Measuring Quality of Life:

A Psychometric Evaluation of a new Well-being scale for Patients with Dementia

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Abstract

Background: Improving well-being in addition to physical health has become an import goal in the health care system. A new observational well-being scale has been created inspired by previously designed instruments. This study focuses on the psychometric evaluation of this well-being scale for patients with dementia.

Methods: The sample consists of Dutch residents (n=168) between the ages of 59 and 99 with a mean age of 85 years (SD=7.3). The first step of this study is to examine the factor structure in order to assess the current scoring process and determine the structure of well-being for patients with dementia. Then Cronbach's alpha and split-half reliability are calculated in order to evaluate the internal consistency.

Results: An exploratory factor analysis provided support for a 4-factor model each consisting of 10 to 23 items. Moderate to strong correlations were found between the factors. Most items correlated strongly with multiple factors. A good internal consistency was found for the total scale (α=.96, r=.95) and as well for the subscales social well-being (α=.94, r=.94), psychological well-being (α=.84, r=.73), emotional well-being (α=.93, r=.90), and cognition (α=.88, r=.81).

Conclusion: This well-being scale appears to be a reliable and valid instrument with a high practical value. The factorial structure coincides with the three dimensions of well-being, namely emotional, psychological, and social well-being, whereas the fourth factor's key characteristic appeared to be cognition. The items regarding cognition should be kept in questionnaire, if it is used for monitoring well-being, because of the high practical value. In order to be used for scientific research it would be preferable to delete the items in cognitive factor and replace some of the items focused on anxiety with items measuring positive individual functioning. This way the scale would align with current developments in positive psychology. This well-being scale could then be used to compare different nursing homes or treatments. The high internal reliability suggests that the scale can be used to monitor changes in well-being in an individual.

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1 Introduction

With the aging of societies all over the world, dementia has become one of the most common diseases (Damman, Hendriks, & Sixma, 2009). Around 20% of people over 80 suffer from some sort of dementia in the Netherlands (Groene, 2011) and more than 40% of people over 85 (Gezondheidsraad, 2002). Symptoms of dementia include amongst others a continuing decline in memory and other cognitive abilities, and impaired social functioning (Raad voor de Volksgezondheid en Zorg (RVZ), 1998). Dementia has thus a strong impact on the physical and mental health of the patients, their families and the caregivers (Baumgarten et al., 1992; Cohen et al., 2006).

Improving care for people with dementia is a crucial goal for many countries. One way of improving care for patients with dementia is improve the quality of life of the patient. An advantage of this approach is that it is much easier for health care professionals to affect the quality of life than to affect the course of dementia (Oates, Weston, & Jordan, 2000).

The psychosocial aspect of care has thus become important in improving geriatric care in addition to the medical treatment (Heszen-Klemens & Lapińska, 1984). Patients in a nursing home stay there mostly for a longer period of time and that is why other aspects of life in addition to the physical health of the patient, such as the living environment and the social life, should play a major role in geriatric care (Fitzpatrick, 1984). The World Health Organization (WHO) defines health as a "state of complete physical, mental, and social well-being and not merely the absence of disease" (World Health Organization, 1960). The effects of health care should therefore include an improved physical health, and an improved quality of life (Damman, 2010). Well-being has been defined as "the personal feeling of physical and psychological well-being" (Richters, 2012). Consequently, the concept of quality of life puts the emphasis on the satisfaction with life (Delnoij & Hendriks, 2008).

There are thought to be three core components of well-being, namely emotional, psychological, and social well-being (Westerhof & Bohlmeijer, 2010). These three components together are the basis for positive mental health (Westerhof & Bohlmeijer, 2010). Emotional well-being is thereby connected to the experienced life satisfaction, positive affect and the absence of

negative affect (Diener, Suh, Lucas, & Smith, 1999). Psychological well-being is defined as positive functioning in one's individual life and social well-being is defined as positive functioning in a community (Westerhof & Bohlmeijer, 2010).

Arcares (now ActiZ), the Dutch association for residential and home care organizations and infant and child health clinics, concluded in a literature and interview study that well-being for patients in nursing homes can be structured into not three, but four different domains, namely "Physical well-being and health", "Mental well-being", "Living situation" and "Participation" (Van Beek, De Boer, Van Nispen, & Wagner, 2005). This model is widely used in the Dutch health care system in order to evaluate the well-being of patients. "Physical well-being and health" includes according to Klein and Boals (2001) the experienced health, physical impairment, physical care and the enjoyment of food and drinks. "Mental well-being" includes the level of autonomy, having privacy, the experiencing of one's own identity, interest in learning new things, and spirituality. The domain "living situation" includes feeling at home, experienced safety, to be in control of the structure of the day, purpose and the financial situation of the client. "Participation" includes social contacts such as those with family, friends, other patients and caregivers, the way these contacts are experienced, the social roles of patients and the experienced happiness and satisfaction.

In order to monitor and enhance quality of life, it is necessary to collect precise data about those issues that define the quality of life for each individual patient with dementia. Quality of life means something different for each and every one and is thus very subjective. This is why most measures are based on self-reports. However, this has proven to be very difficult with people with dementia, because of the cognitive impairments caused by dementia (Brown, 2007). These impairments can lead to a feeling of disempowerment and make it difficult for the patient to express complaints with the quality of care (Fossey, Lee, & Ballard, 2002). It is thus often necessary to use observational measures for this group of patients.

The most comprehensive measurement instrument for quality of life for people with dementia in the Netherlands is currently the Qualidem (Avis, Bond, & Arthur, 1997). The Qualidem is a reliable observational rating scale, which is easy to administer (Bouman et al., 2011). It is a multidimensional scale with 37 items and nine subscales, which are "Care relationship", "Positive affect", "Negative

affect", "Restless tense behavior", "Positive self-image", "Social relations", "Social isolation", "Feeling at home" and "Having something to do" (Wright & Chung, 2001). 19 items are not applicable for patients with severe cognitive impairment (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2007). In spite of being a widely respected and reliable instrument, the Qualidem has been criticized for its mostly negative phrased questions (Kacewicz, Slatcher, & Pennebaker, 2007).

To overcome these problems and to align with the current developments in positive psychology a new well-being scale for patients with dementia (Welzijnsmeter in Dutch) (Richters, 2012) was recently created. The goal of the well-being scale was to be more in accordance with practical needs than the Qualidem, so that the results of the well-being scale would directly indicate where and how the care should be adjusted. In the last two decennia, positive psychology has become an important school of thinking (Seligman & Csikszentmihalyi, 2000). The focus thereby lies not only on the treatment of disease, but also on increasing the quality of life and mental well-being (Westerhof & Bohlmeijer, 2010). Since there is no cure for dementia and the course of the disease is progressive, accepting the disease and adjusting to the new situation is important (Steeman, Casterlé, Dierckx, Godderis, & Grypdonck, 2006).

During the development of the well-being scale items from other questionnaires were edited to align with the developments in positive psychology. That means in this case that the items were based on positive assumptions if possible. The questionnaires used as inspiration were the Qualidem (Avis et al., 1997), the Dutch Behavioral Rating Scale for Geriatric Inpatients (Pennebaker, 1997), the Neuropsychiatric Inventory (NPI) (Baikie & Wilhelm, 2005), the Cornell-Brown Scale (Esterling, L'Abate, Murray, & Pennebaker, 1999) and the Care Dependency Scale (CDS) (Connolly Baker & Mazza, 2004). The resulting well-being scale is an observational instrument to be filled out by health care professionals consisting of 82 items. It implements the four domains of quality of life defined by ActiZ, as the four major dimensions. These four dimensions in turn have subscales. The dimension "Mental well-being" contains the subscales "Anxiety", "Aggression", "Mood" and "Agitation". The dimension "Living situation" contains the subscales "Living situation" and "Relationship with the employees". The dimension "Physical well-being and health" contained the subscales "Physical well-being", "Decorum" and "Confused behavior". The dimension "Participation" contains the following

two subscales: “Engagement” and “Social contacts”. Each subscale is thereby connected to recommendations, which support the health care professionals in deciding how to improve the care with regards well-being in the corresponding category for the patient (Appendix 2 Guidelines well-being scale).

This scale has not yet been formally validated and that is what this study is set out to do. This is necessary in order to be able to use the well-being scale for comparing groups and for detecting changes in the individual over time. The first step of this study is to examine the factor structure in order to assess the current scoring process and determine the structure of well-being for patients with dementia. Then Cronbach’s alpha and split-half reliability of the well-being scale are calculated in order to evaluate the internal consistency.

Research questions:

1. **What is the factor structure of the new well-being scale for patients with dementia?**
2. **Can the four dimensions of quality of life assumed by Acares used in the questionnaire be replicated or are the three dimensions of well-being, emotional, psychological, and social well-being based on Keyes (2010) a better fit?**
3. **Can an acceptable internal consistency be found for the total well-being scale and the subscales?**

2 Method

2.1 PARTICIPANTS

The study took place in the nursing home “de Posten” in Enschede. The sample consisted of Dutch residents (n=168) between the ages of 59 and 99 with a mean age of 85 years (SD=7.3). 72% of the participants were female (n=121) and 28% were male (n=47). The participants stayed in 11 different departments. The questionnaire was administered up to five times per patient over the course of two years resulting in 256 completed questionnaires. For the analysis the first available measurement of each participant was chosen. The entry criterion for the patients was a diagnosis of some sort of dementia in the medical record.

