Well-being in gerontopsychiatric nursing home residents

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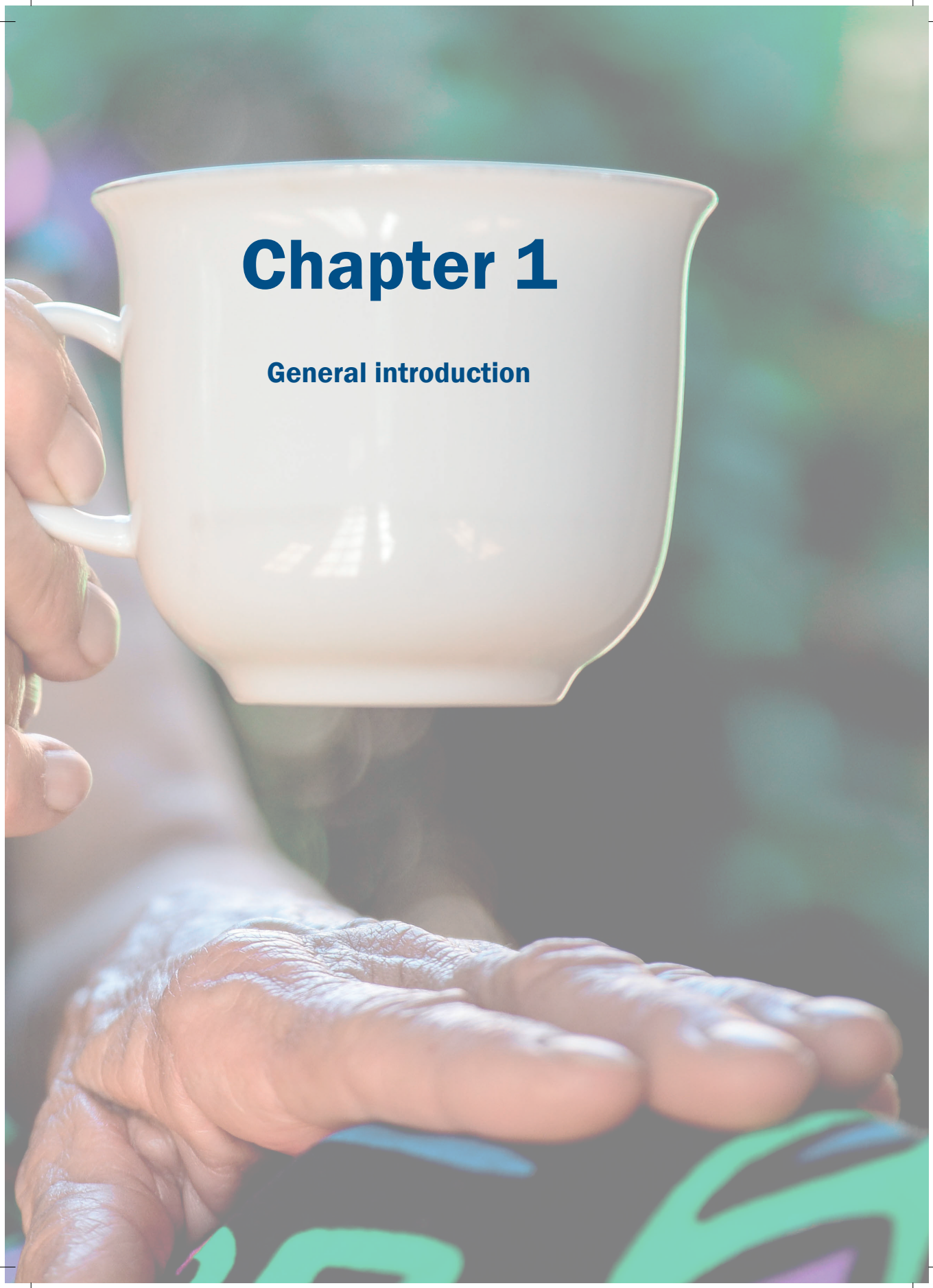

