. G. (2016). Using structural equation modeling to detect response shifts and true change in discrete variables: An application to the items of the SF-36. *Quality of Life Research*, *25*, 1361–1383. https://doi.org/10.1007/s11136-015-1195-0

Wassef, W., DeWitt, J., McGreevy, K., Wilcox, M., Whitcomb, D., Yadav, D., … Bova, C. (2016). Pancreatitis quality of life instrument: A

psychometric evaluation. *American Journal of Gastroenterology*, *111*, 1177–1186. https://doi.org/10.1038/ajg.2016.225

Windsor, L. C., & Murugan, V. (2012). From the individual to the community: Perspectives about substance abuse services. *Journal of Social Work Practice in the Addictions*, *12*, 412–433.

Winn, W. (1991). Learning from maps and diagrams. *Educational Psychology Review*, *3*, 211–247.

Wu, J., Hu, L., Zhang, G., Liang, Q., Meng, Q., & Wan, C. (2016). Development and validation of the nasopharyngeal cancer scale among the system of quality of life instruments for cancer patients (QLICP-NA V2.0): Combined classical test theory and generalizability theory. *Quality of Life Research*, *25*, 2087–2100. https://doi.org/10.1007/s11136-016-1251-4

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

How to cite this article: Buitenweg DC, Bongers IL, van de Mheen D, van Oers HAM, Van Nieuwenhuizen C. Worth a thousand words? Visual concept mapping of the quality of life of people with severe mental health problems. *Int J Methods Psychiatr Res*. 2018;27:e1721. https://doi.org/10.1002/mpr.1721