2.2 PROCEDURE & DESIGN

The proxy-informant based online questionnaire had to be filled out together by two health care professionals, who observed the patient over a period of time. The first time the questionnaire was filled out was usually after the patient stayed at the nursing home for at least six weeks and after that twice a year. The professionals received verbal and written instructions from Drs. K. Richters (Appendix 1 The well-being scale). The written instructions were shown again on the first page of the questionnaire every time it was filled out. The observers were asked to rate how often they observed each behavior in the last two weeks. It takes approximately 10 minutes to fill out the questionnaire. The current data were collected between November 2012 and October 2014.

2.3 MEASURES

The questionnaire starts with five questions about descriptive variables such as sex, age, responsible health care professional and current department of the nursing home. The well-being scale measures well-being in patients with dementia and confused or problematic behavior of the patient. It consists of 82 statements related to behavior in the last two weeks.

It uses a 4-point Likert scale to rate the observed behavior ranging from 1 to 4 *(never, rarely, often, always)* with the added option *not possible to observe*. *Never* is defined as not once in the observational period of time, *rarely* is defined as once in the observational period of time, *often* is defined as two or three times in the observational period of time and *always* as almost daily in the

observational period of time. The option *not possible to observe* was added, because some of the items could not be answered reliably through observational measures by the health care professionals for some of the patients with severe dementia. A high number of items answered with *not possible to observe* might therefore indicate a lower quality of life or a more severe stage of dementia. An alternate explanation however is that the observer does not know the patient well enough or that the patient exhibits a limited range of movements and reactions. The well-being scale contains 28 items measuring "Physical well-being and health", 25 items measuring "Mental well-being", 12 items measuring "Living situation" and 17 items measuring "Participation". 50 items were worded positively and 32 were worded negatively. The 50 positive items were reverse scored so that high values indicate more well-being.

The scoring is done automatically and a pie-chart of the results is created (Appendix 3 Example Output for caregivers). The pie-chart color-codes the questionnaire on an item level and is structured into the four dimensions. A green chart indicates a high level of well-being. White means the item was not possible to observe. If you click on a red item advice on how to improve care with regard to the corresponding aspect of well-being is shown.

2.4 STATISTICAL ANALYSIS

The Statistical Package for the Social Sciences 20.0 (SPSS 20.0) was used for all statistical analysis. First, in order to check for "floor" and "ceiling" effects the percentage of patients with the highest or lowest scores were calculated for each item. A "floor" or "ceiling" effect was considered to be present, when the percentage for the highest or lowest scores of an item was above 60%. Some of these items have a possible clinical relevance similar to a checklist, but would distort the psychometric findings. Seven items (Table 1) exhibited large "floor" or "ceiling" effects and were not used in the following analysis, because they might distort the results. This left 75 remaining items. There were four items with "floor" effects and three items with "ceiling" effects.

Table 1. *Floor and ceiling effects*

Item	% never	% always
Gooit met voorwerpen (Item 11)	84%	
Maakt met opzet dingen kapot (Item 12)	88%	
Is bang voor onbekenden (Item 20)	66%	
Ziet er gewassen en verzorgt uit (Item 33)		73%
Gebruikt normale seksuele omgangsvormen(Item 34)		73%
Trekt kleding uit op ongewenste plaatsen(Item 37)		80%
Accepteert medicatie (Item 77)		70%

Percentages under 60 are left blank

Secondly, the Shapiro-Wilk test was used in order to determine whether the total scores and the scores of the subscales are distributed normally. Results indicated a normal distribution of the scores for the total well-being scale (p=.08). A normality plot of the total score also indicated that the results are likely to have a normal distribution (Figure 1).

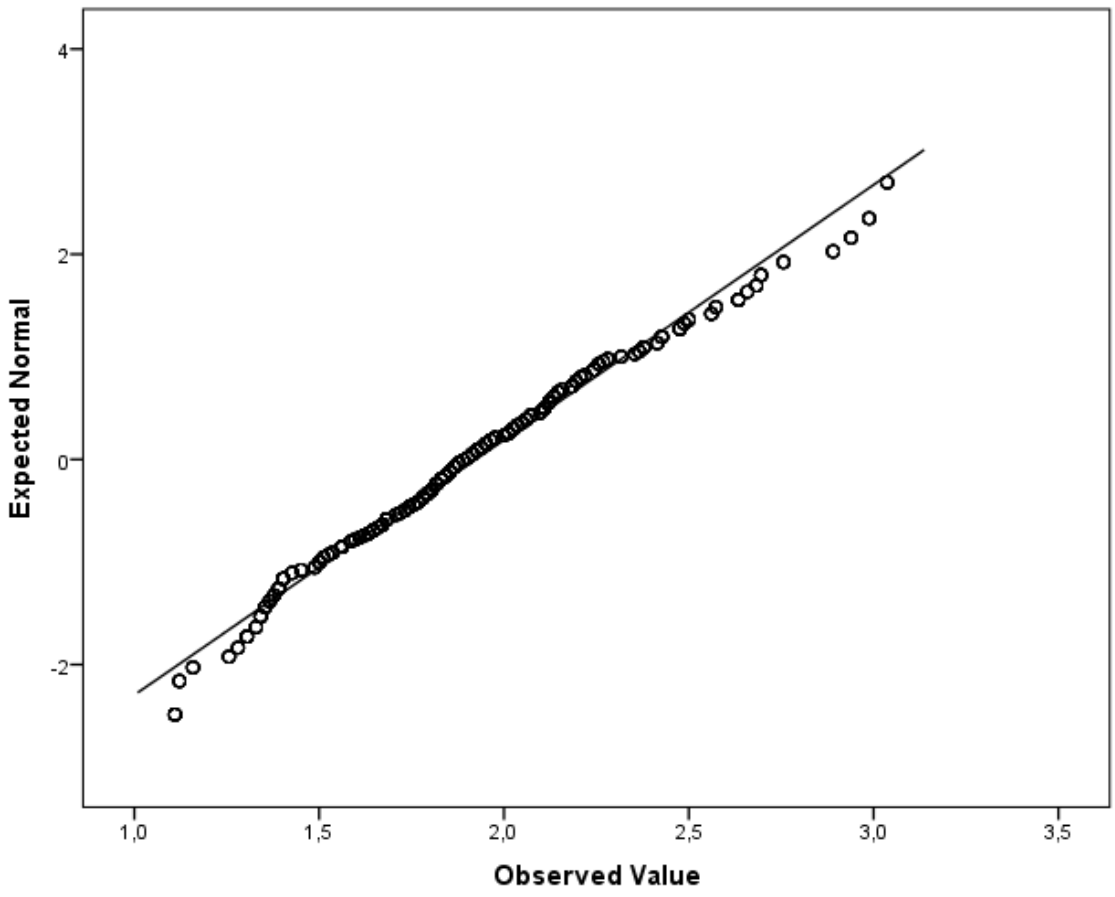

Figure 1. *Normality plot of the total score*

The answer *not possible to observe* was treated as a missing value. 3.27% of the answers were therefore missing values. In order to be able to conduct the factor analysis multiple imputation in SPSS was used to create five distinctive datasets without missing values (Rubin, 2004).

Thirdly, an exploratory factor analysis was conducted with all five imputed datasets. The resulting factor structure differed only marginally between the different datasets. For all following analysis imputation number two was arbitrarily chosen. To obtain the number of factors the *eigenvalues greater than 1* rule and the corresponding scree plot of the eigenvalues was used. Furthermore, maximum likelihood estimation with direct oblimin rotation was used to determine how the items are distributed over the factors. Oblimin rotation was chosen because of the expected correlation between the factors. Afterwards the correlation between the found subscales was calculated. Items were regarded as having multiple loadings, if the factor loading for an item was higher than .40 for more than one factor.

The items were then grouped into the corresponding hypothetical categories of emotional, psychological and social well-being according to Keyes (2005). The items, which could not be assigned to one of the dimension based on Keyes (2005), were grouped into categories with regard to similarities in the content of the items (Table 3) in order to be able to control for convergent validity. The Pearson correlation-coefficients between the found dimensions and between the factors and the categories were then calculated to determine the discriminant validity.

Fourthly, Cronbach's alpha and the split-half reliability was calculated for the total scores and each subscale in order to evaluate the internal consistency. Additionally, Cronbach's alpha, if the individual item would be removed from the scale, was calculated for every item. On the basis of the results items were either kept in the questionnaire for further analysis or deleted, if this increased Cronbach's alpha substantially.