Chapter 1

General introduction

The gerontopsychiatric population

Since the 1970's, mental health care policy has worked toward deinstitutionalization of psychiatric health care services in The Netherlands as well as in other European countries (Trimbos-instituut, 2012). Due to this process of deinstitutionalization, the number of conventional psychiatric inpatient beds has significantly decreased, and many of the older psychiatric patients in need of long term care are now admitted to nursing homes (Bartels, Miles, Dums, & Levine, 2003; Priebe et al., 2008). This gerontopsychiatric population consists of older people with a combination of age-related limitations and serious psychiatric disorders, other than dementia. Due to deinstitutionalization only patients in need of the highest level of care are admitted to nursing homes. A substantial proportion of the nursing home population falls within the gerontopsychiatric category. Gerontopsychiatric patients are found to constitute about 18 percent of the nursing home population in the US (Fullerton, McGuire, Feng, Mor, & Grabowski, 2009), where they generally live in temporary care, or in mainstream nursing homes, alongside residents with dementia (Fullerton et al., 2009; Grabowski, Aschbrenner, Rome, & Bartels, 2010). In The Netherlands this population mostly lives in specialized wards within regular nursing homes, or in specialized psychiatric nursing homes, forming a little over eight percent of the total nursing home population (Stuurgroep Gerontopsychiatrie, 2012).

Recently some studies have been conducted on characteristics of the gerontopsychiatric population. In terms of demographics, gerontopsychiatric residents are often younger, unmarried, with no family representation, and a larger proportion is male when compared to other nursing home residents (Collet, De Vugt, Verhey, Engelen, & Schols, 2018; Van den Brink, Gerritsen, Voshaar, & Koopmans, 2013). When compared to patients with dementia there is a higher incidence of psychiatric and behavioral problems (Collet, De Vugt, Verhey, Engelen, & Schols, 2016; Van den Brink, Gerritsen, De Valk, Voshaar, & Koopmans, 2017; Van den Brink et al., 2013). The gerontopsychiatric population has been shown to be a diverse group when it comes to mental and physical health. They were found to have a median of seven chronic physical conditions, such as diseases of the circulatory system (heart and blood vessels) (78.9%), diseases of the digestive system (66.2%) and endocrine, metabolic or nutritional diseases (58.5%) (Van den Brink et al., 2017). Impairment in cognitive functioning was found to be common among the gerontopsychiatric residents, even if patients with dementia were excluded. Among gerontopsychiatric residents, nearly half of the patients had cognitive impairment (MMSE ≤ 23) and almost 70% had frontal impairment (FAB ≤ 12) (Van den Brink et al., 2017). These findings are in accordance with earlier studies which show that cognitive problems are frequently found among older psychiatric patients without dementia (Friedman et al., 2001).

Well-being

In nursing home care in Western societies, the biomedical model as the predominant model for treatment has been replaced by more person centered care (Brownie & Nancarrow, 2013; Koren, 2010). The Dutch government recently described good nursing home care as care that focuses on the needs of the resident, in all the domains of life that are important for their well-being (Ministerie van VWS, 2018). This also applies to the gerontopsychiatric nursing home population.

There are several definitions of both well-being and quality of life. However, Camfield and Skevington (2008) concluded that based on these definitions, the two concepts can be used interchangeably. This point of view is also adopted in this thesis. Well-being and quality of life are broad and abstract constructs, defined in the literature in many different ways and from many different perspectives. The World Health Organization (WHO) describes quality of life as subjective, multidimensional and with both positive and negative dimensions (WHOQOL Group, 1995). This implies that a person's well-being cannot be objectively established. A well-being score will always be subjectively determined by the person themselves and/or by a close proxy. Since there is no such thing as a 'gold standard' there is no way to determine which subjective opinion comes closest to the true well-being of any individual.

The WHO definition also implies that well-being is multidimensional, and within these dimensions both positive aspects (contentment, role functioning, mobility) and negative aspects (pain, fatigue, dependence on medications) play a role. Since well-being is a very broad and subjective concept, several views have been developed on both the content of the dimensions of well-being and the way in which they are related.