A Cronbach's alpha > 0.70 was seen as acceptable and a Cronbach's alpha above 0.80 as high (Kline, 2013). For all calculations a significance level (p) equal to or lower than 0.05 was used. Correlations with other items or dimensions around 0.20 were considered low and correlations around 0.50 moderate (Swerdlik & Cohen, 2005).

Furthermore, the inter-item correlation was calculated in order to find overlapping items. Items with correlations above .70 were considered redundant.

To test whether the factor model was appropriate for the data the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's test of Sphericity were conducted. The KMO was equal to .81, and the Bartlett's test of Sphericity produced an approximate Chi-square of 10032.55, $p < .001$, both suggesting that the sample was factorable.

3 Results

3.1 Factorial Structure

In order to examine the structure of the well-being scale, an exploratory factor analysis was conducted. The analysis revealed 16 factors with an eigenvalue greater than one explaining 71.95% of the variance. The first factor had an initial eigenvalue of 21.93 explaining 29.24% of the variance and the second factor an eigenvalue of 5.81 explaining only 7.75% of the variance. The point of inflexion of the curve in the scree plot could be found between three and seven factors (Figure 2).

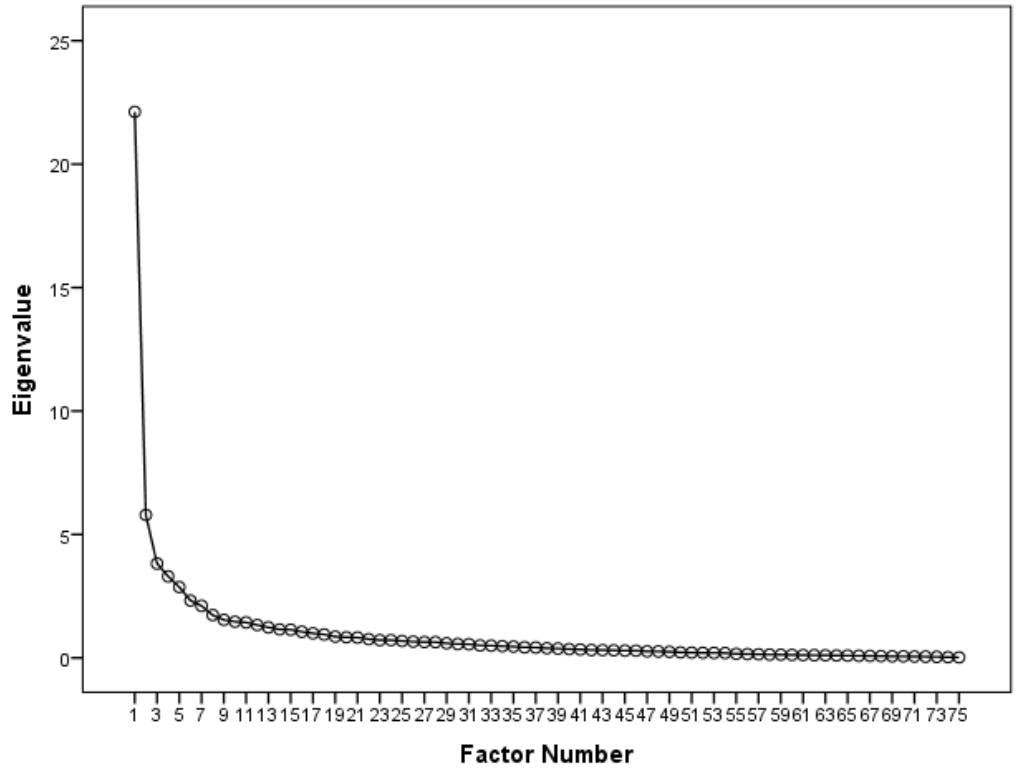

Figure 2. *Scree Plot*

A second exploratory factor analysis with a fixed number of up to 16 factors would have been fitting, but a factor analysis with more than four factors would have led to some of the factors containing only one item. Therefore an exploratory factor analysis with only four factors was conducted. The four factors explained 46.49% of the variance. The first factor had an initial eigenvalue of 21.93 explaining 29.24% of the variance, the second factor an eigenvalue of 5.81

explaining 7.75% of the variance, the third an eigenvalue of 3.82 explaining 5.15% of the variance, and the fourth an eigenvalue of 3.26 explaining 4.35% of the variance.

The distribution of the items over the factors differed extensively from the proposed structuring into “Physical well-being and health”, “Mental well-being”, “Living situation” and “Participation” based on the findings of Acares (Van Beek et al., 2005).

Three of the four factors corresponded mostly with the three dimensions of well-being, namely emotional, psychological, and social well-being (Westerhof & Bohlmeijer, 2010), whereas the fourth factor’s key characteristic was named cognition based on item content (Table 2).

The emotional dimension contained items about positive and negative affect, the psychological dimension items about anxiety, the social items about participation, and the cognitive dimension items about cognitive functioning. The factor loading of each item was >.30 or on the hypothesized factor, except for two items, the item about autonomy at .29 (Item 82) and the item about physical discomfort at .21 (Item 30).

The subscale psychological well-being is likely to have a normal distribution (p=.06). This was not the case for the subscale social well-being (p=.03), for emotional well-being (p=.00) and cognition (p=.00), which showed a departure from normality.

Almost half of the items displayed moderate to strong loadings with multiple factors (45.33%). Some of these items exhibited no distinctive difference in the loading between two factors. The two items about feeling safe in one’s own apartment or department (Item 74 and 75) correlate highly with both emotional and social well-being, as well as the question about feeling good (Item 4) and the question about working to make the stay pleasant. The item about recognizing familiar people (Item 53) and the item about reading a newspaper or watching the news correlated highly with both cognition and social well-being. The high correlation for recognizing familiar people could be explained by the fact that being able to recognize someone plays an important role in social well-being.

Table 2. *Exploratory Factor Analysis with Four-factor Oblimin Rotation on the items of the well-being scale*

Theoretical dimension of quality of life	***Item (How often did you observe … in the last 2 weeks?)***	S	P	E	C
Emotional well-being (E)					
Positive affect	Vertrouwt medewerkers (Item 78)	.40	.31	**-.80**	
Positive affect	Heeft een prettig contact met medewerkers (Item 80)	.61	.27	**-.77**	
Positive affect	Reageert opstandig (Item 13)	.33	.32	**-.76**	.27
Negative affect	Reageert geïrriteerd (Item 14)	.34	.35	**-.75**	.26
Positive affect	Gedraagt zich netjes in gezelschap (Item 36)	.53		**-.71**	.46
Positive affect	Is vriendelijk (Item 6)	.48	.33	**-.71**	
Positive affect	Is rustig en begripvol (niet snel boos) (Item 8)	.46	.31	**-.70**	.30
Negative affect	Is verbaal agressief (Item 9)	.27	.28	**-.68**	
Positive affect	Werkt mee als dat gevraagd wordt (Item 79)	.42		**-.68**	.41
Negative affect	Maakt kwetsende of tactloze opmerkingen (Item 39)		.37	**-.65**	
Negative affect	Is fysiek agressief (Item 10)	.39		**-.65**	.27
Positive affect	is beleefd (bijvoorbeeld: scheldt nooit iemand uit) (Item 38)			**-.63**	.30
Positive affect	Is geduldig (Item 7)	.33	.37	**-.58**	
Negative affect	Is opgewonden en gespannen (Item 22)	.29	.50	**-.57**	.32
Positive affect	Accepteert hulp tijdens de ADL (Item 78)			**-.55**	
Positive affect	Gedraagt zich rustig en ontspannen (Item 19)	.46	.48	**-.54**	.43
Feeling at home	Voelt zich veilig op eigen afdeling (Item 75)	.47	.29	**-.54**	.26
Negative affect	Is ongedurig en onrustig (Item 25)		.47	**-.50**	.44
Negative affect	Beschuldigt anderen onterecht (Item 48)		.44	**-.50**	
Feeling at home	Voelt zich veilig in eigen woning / appartement (Item 74)	.47	.27	**-.49**	.43
Negative affect	Is overtuigd van bepaalde, onrealistische gedachten (Item 51)	.26	.28	**-.45**	.41
Feeling at home	Vindt wonen op de afdeling prettig (Item 71)	.39		**-.43**	
Physical health	Heeft pijn (Item 29)		.26	**-.37**	
Psychological well-being (P)					
Anxiety	Zegt angstig of bang te zijn (Item 17)		**.80**		.25
Anxiety	Lijkt angstig/bang te zijn (Item 18)		**.78**	-.29	.41
Anxiety	Is overstuur (Item 16)		**.75**	-.45	
Anxiety	Is in paniek (Item 15)		**.72**	-.33	.28
Anxiety	Huilt (Item 3)		**.57**		
Anxiety	Schrikt in onverwachte situaties (Item 21)		**.56**	-.42	.31
Physical health	Lijkt zich gezond te voelen (Item 26)	.26	**.43**	-.42	
*Negative affect**	Beweert dat anderen hem/haar niet mogen (Item 44)		**.41**	-.36	
Anxiety	Roept (Item 47)	.28	**.35**	-.30	
Autonomy	Stelt zich - gezien eigen mogelijkheden - té afhankelijk op (Item 82)		**.29**		
Social well-being (S)					
Social integration	Geniet van bezigheden (Item 54)	**.84**	.28	-.30	.32
Social integration	Heeft graag contact met medecliënten (Item 64)	**.79**		-.34	
Social integration	Heeft graag contact met medewerkers (Item 65)	**.74**	.34	-.52	.29
Positive affect*	Lijkt zich te amuseren (Item 63)	**.74**	.34	-.52	.29
Social contribution	Wil graag meedoen met activiteiten (Item 60)	**.73**		-.27	.33
Social integration	Geniet van contacten met anderen (Item 67)	**.73**	.36	-.46	
Social acceptance	Is opgewekt (Item 2)	**.70**		-.42	
Social acceptance	Gaat vriendschappelijk om met anderen (Item 69)	**.70**		-.34	.28
Social acceptance	Is zorgzaam voor medecliënten (Item 68)	**.69**		-.30	.33
Positive affect*	Geniet van dagelijkse dingen (Item 1)	**.68**	.47	-.47	
Social integration	Is geliefd bij medecliënten (Item 70)	**.65**		-.37	.33
Social contribution	Werkt mee aan een prettig verblijf (Item 73)	**.63**		-.62	.30
Positive affect*	(glim)lacht (Item 5)	**.61**	.28	-.48	

Table 2. (continued) *Exploratory Factor Analysis with Four-factor Oblimin Rotation on the items of the well-being scale*

Theoretical dimension	***Item (How often did you observe … in the last 2 weeks?)***	S	P	E	C
Social contribution	Neemt initiatieven voor bezigheden (Item 55)	**.61**			.39
Social integration	Zoekt contact met medewerkers (Item 81)	**.61**		-.35	.31
Social integration	Zegt voldoende hulp te krijgen (Item 28)	**.60**		-.56	.49
Other	Kijkt naar televisie (Item 59)	**.57**			
Positive affect*	Lijkt zich goed te voelen (Item 4)	**.56**	.44	-56	
Other	Leest krant / kijkt journaal (Item 58)	**.56**			.52
Other	Is geïnteresseerd in boeken/tijdschriften (Item 62)	**.55**			.36
Other	Maakt gebruik van beschikbare voorzieningen (bv tuin/keuken) (Item 61)	**.50**			.32
Social contribution	Wil eigen hobby's blijven uitvoeren (Item 56)	**.49**			.35
Other	Luistert naar radio/cd speler (Item 57)	**.48**			.31
Positive affect*	Geniet van eigen woonruimte (Item 72)	**.48**		-.27	.39
Social integration	Heeft graag contact met familieleden (Item 66)	**.42**		-.33	
*Cognitive abilities**	Accepteert eten en/of drinken (Item 27)	**.41**		-.28	
Physical health	Heeft lichamelijke ongemakken (bijvoorbeeld jeuk of obstipatie) (Item 30)	**.21**			
Cognition (C)					
Cognitive abilities	Gebruikt onbegrijpelijke taal (Item 41)	.35		-.34	**.71**
Cognitive abilities	Herkent eigen woning/kamer/appartement (Item 52)	.50			**.65**
Cognitive abilities	Heeft een helder bewustzijn (Item 49)	.48		.41	**.62**
Cognitive abilities	Mompelt, herhaalt zinnen/woorden (Item 40)	.29	.40	.41	**.61**
Cognitive abilities	Hanteert gebruikelijke tafelmanieren (Item 35)	.48		.50	**.61**
Cognitive abilities	Lijkt zich bewust van gevolgen van eigen handelen (Item 43)	.40			**.59**
Cognitive abilities	Loopt, friemelt, wrijft, schommelt of draait (Item 23)		.27		**.56**
Cognitive abilities	Maakt op juiste wijze gebruik van hulpmiddelen (bijvoorbeeld rollator of hoortoestel) (Item 46)	.33			**53**
Cognitive abilities	Maakt op juiste wijze gebruik van toilet (Item 45)	.44			**.51**
Cognitive abilities	Praat snel en veel (Item 24)		.31	.38	**.50**
Cognitive abilities	Herkent bekende anderen (Item 52)	.43			**.44**
Cognitive abilities	Ziet/hoort dingen die anderen niet zien/horen (Item 50)				**.43**
Cognitive abilities	Dwaalt doelloos rond (Item 42)				**.41**
Physical health	Is continent (Item 32)	.33			**.41**
Physical health	Heeft normaal dag- en nachtritme (Item 31)	.31	.29	-.33	**.35**

Bold. Highest factor loading for the item. Loadings under .20 are left blank.
*. Theoretical dimension of emotional, psychological, and social well-being belonging to a different dimension
Italic. Theoretical dimension of emotional, psychological, and social well-being not based on Keyes (2005)

Table 3. *The dimensions of emotional, psychological, social well-being, and cognition based on: Keyes (2005)*

Dimension	Description
Emotional well-being	
Awowed happiness	Feeling happy.
Positive affect	Feeling cheerful, in good spirits, happy, calm, and peaceful, satisfied, and full of life.
Avowed life satisfaction	Feeling satisfied with life in general or specific areas of one's life.
Negative affect	*Not feeling cheerful, in good spirits, happy, calm, and peaceful, satisfied, and full of life.*
Feeling at home	*Feeling safe in and attached to the current living situation.*
Psychological well-being	
Self-acceptance	Holding positive attitudes towards oneself and past life and conceding and accepting varied aspects of self.
Environmental mastery	Exhibiting the capability to manage a complex environment, and the ability to choose or manage and mold environments to one's needs.
Positive relations with others	Having warm, satisfying, trusting personal relationships and being capable of empathy and intimacy.
Personal growth	Showing insight into one's own potential, having a sense of development, and being open to new and challenging experiences.
Autonomy	Exhibiting a self-direction that is often guided by one's own socially accepted and conventional internal standards and resisting unsavory social pressures.
Purpose in life	Holding goals and beliefs that affirm one's sense of direction in life and feeling that life had a purpose and meaning.
Anxiety	*Feeling uneasy and scared.*
Social well-being	
Social contribution	Feeling that one's own life is useful to society and that the output of one's activities is valued by or valuable to others.
Social integration	Having a sense of belonging to a community and deriving comfort and support from that community.
Social actualization	Believing that people, social groups, and society have potential and can evolve or grow positively.
Social acceptance	Having a positive attitude towards others while acknowledging and accepting people's differences and their complexity.
Social coherence	Being interested in society or social life, and feeling that society and culture are intelligible, somewhat logical, predictable, and meaningful.
Cognition	
Cognitive abilities	*Abilities with regard to attention, concentration, orientation, short-term memory, long-term memory, and language.*
Physical health	*Physical impairments and physical health.*
Other	*Miscellaneous*

Italic. Categories based on content of the items

The Pearson correlation-coefficients between the four dimensions were calculated to determine the discriminant validity. The four factors were moderately to strongly interrelated. The highest correlation occurred between social and emotional well-being (r=.64), followed by social well-being and cognition (r=.61), psychological and emotional well-being (r=.58), cognition and emotional well-being (r=.51), cognition and psychological well-being (r=.40), and the lowest between social and psychological well-being (r=.38) (Table 4).

Table 4. *Correlation between the four dimensions (Pearson Correlation)*

Factor	S	P	E	C
Social well-being (S)	1.00			
Psychological well-being (P)	.38*	1.00		
Emotional well-being (E)	.64*	.58*	1.00	
Cognition (C)	.61*	.40*	.59*	1.00

* P<0.01

The Pearson correlation-coefficients of each category with the four found factors emotional, psychological, and social well-being, and cognition were calculated in order to determine the convergent validity. In particular if the category correlated most strongly with their hypothesized factor.

Pearson correlation-coefficients showed that most of the categories correlated most strongly with their supposed dimension (Table 5). Emotional well-being correlated strongly with positive affect (r=.95), negative affect (r=.91) and to a lesser extend with feeling at home (r=.64). Psychological well-being correlated strongly with anxiety (r=.97) and less strongly with autonomy (r=.47). Social well-being correlated strongly with its three found categories social integration (r=.93), social acceptance (r=.86), and social contribution (r=.84). Cognition correlated strongly with cognitive abilities (r=.99), but the category physical health correlated the strongest with psychological well-being (r=.57).