There are models that describe specific goals or needs that are important for a high level of well-being e.g. Maslow's model (Maslow, 1943), that connects well-being to the achievement of universal goals, or the fulfillment of needs. Another model, that breaks these universal models down into smaller, more personal needs is the Social Production Function model (Lindenberg, 1986). In this model (see Figure 1) subjective well-being is regarded as the main goal of human actions, which consists of two universal goals, namely physical and social well-being. These two universal goals can be achieved via more specific goals named 'instrumental goals' as they are both goals and also instruments to achieve the universal goals of well-being. These five instrumental goals are: stimulation, comfort (to achieve physical well-being), status, behavioral confirmation and affection (to achieve social well-being) (Ormel, Lindenberg, Steverink, & Verbrugge, 1999). The SPF model was carefully based on various existing theories of well-being, see Van Bruggen (2001) for an

overview. Dimensions were measured in a questionnaire among a random sample of 1045 participants aged between 18 and 65 years. The structure of universal and first order goals was confirmed in a confirmatory factor analysis (Nieboer, Lindenberg, Boomsma, & Bruggen, 2005). In Figure 1 some examples are given of resources, endowments and activities that can contribute towards achieving the instrumental goals. For the instrumental goal 'affection' for example, 'a good relationship with family members' could be an important source.

Top level	Subjective Well-being				
Universal goals	Physical Well-being		Social Well-being		
First-order instrumental goals	Stimulation/ activation (optimal level of arousal	Comfort (absence of physiological needs; pleasant and safe environment)	Status (control over scarce resources	Behavioral Confirmation (approval for "doing the right things")	Affection (positive inputs from caring others)
Activities and endowments (means of production for instrumental goals) (examples)	Physical and mental activities producing arousal	Absence of pain, fatigue, thirst, hunger, vitality, good housing, appliances, social welfare, security	Occupation, life style, excellence in sports or work	Compliance with external and internal norms	Intimate ties, offering emotional support
Resources (examples	Physical and mental effort	Food, health care, money	Education, social class, unique skills	Social skills, competence	Spouse, empathy, attractiveness

Figure 1. The Social Production Function model, Source: Ormel et al. (1999)

According to the WHO, a well-being model should minimally contain the following three dimensions: physical well-being, social well-being and psychological well-being (WHOQOL Group, 1995). In the described SPF-model, the dimension of psychological well-being is not included. A model that is primarily concerned with the psychological dimension of well-being is Ryff's model of eudaimonic well-being. Ryff and Singer (2000) describe eudaimonic well-being as 'the striving for perfection that represents the realization of one's true potential'. Psychological well-being consists of six elements, according to this theory (Ryff, 1989; Ryff & Singer, 1998): autonomy, personal growth, self-acceptance, life purpose, mastery and positive relatedness. In this thesis the SPF- model was used in an adapted version, with psychological well-being, as derived from Ryff's model, added as a universal goal. The first order instrumental goals to accomplish this universal

goal were self-acceptance, autonomy and purpose in life, based on Ryff's model of eudaimonic well-being. The other three components of well-being were excluded for different reasons. Positive relatedness was thought to be sufficiently addressed in the social well-being domain. Personal growth (or, realizing your potential), was considered to be a difficult component to apply to the situation of the gerontopsychiatric nursing home resident, considering in general that in the later years in life the direction of peoples interest is more retrospective, evaluating and reflecting on life (Andersson, Hallberg, & Edberg, 2008). Evaluation of life, including the extent to which someone's potential has been realized, was seen as a part of the component 'purpose in life', so that personal growth was omitted from the model. Finally autonomy or 'living by your own convictions' was excluded as a separate component, but the subject matter was included in the component of 'environmental mastery'. For a complete picture of the model, see Figure 2.