Table 5. *Bivariate of the dimensions of the well-being scale (Pearson Correlation)*

Dimension	Cognition	Emotional well-being	Psychological well-being	Social well-being	Total	n
Emotional well-being						
Positive affect	.62*	**.95***	.54*	.77*	-.39*	16
Negative affect	.48*	**.91***	.61*	.47*	-.29*	9
Feeling at home	.42*	**.64***	.31*	.57*	-.29	3
Psychological well-being						
Autonomy	.09*	.20*	**.47***	.22*	-.14	1
Anxiety	.44*	.54*	**.97***	.36*	-.31*	7
Social well-being						
Social contribution	.51*	.52*	.27*	**.84***	-.35*	4
Social integration	.53*	.61*	.34*	**.93***	-.38*	8
Social acceptance	.46*	.51*	.32*	**.86***	-.30*	3
Cognition						
Cognitive abilities	**.99***	.60*	.38*	.62*	-.23	13
Physical health	.49*	.41*	**.57***	.42*	-.26*	5
Other	.54*	.32*	.13	**.76***	-.18*	5

Big. Highest Correlation; * P<0.01

3.2 Internal Consistency

To examine the internal consistency Cronbach's Alpha was calculated. Cronbach's Alpha was .94 for social well-being, .84 for psychological well-being, .93 for emotional well-being, .88 for cognition, and .96 for the whole scale (Table 6). The high Cronbach's Alpha indicates a high internal consistency. It was not possible to increase Cronbach's Alpha significantly through the deletion of an item, nor was it deemed necessary.

Table 6. *Internal consistency*

Factor	Cronbach's alpha	Spearman-Brown Coefficient	Number of items
Social well-being (S)	.94	.94	28
Psychological well-being (P)	.84	.73	10
Emotional well-being (E)	.93	.90	22
Cognition (C)	.88	.81	15
Total	.96	.85	75

To examine the split-half reliability the Spearman-Brown Coefficient was calculated. The Spearman-Brown Coefficient was .94 for social well-being, .73 for psychological well-being, .90 for emotional well-being, .81 for cognition, and .95 for the whole scale (Table 6) indicating a high internal consistency as well.

A high inter-item correlation (>.70) occurred six times (Table 7) with 10 items affected. These items exhibited nevertheless differences in content validity. The item about physical aggression and

the item about verbal aggression for example had a high inter-item correlation, but they differed with regard to content.

Table 7. *Inter-item correlation*

Item 1	Item 2	Correlation
“Geniet van dagelijkse dingen” (Item 1)	“Is opgewekt” (Item 2)	.74
“Is fysiek agressief” (Item 10)	“Is verbaal agressief” (Item 9)	.74
“Is fysiek agressief” (Item 10)	“Gooit met voorwerpen” (Item 11)	.70
“Maakt met opzet dingen kapot” (Item 12)	“Gooit met voorwerpen” (Item 11)	.78
“Reageert opstandig” (Item 13)	“Reageert geïrriteerd” (Item 14)	.80
“Is overstuur” (Item 16)	“Is in paniek” (Item 15)	.71

4 Discussion

This study set out to evaluate the psychometric qualities of a new well-being scale for patients with dementia. This well-being scale appears to be a reliable and valid instrument with a high practical value. The factorial structure coincides largely with the three dimensions of well-being, emotional, psychological, and social well-being (Westerhof & Bohlmeijer, 2010), but not all sub-dimensions were present. The fourth factor's key characteristic appeared to be cognition. The high internal reliability suggests that the scale can be used to monitor well-being in an individual. The proposed structure "Physical well-being and health", "Mental well-being", "Living situation" and "Participation" based on the findings of Acares (Van Beek et al., 2005) could not be replicated.

The questionnaire contains a high number of items with regard to cognition. These items might have been included, because the awareness of cognitive impairments tends to influence the well-being of patients with dementia (Kitwood & Bredin, 1992). It is important to consider that this instrument measures the observed cognitive functioning and not the awareness of one's own cognitive impairments, because the awareness has a much stronger impact than the impairments themselves (Selai & Trimble, 1999). Cognitive impairments may lead to patients not being able to experience some aspects of life that influence well-being. It might be that this dimension indirectly measures facets of well-being that require a lot of cognitive resources. The cognitive factor is the only factor, which does not fit directly into a model of well-being. Items in this factor measure therefore the progression of dementia rather than the level of well-being. These items should be excluded if the well-being-scale is used for scientific research about well-being, because the cognitive items do not measure well-being although there might be a correlation.

Except for the psychological domain, most items were worded positively focusing on the strength and skills of the person and not on their illness or on their impairments. Most of the items in the psychological domain were related to anxiety, which is a common symptom of dementia (Ballard, Boyle, Bowler, & Lindesay, 1996). Surprisingly, the number of items with regard to depression was very low. Depression has as well a high comorbidity with dementia (Katz, 1997) and a strong impact on the well-being of a patient (Wells et al., 1989). The lack of items measuring symptoms of

depression might be due to the fact that a patient with depression is unobtrusive compared to patient with anxiety.

The first factor in the exploratory factor analysis explained almost four times the variance of the second factor, suggesting an essentially one-dimensional structure. It might therefore be reasonable to use the total score as an indicator for well-being. Results of the factor analysis showed however a reasonably distinctive grouping into the four factors, with a few exceptions. A few items correlate strongly with both emotional and social well-being. The same is true for emotional and psychological well-being, and cognition and social well-being. A multidimensional model might thus also be appropriate.

Emotional well-being correlated strongly with psychological, and social well-being, and cognition. Only a moderate correlation was found between social and psychological well-being and between cognition and psychological well-being. The correlations between the factors were expected to be elevated, because the type of factor analysis was chosen on the basis of an assumed correlation between the factors. The strong to moderate correlations between social, psychological and emotional well-being have also been found in previous research (Lamers, Westerhof, Bohlmeijer, ten Klooster, & Keyes, 2011). Psychological well-being is the factor with the lowest correlations with the other factors. The correlations are still moderate with social well-being and cognition and just as strong with emotional well-being. This might be the case, because the psychological factor contains mostly items measuring anxiety. The two continua-model of mental health states that positive mental health is more than the absence of psychopathology (Westerhof & Bohlmeijer, 2010). The psychological domain however measures mostly the psychopathology and not positive mental health. This is probably due to the specific characteristics of patients with dementia.

These correlations support the hypothesis that well-being is a multidimensional construct with strongly interconnected dimensions. The interconnectedness became also apparent through the many items having multiple factor loadings. There are no strict guidelines on how to deal with items with multiple loadings, especially if the factors are expected to be interconnected. Nevertheless, most studies agree that a distinction between the factors should be preferred (Wegmann, Thompson, &

Bowen, 2011). In the strong cases of multiple loadings a revision or deletion of the items should be considered in order to be able to measure well-being more precisely.

These findings were largely supported by the convergent validity between the categories and their hypothesized dimensions (Table 5). The category positive affect correlates very highly with the dimension emotional well-being, although quite a few items with this label correlate also highly with social well-being. The category feeling at home correlates highly with both emotional and social well-being. This indicates a strong interconnectedness between emotional and social well-being, because there appear to be items measuring both constructs at the same time.

In order to see which categories were used most in each dimension the number of items for each category in each dimension was calculated. The categories, with the highest number of items in their scale, were positive and negative affect in the dimension emotional well-being, anxiety in psychological well-being, social integration in social well-being and cognitive abilities in cognition. More items with regard to the self-dependency of the patient were expected, because the patients are not living on their own anymore. The following categories of well-being based on Keyes (2005) did not appear in the item-pool, social coherence, self-acceptance, environmental mastery, purpose in life, personal growth, social actualization, and avowed life satisfaction. The level of well-being concerning purpose in life and personal growth has been show to decrease substantially with age (Ryff & Keyes, 1995) and with cognitive decline caused by dementia (Wilson et al., 2013).The level of well-being in environmental mastery and autonomy tends to increase with age (Ryff, 1995), but not for patients with dementia (Andrew, Fisk, & Rockwood, 2012). Each of the above-mentioned categories, which did not appear in the item pool, requires an extensive cognitive infrastructure (Wilson et al., 2013). It is therefore expected that including these categories would have led to a lower score of well-being, because patients with cannot attain these aspects of well-being. Most of these abstract constructs are furthermore very difficult measure reliable through observation. Measuring these categories in patients with dementia is thus not crucial, because low scores are expected in all of them.

Some categories were created in addition to those based on Keyes (2005) to classify the items, which did not fit into the existing categories. There was a group of items related to negative affect in the dimension emotional well-being. This might have been the case, because one of the symptoms of

dementia is a higher level of negative affect (Haley, Levine, Brown, Berry, & Hughes, 1987). Negative affect in spite of not being unrelated to positive affect has been shown to have enough variation to be measured independently (Diener, 1994). Additionally items with regard to feeling at home were found in this dimension. Feeling safe in the current living situation is believed to have a strong impact on the well-being of the patient (Ettema et al., 2007). The dimension psychological well-being was expanded with the category anxiety, which plays a major role in most patient's course of the disease (Ballard et al., 2000). One additional factor was found containing items about cognitive abilities. This factor was named cognition. Cognitive abilities are expected to play a role in the well-being of a dementia patient (Whitehouse & Rabins, 1992). Additionally items related to physical health were part of the questionnaire. Physical health has been shown to influence well-being (Whitehouse & Rabins, 1992) and might therefore indirectly measure well-being. The category physical health correlates highly with both psychological well-being and cognition. This category measures physical impairments and limitations in what the person is able to do. Cognition and physical health are interrelated as both tend to decrease with the progression of dementia (Dewey & Saz, 2001). Both categories are therefore measuring the progression of dementia rather than well-being.

The items, which did not fit into any of the categories, deal mostly with reading, watching television and listening to the radio. These items have a high correlation with social well-being. This might be the case, because these activities tend to be executed in the living room in company of others. The items in the added categories might have been necessary to account for the specific influences on well-being for patients with dementia. No category correlates highly with the total score indicating again that well-being is a multidimensional construct.

The items with large floor and ceiling effects should not be used in a psychometric analysis and might not be useful to monitor well-being. Most of these items have nevertheless clinical relevance for example the item regarding the acceptance of medication (Item 77), the item about throwing stuff (Item 11) or the item about destroying things on purpose (Item 12). It might be better if these items were part of a checklist before or after the questionnaire and the results were shown apart from the results of the well-being scale, when the scale is used for monitoring.

A high inter-item correlation occurred six times. This number was not deemed high enough to create a need for a short-form of the well-being scale. For some of the items, which were answered mostly identical, a differentiation could still be important for individual clinical purposes e.g., the item about being physically aggressive (Item 10) and the item about being verbally aggressive (Item 9). These two items were mostly answered similarly, but if they are not it could mean a huge difference for the health care professional. Nevertheless might it be favorable to combine these two items when used in a scientific context.

The option to answer “not possible to observe” was problematic from a psychometric point of view and for the observers, because of the different possible meanings of the answer. It might mean that the patient can’t or won’t execute the behavior, or that the patient wasn’t observed carrying it out. The implications of these meanings are very different. That the patient can’t execute a certain behavior might indicate a lower level of well-being, and that he wasn’t observed executing the behavior might indicate that the patient does it rarely or privately. There is no definition what “not possible to observe” means in the current instruction. It is therefore necessary to add a distinct definition of the answer not possible to observe to the manual.

The current scoring process is done automatically and the output consists of a pie-chart (Appendix 3 Example Output for caregivers). The pie-chart color-codes the questionnaire on item basis. A green chart indicates a high level of well-being and red a low level of well-being. White means not possible to observe. If you click on a red item advice how to improve the corresponding aspect well-being is shown. The structure of well-being used in the scoring process, was chosen for practical reasons. It was already in use for evaluating well-being in the Netherlands and therefore known to most health care professionals. This structure could not be replicated through the exploratory factor analysis. Furthermore, the scoring on an item level comes at the risk, because one falsely negative answer could distort findings by standing out as a red part of the otherwise green pie-chart. The advantage of this scoring method is that it is possible to see on the first view if the results are predominantly positive or negative (green or red). It is nevertheless advised to use average scores per subscale as an output in scientific research, e.g. in the form of a bar chart, to avoid overvaluing individual items.

The idea to directly integrate feedback and advice for improvement in the output is very good, but it would be better if it would appear directly and not only if you click on the corresponding item. The simplified access might lead to a higher adoption rate of the recommendations.

There are some limitations to this study. For one, the study was conducted in only one nursing home with a limited number of participants and the results might therefore not be applicable for generalization. Additionally the well-being scale is limited by its observational nature. It is very difficult to observe the subjective part of well-being and to take into account that everyone judges the importance of factors influencing well-being differently. Some patients might find a category integral for their well-being, while others might not care for the same category. There are some aspects of well-being, which are increasingly difficult to assess in patients with dementia, because of cognitive or physical impairments. Items about these aspects were mostly absent from the item-pool. A possible reason for this is that improvement in these aspects is unlikely and that knowing about these aspects would likely not help the caregivers in improving the current health care.

Although there are some limitations, the findings of this study underline that the well-being scale is a useful and reliable instrument for measuring well-being for patients with dementia. The three main factors of well-being (Keyes, 2005) were present in this instrument with an added fourth factor that appears to be cognition. Cognition had been previously linked with well-being, because some aspects of well-being require vast cognitive resources (Wilson et al., 2013). The content of each factor differed from the content in a normal population as expected, because of the different needs and circumstances of patients with dementia.

A confirmatory factor analysis on the structure of well-being is recommended in order to gain insight if the four factors together measure the construct well-being, or if the three factors without the factor cognition are a better fit. For further validation of the well-being scale a new study should focus on analyzing the correlation with other instruments measuring well-being.

Research into what defines well-being for people with dementia and how cognition and physical health influences well-being becomes exceedingly difficult with the progression of the disease. It is furthermore questionable from a practical standpoint if this scale should focus on these

aspects, because improvements in these types of well-being are unlikely to be accomplished. It might nevertheless be possible to slow down the decline.

In order to be used for scientific research it might be preferable to delete the items in cognitive factor and replace some of the items focused on anxiety with items measuring positive individual functioning. This way the scale would align with current developments in positive psychology. This well-being scale could then be used to compare different nursing homes or treatments.

With regard to the current use of monitoring well-being in the individual patient it might be favorable to keep the questions regarding cognition and psychopathology and even expand the scale with a few questions regarding depressive symptoms. These questions have a high practical value, because they can be directly tied to recommendation on how to improve care in the respective aspect. If for example depressive symptoms in a patient are discovered and the recommendation helps in treating these symptoms, the overall well-being will probably increase.

The creation of the well-being scale is an important step towards making living in a nursing home more pleasant for the patient. Gaining information about which aspects of well-being need improvement and which are already good and distributing this to the caretakers can help them to focus on improving care with regard to the well-being of the patient. Although well-being means something different for each and every one, the well-being scale proves to be a reliable tool for monitoring quality of life.

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Appendix

APPENDIX 1 THE WELL-BEING SCALE

MENTAAL WELBEVINDEN					
Stemming					
1. Geniet van dagelijkse dingen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
2. Is opgewekt	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
3. Huilt	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
4. Lijkt zich goed te voelen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
5. (glim)lacht	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
6. Is vriendelijk	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
7. Is geduldig	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
Agressie					
8. Is rustig en begripvol (niet snel boos)	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
9. Is verbaal agressief	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
10. Is fysiek agressief	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
11. Gooit met voorwerpen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
12. Maakt met opzet dingen kapot	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
13. Reageert opstandig	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
14. Reageert geïrriteerd	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
Angst					
15. Is in paniek	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
16. Is overstuur	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
17. Zegt angstig of bang te zijn	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
18. Lijkt angstig/bang te zijn	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
19. Gedraagt zich rustig en ontspannen					
20. Is bang voor onbekenden	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
21. Schrikt in onverwachte situaties	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
Agitatie					
22. Is opgewonden en gespannen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
23. Loopt, friemelt, wrijft, schommelt of draait	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
24. Praat snel en veel	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
25. Is ongedurig en onrustig	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**

LICHAMELIJK WELBEVINDEN EN GEZONDHEID					
Lichamelijk Welzijn					
26. Lijkt zich gezond te voelen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
27. Accepteert eten en/of drinken	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
28. Zegt voldoende hulp te krijgen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
29. Heeft pijn	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
30. Heeft lichamelijke ongemakken (bijvoorbeeld jeuk of obstipatie)	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
31. Heeft normaal dag- en nachtritme	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
32. Is continent	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
Decorum					
33. Ziet er gewassen en verzorgd uit	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
34. Gebruikt normale seksuele omgangsvormen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
35. Hanteert gebruikelijke tafelmanieren	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
36. Gedraagt zich netjes in gezelschap					
37. Trekt kleding uit op ongewenste plaatsen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
38. Is beleefd (bijvoorbeeld scheldt nooit iemand uit)	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
39. Maakt kwetsende of tactloze opmerkingen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
Verward gedrag					
40. Mompelt, herhaalt zinnen/woorden	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
41. Gebruikt onbegrijpelijke taal	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
42. Dwaalt doelloos rond	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
43. Lijkt zich bewust van gevolgen van eigen handelen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
44. Beweert dat anderen hem/haar niet mogen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
45. Maakt op juiste wijze gebruik van toilet	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
46. Maakt op juiste wijze gebruik van hulpmiddelen (bijvoorbeeld rollator of hoortoestel)	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
47. Roept	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
48. Beschuldigt anderen onterecht	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
49. Heeft een helder bewustzijn	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
50. Ziet/hoort dingen die anderen niet zien/horen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
51. Is overtuigd van bepaalde, onrealistische gedachten	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
52. Herkent eigen woning/kamer/appartement	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
53. Herkent bekende anderen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**