General well-being							
Physical well-being		Social well-being			Psychological well-being		
Comfort	Stimulation	Affection	Behavioral confirmation	Status	Self-acceptance	Environmental mastery	Purpose in life
Absence of physiological needs, pleasant and safe environment	Optimal level of arousal	Positive inputs from caring others	Approval for doing the right things	Control over scarce resources	Positive attitude toward self, acceptance of good and bad qualities	Ability to create contexts suitable to personal needs and values	Holding beliefs that give life purpose, having aims and objectives for living

Figure 2. Combined SPF model with psychological well-being

Well-being in the gerontopsychiatric population

In their recent study, Diener, Seligman, Choi, and Oishi (2018) confirmed that the characteristics strong social relationships, basic material needs and good physical health were essential, although not sufficient for people to be happy. Also learning something new, and being free to choose how to spend time was associated with higher well-being (Diener et al., 2018). As described in the first part of this introduction, chronic physical conditions are common in the gerontopsychiatric population, limiting the chances of

experiencing a good physical health. Also strong social relationships tend to be harder to maintain when also dealing with a mental disorder (Houtjes et al., 2014; Kalin et al., 2015). Due to these health- and social contact issues that apply to many gerontopsychiatric nursing home residents, achieving a high level of well-being is expected to be particularly difficult in this population.

The expected low level of well-being in the gerontopsychiatric population makes it more urgent to examine the actual level of well-being in this population, and to carry out research aimed at increasing the level of well-being. Research, for example, on how to measure well-being in this population, on the relationship between well-being and other factors and behaviors. Behavioral problems for example are a common problem in gerontopsychiatric nursing home care (Van den Brink et al., 2017). Several behavioral problems have been found to be associated with lower levels of well-being in nursing home residents with dementia (Samus et al., 2005; Ven-Vakhteeva, Bor, Wetzels, Koopmans, & Zuidema, 2013; Winzelberg, Williams, Preisser, Zimmerman, & Sloane, 2005). Increased knowledge of the relationship between behavioral problems and well-being in the gerontopsychiatric population may provide useful information, both to prevent the occurrence of behavioral problems and to increase the level of well-being.

Measuring well-being

A new measurement instrument, why?

To study well-being, it is important to have a valid instrument for the measurement of the construct. There are instruments for the measurement of well-being among nursing home residents with dementia. However, these are not necessarily suitable for use among the gerontopsychiatric nursing home population, as this population differs in several ways from nursing home residents with dementia.

The primary difference relates to the cognitive abilities of both groups. Although there are cognitive disorders in the gerontopsychiatric population, e.g. in decision making and abstract thinking (Alexopoulos, Meyers, Young, & et al., 2000; Fucetola et al., 2000), difficulties with language and memory that are common in people with dementia (Jonker, Verhey, & Slaets, 2010) are not as apparent in the gerontopsychiatric population. The specific limitations in this population on decision making and abstract thinking, and the relatively intact abilities, in terms of language and memory provide potential for a different approach in the development of a measurement instrument when compared to the nursing home population with dementia.

There are also considerable differences in demographic variables between nursing home residents with dementia and gerontopsychiatric nursing home residents, as mentioned in the first paragraphs of this Chapter. Differences in demographics such as age, marital status and care dependency (Van den Brink et al., 2017; Van den Brink et al., 2013) can lead to differences in daily experience of the population. To be able to achieve a clear image of the level of well-being in the gerontopsychiatric population it is vital to use a valid measurement instrument that takes account of the specific context and daily experience of this population, and also for the cognitive limitations of the gerontopsychiatric population. Instruments that are complex, or contain items that are irrelevant for the participant might lead to low response rates (Luzny & Ivanova, 2009).

Sources of information in the measurement of well-being

Although the resident is the primary source to provide information on a concept as subjective as well-being, in the gerontopsychiatric population there is a relatively large proportion of people unwilling or unable to participate in an interview or questionnaire (Depla, De Graaf, & Heeren, 2005; Smalbrugge et al., 2006). It is therefore important to have a secondary source to measure well-being, not only by the resident themselves, but also using an observant, preferably someone who is well acquainted with the resident, and spends much time in close proximity to the resident (Huang, Chang, Tang, Chiu, & Weng, 2009). The availability of a proxy measure has the additional advantage that it creates the possibility of measuring well-being from different points of view, using different resources. According to Sloane et al. (2005), in the absence of a gold standard, a combination of results from different viewpoints could provide the most complete picture of well-being.