PARTICIPATIE					
Bezigheden					
54. Geniet van bezigheden	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
55. Neemt initiatieven voor bezigheden	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
56. Wil eigen hobby's blijven uitvoeren	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
57. Luistert naar radio/cd speler	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
58. Leest krant / kijkt journaal	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
59. Kijkt naar televisie	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
60. Wil graag meedoen met activiteiten	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
61. Maakt gebruik van beschikbare voorzieningen (bv tuin/keuken)	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
62. Is geïnteresseerd in boeken/tijdschriften	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
63. Lijkt zich te amuseren	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
Sociale contacten					
64. Heeft graag contact met medecliënten	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
65. Heeft graag contact met medewerkers	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
66. Heeft graag contact met familieleden	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
67. Geniet van contacten met anderen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
68. Is zorgzaam voor medecliënten	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
69. Gaat vriendschappelijk om met anderen	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
70. Is geliefd bij medecliënten	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
WOON- EN LEEFOMSTANDIGHEDEN					
Woonomstandigheden					
71. Vindt wonen op de afdeling prettig	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
72. Geniet van eigen woonruimte	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
73. Werkt mee aan een prettig verblijf	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
74. Voelt zich veilig in eigen woning / appartement	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
75. Voelt zich veilig op eigen afdeling	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
Relatie met medewerkers					
76. Accepteert hulp tijden de ADL	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
77. Accepteert medicatie	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
78. Vertrouwt medewerkers	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
79. Werkt mee als dat gevraagd wordt	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
80. Heeft een prettig contact met medewerkers	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
81. Zoekt contact met medewerkers	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**
82. Stelt zich - gezien eigen mogelijkheden - té afhankelijk op	**Altijd**	**Regel-Matig**	**Zelden**	**Nooit**	**Niet kunnen observeren**

APPENDIX 2 GUIDELINES WELL-BEING SCALE

Advies welzijnsmeter participatie

- Sluit aan bij de vroegere voorkeuren en hobby's.
- Overvraag niet.
- Bied zoveel mogelijk gelegenheid om positieve ervaringen op te doen.
- Geef iemand de kans om zoveel mogelijk zelfstandig te doen.
- Zorg voor een goede balans tussen activiteiten en ontspanning.
- Bied regelmatig de gelegenheid aan de cliënt om even, kortdurend contact te hebben.
- Bied reminiscentie- en muziekactiviteiten aan.
- Vermijd zoveel mogelijk veranderingen in het vaste programma.
- Bied iemand in de eindfase van dementie geschikte snoezelactiviteiten en PDL aan.

Advies mbt stemming/ depressie

- Bied veiligheid en bevestiging.
- Zorg voor een rustige en vertrouwde omgeving.
- Leg stap voor stap uit wat je doet. Houd oogcontact en ga na of de cliënt je begrijpt.
- Bied activiteiten aan waarbij geen fouten gemaakt kunnen worden.
- Blijf geduldig en blijf vragen vriendelijk beantwoorden.
- Maak duidelijke afspraken. Geef aan wanneer je komt en wanneer niet.
- Biedt gedoseerd contact aan.
- Wees consequent in je benadering.
- Bekrachtig positief gedrag; geef complimenten.
- Negeer ongewenst gedrag zoveel mogelijk.
- Accepteer ongewenst gedrag als je inschat dat de cliënt zijn gedrag niet kan veranderen.
- Pas het werktempo zo nodig aan.
- Overvraag en 'corrigeer' niet.
- Stimuleer deelname aan activiteiten die de cliënt nog goed kan en leuk vindt.
- Stimuleer sociale contacten.
- Probeer iemand die voor een bepaalde situatie bang is, langzaam aan deze situatie te laten wennen, of pas de situatie aan.
- Bied je hulp aan waar dat nodig is, maar laat iemand altijd zelf doen wat diegene nog zelf kan, ook al gaat er wel eens iets mis.
- Bied zo nodig lichamelijk contact aan.

Advies mbt bezigheden

- Zorg voor een geregelde, overzichtelijke en vaste daginvulling.
- Zoek een goede balans tussen inspanning en ontspanning.
- Ga regelmatig na hoe het activiteitenprogramma van een bewoner eruit ziet. Pas het activiteitenprogramma zo nodig aan.

Angst

- Bied veiligheid en bevestiging.
- Zorg voor een rustige en vertrouwde omgeving.

- Leg stap voor stap uit wat je doet. Houd oogcontact en ga na of de cliënt je begrijpt.
- Bied activiteiten aan waarbij geen fouten gemaakt kunnen worden.
- Blijf geduldig en blijf vragen vriendelijk beantwoorden.
- Maak duidelijke afspraken. Geef aan wanneer je komt en wanneer niet.
- Biedt gedoseerd contact aan.
- Wees consequent in je benadering.
- Bekrachtig positief gedrag; geef complimenten.
- Negeer ongewenst gedrag zoveel mogelijk.
- Accepteer ongewenst gedrag als je inschat dat de cliënt zijn gedrag niet kan veranderen.
- Pas het werktempo zo nodig aan.
- Overvraag en ‘corrigeer’ niet.
- Stimuleer deelname aan activiteiten die de cliënt nog goed kan en leuk vindt.
- Stimuleer sociale contacten.
- Probeer iemand die voor een bepaalde situatie bang is, langzaam aan deze situatie te laten wennen, of pas de situatie aan.
- Bied je hulp aan waar dat nodig is, maar laat iemand altijd zelf doen wat diegene nog zelf kan, ook al gaat er wel eens iets mis.
- Bied zo nodig lichamelijk contact aan.

Prikkelbaarheid

- Ga niet in discussie.
- Word niet boos.
- Geef iemand de tijd om zich voor te bereiden op een verzoek.
- Bied gelegenheid om het na een tijdje ‘opnieuw te doen’.

Agressie voorkomen

- Bied structuur, duidelijkheid, veiligheid en een rustige omgeving aan.
- Zorg voor een rustige dagelijkse routine, waarin ruimte is voor lichaamsbeweging en activiteiten.
- Laat iemand zoveel mogelijk eigen keuzes maken en vraag toestemming.
- Eis niet te veel en bied hulp op een onopvallende manier en zonder aandringen.
- Neem voldoende tijd om duidelijk uit te leggen wat er precies gebeurt. Zelfs als de cliënt je niet begrijpt, kan de kalmerende toont waarop je spreekt iemand geruststellen.
- Probeer situaties waarin je haast hebt zoveel mogelijk te voorkomen. Haast of ongeduld slaan vaak over op de cliënt.
- Spreek je waardering uit als de cliënt iets zelfstandig doet en vraag iemand te helpen met eenvoudige karweitjes.
- Ga niet tegenover, maar naast iemand staan.
- Gebruik weinig gebaren.
- Maak en houd oogcontact.
- Glimlach.
- Voorkom onbegrip door te laten zien wat je wilt. Laat bijvoorbeeld een washandje zien als je wilt dat iemand zich wast.

Omgaan met agressie

- Blijf kalm.

- Houd oogcontact.
- Neem de cliënt serieus.
- Voel je niet persoonlijk aangevallen.
- Let op je lichaamstaal.
- Gebruik korte, eenvoudige zinnen en praat zacht.
- Voorkom dat je in de aanwezigheid van de cliënt over hem of haar praat.
- Probeer de cliënt niet van veraf tot de orde te roepen.
- Reageer niet op dreigementen door ook te gaan dreigen.
- Vraag de cliënt wat hem dwarszit.
- Luister naar klachten.
- Respecteer de persoonlijke ruimte.
- Stel geen eisen die voor de cliënt op dat moment te hoog gegrepen zijn.
- Wees alert op gevaren. Let ook op veiligheid van de cliënt.
- Schaam je niet om hulp in te roepen.
- Laat je niet meeslepen door je eigen emoties.

Agitatie

- Zorg voor een geregelde, overzichtelijke en vaste daginvulling.
- Zoek een goede balans tussen inspanning en ontspanning.
- Ga regelmatig na hoe het activiteitenprogramma van een bewoner eruit ziet. Pas het activiteitenprogramma zo nodig aan.
- Maak een lijst met mogelijke oorzaken van iemands agitatie, onderzoek welke oorzaak het meest waarschijnlijk is en doe daar vervolgens wat aan.

Verstoord dag- en nachtritme

- Bied vaste tijden van opstaan en slapen gaan.
- Laat iemand overdag wel dutten, maar niet slapen.
- Let op hongermomenten in de nacht en de vroege ochtend.
- Bied voldoende gelegenheid voor lichaamsbeweging.
- Zorg voor voldoende (dag)licht en frisse lucht.

Verstoorde toiletgang

- Bied vaste toilettijden.
- Let goed op eventuele signalen.

Afweergedrag bij eten of drinken

- Onderzoek de mogelijkheid van lichamelijke oorzaken.
- Laat iemand zo nodig eten waar hij of zij dat wil.
- Bied eten aan wat iemand lekker vindt.
- Bied op tijd wat anders aan.
- Concentreer je op degene die je helpt en laat je niet afleiden.
- Laat zo nodig een collega in jouw plaats helpen.
- Help iemand even ‘op weg’ als dat nodig is.
- Zorg voor een rustige en overzichtelijke omgeving.
- Bied meerdere momenten aan waarop iemand kan kiezen uit verschillende dingen om te eten.

- Maak kleine groepen om samen te eten.

Ontremming

- Ga niet in op vloek- of scheldgedrag; blijf rustig en professioneel.
- Vat het gedrag niet op als persoonlijk tegen jou gericht maar als een uiting van de dementie.
- Blijf respectvol in je benadering.
- Spreek duidelijk en in korte zinnen.
- Bied duidelijkheid, wees consequent en geef grenzen aan.
- Bekrachtig positief gedrag; geef complimenten.
- Negeer het ongewenst gedrag zoveel mogelijk.
- Bied zinvolle bezigheden die aansluiten bij vroegere interesses.
- Als je inschat dat de cliënt zijn gedrag niet kan veranderen, accepteer dit dan.
- Bied iemand afgepaste porties aan.
- Zet etenswaren uit het zicht en de reikwijdte van de cliënt.

Seksuele ontremming

- Geef rustig en duidelijk aan dat je niet ingaat op de wensen van de cliënt en blijf rustig en professioneel.
- Vat het gedrag niet op als persoonlijk tegen jou gericht maar als een uiting van de dementie.
- Blijf respectvol in je benadering.
- Spreek duidelijk en in korte zinnen.
- Bied duidelijkheid, wees consequent en geef grenzen aan.
- Bekrachtig positief gedrag; geef complimenten.
- Negeer het ongewenst gedrag zoveel mogelijk.
- Als je inschat dat de cliënt zijn gedrag niet kan veranderen, accepteer dit dan.
- Begeleid een cliënt zo nodig naar het eigen appartement.

Rusteloosheid en dwalen

- Zorg voor manieren waarop iemand zich in huis kan oriënteren.
- Maak eventueel gebruik van domotica.
- Voorkom verveling.
- Pas de leefomgeving aan en zorg daarbij voor een stimulerende en afleidende omgeving.

Decorumverlies

- Wees je ervan bewust dat het gedrag niet met opzet wordt uitgevoerd.
- Maak het gedrag bespreekbaar en leg rustig uit dat jij en de mensen in de omgeving het gedrag niet kunnen accepteren.
- Probeer de acceptatie bij de mensen in de omgeving te vergroten.
- Word niet boos. Leid als dat nodig is de dementerende rustig naar een andere ruimte.
- Probeer iemand die boos is, af te leiden.
- Geef zelf een goed voorbeeld.
- Stel je erop in dat iemand zich niet meer kan gedragen zoals het hoort. Verwacht dat ook niet.
- Gebruik humor.

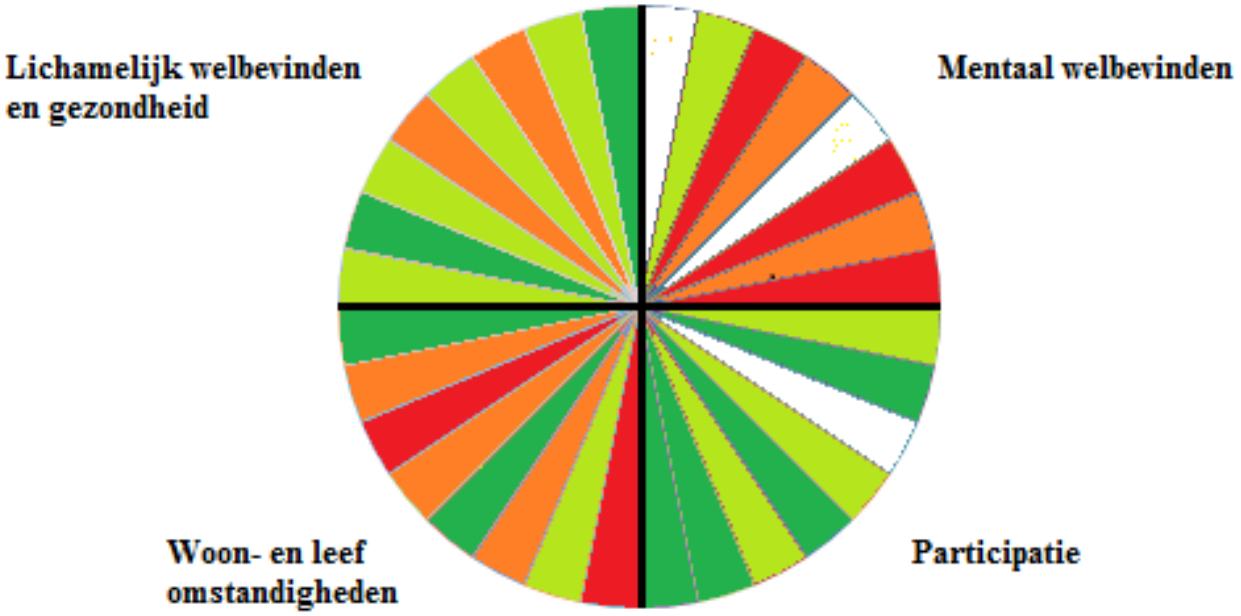
Wanen en hallucinaties

- Schakel zo nodig een arts in.
- Ga niet in discussie over de inhoud van de hallucinaties of wanen. Ga er niet tegen in, maar bevestig het ook niet.
- Vraag wat de bewoner ervaart en toon begrip.
- Richt je op de onderliggende gevoelens (‘Ik zie dat u er bang van wordt’).
- Probeer iemand af te leiden.
- Zorg voor niet te veel veranderingen in de omgeving en in de dagelijkse routine.
- Vat beschuldigingen niet persoonlijk op.
- Bevestig iemand in ideeën die wél kloppen met de werkelijkheid.
- Zorg voor een veilige omgeving met niet teveel omgevingsprikkels.

Apathie

- Sluit aan bij de vroegere voorkeuren en hobby’s.
- Overvraag niet.
- Bied zoveel mogelijk gelegenheid om positieve ervaringen op te doen.
- Geef iemand de kans om zoveel mogelijk zelfstandig te doen.
- Zorg voor een goede balans tussen activiteiten en ontspanning.
- Bied regelmatig de gelegenheid aan de cliënt om even, kortdurend contact te hebben.
- Bied reminiscentie- en muziekactiviteiten aan.
- Vermijd zoveel mogelijk veranderingen in het vaste programma.
- Bied iemand in de eindfase van dementie geschikte snoezelactiviteiten en PDL aan.

APPENDIX 3 EXAMPLE OUTPUT FOR CAREGIVERS



Each piece of the pie chart symbolizes an item. The color coding goes as follows:

Always; often, rarely, Never, not possible to observe (in white)

APPENDIX 4 INSTRUCTION WELL-BEING SCALE

Vul de welzijnsmeter uiterlijk 1 week voor het BZO in voor de bewoners met een 5VV en 7VV.

1. Lees zo nodig de informatie en instructie op het beginscherm.

2. Klik op **'start'**.

3a. Meet je een cliënt voor de 1e keer?
Klik op 'Start meting' en vul de gegevens van de cliënt in.

3b. Is de cliënt al eerder gemeten?
Klik op 'Start meting' en vul de eerste letters van de achternaam in. Je ziet nu een of meerdere suggesties van namen die beginnen met de letters die je hebt ingevuld.
Klik op de naam van de cliënt die je zoekt. Alle overige informatie van die cliënt wordt nu automatisch ingevuld.

4. Klik op **'Gegevens invullen'**.
Vul nu het volgende in:
Je eigen gegevens.
De leefgebieden die je wilt meten.

5. Klik op **'Start nieuwe meting'.**
Klik bij elke uitspraak wat - op basis van jouw observatie(s) - het meest bij de cliënt

past. Als je over de uitspraak geen observatie beschikbaar hebt, klik je op ‘Niet kunnen observeren’ (Let op: bij vragen als ' Luistert naar radio/cd speler' of 'kijkt naar televisie' vul in 'niet kunnen observeren' als de bewoner dit nooit heeft gedaan en er geen veranderingen zijn.)

Met de score geef je het volgende aan:

Altijd =	bijna dagelijks in de observatieperiode.
Regelmatig =	twee tot drie keer per week in de observatieperiode.
Zelden =	één keer in de observatieperiode.
Nooit =	geen enkele keer in de observatieperiode.

Klik op ‘Vorige’ als je een antwoord wilt herstellen.

6. Klik op **‘Bekijk resultaat’** (niet op ‘start nieuwe meting’, want het is nog niet opgeslagen!) als je het resultaat van de meting wilt zien. Je ziet dan een taartfiguur. Hoe groener, des te beter; hoe roder, hoe meer het welzijn onder druk staat.

Beweeg met de muis over de taart. Dan lees je de onderverdeling van de vier leefgebieden.
Wil je tips die je kunt gebruiken om zo goed mogelijk met deze cliënt om te gaan? **Klik op een deel waarvoor je tips wilt.** Je leest dan de tips voor dat bepaalde onderdeel. Je kunt ze toevoegen aan het document.
Klik op ‘Opslaan’ als je het document wilt opslaan. Klik dan op het pijltje naast 'opslaan' dat onderin het scherm verschijnt en sla het bestand op in jullie bestanden.
Voeg de welzijnsmeter toe aan de documenten in het ECD. Dit doe je door naar de juiste bewoner te gaan in het ECD en bovenin de klikken op 'documenten'. Klik vervolgens op 'document toevoegen' en zoek het juiste bestand op door te klikken op 'bladeren'. Sla het op met als omschrijving 'welzijnsmeter en de datum'.