One of the aims of this thesis is to develop instruments for the measurement of well-being in the gerontopsychiatric population, based on a combination of the Social Production Function model and Ryff's model of eudaimonic well-being, as shown in Figure 2. The instruments are aimed to be complementary, measuring well-being from different sources, firstly from the residents perspective (Chapter 3) and secondly from the perspective of the first responsible nurse (Chapter 4).

Psychiatric and behavioral problems and well-being

When validated instruments for the measurement of well-being are available for the gerontopsychiatric population, the possibility arises to investigate which forms of behavior, or which personal and environmental factors are related to differences in the level of well-being in this population. Enhanced knowledge into these factors may provide more opportunities for evidence based policy to improve well-being.

There are many forms of behavior that influence, or are influenced by the level of well-being. Some forms of behavior, such as doing physical exercise (Penedo & Dahn, 2005), gardening (Rappe, 2005), and interacting with friends (Lee & Ishii-Kuntz, 1987), are positively associated with well-being. In this way, there are also forms of behavior, that are negatively related to well-being. Apathy for example, as a symptom of schizophrenia, was found to be negatively related to well-being (Strauss, Sandt, Catalano, & Allen, 2012).

As mentioned before, psychiatric and behavioral problems among the residents are quite common in the gerontopsychiatric nursing home. Behavioral problems are forms of behavior that have negative impact on the person who performs the behaviors and/or for the people around them, usually co-residents and care-employees when it comes to the gerontopsychiatric resident. It was found that these behaviors can have substantial effects on well-being and the health of care employees (Evers, Tomic, & Brouwers, 2001; Testad, Mikkelsen, Ballard, & Aarsland, 2010), and on the costs of care (Neubauer, Holle, Menn, Grossfeld-Schmitz, & Graesel, 2008).

Especially in settings like the nursing home, were people live in close proximity to people that they did not choose, one can imagine that behavioral problems are likely to be relatively highly prevalent. In a group of 142 gerontopsychiatric nursing home residents, it was found that 85.1% had exhibited one or more agitated behaviors in the last two weeks (Van den Brink et al., 2017). Examples of psychiatric and behavioral problems that are common in gerontopsychiatric nursing homes are irritability, complaining, negativism and constant requests for attention (Van den Brink et al., 2017). The relation between psychiatric and behavioral problems and the level of well-being has been established in the population of nursing home residents with dementia (Samus et al., 2005; Ven-Vakhteeva et al., 2013; Winzelberg et al., 2005), but has to the best of our knowledge not been studied in the gerontopsychiatric population.

Examining the relation between well-being and psychiatric and behavioral problems is highly relevant to better understand the different forms of behavior, and provide directions on how to treat or prevent the occurrence of these behaviors, and to increase well-being among the gerontopsychiatric residents more effectively. Therefore the aim of this thesis is to discuss the relation between well-being and psychiatric and behavioral problems within this specific population.

Outline of this thesis

The main aim of this thesis is to increase insight into well-being in the care for gerontopsychiatric nursing home residents. The ability to measure well-being and also providing increased knowledge on well-being and its related factors can provide essential and practical tools for the increase of well-being in the gerontopsychiatric population. This can make it more feasible for care institutions to include well-being as a primary goal of care.

In Chapter 2 of this dissertation, the current state of research on well-being in this population is summarized and discussed, in a systematic review. The research question in this Chapter is: what is currently known about well-being in the gerontopsychiatric nursing home population, and about factors relating to well-being?

In the Chapters 3 and 4, the development of the Laurens Well-being Inventory for Gerontopsychiatry (LWIG) and the Laurens Well-being Observations for Gerontopsychiatry (LWOG) is described. Both are instruments for the measurement of well-being among gerontopsychiatric nursing home residents, in the form of a structured interview. The aim of Chapter 3 is to develop a measurement instrument for the measurement of well-being, as experienced by the gerontopsychiatric nursing home resident themselves. Chapter 4, aims to develop a complementary measurement instrument, measuring well-being of the gerontopsychiatric nursing home residents as observed by their primary responsible nurse. The development of the questionnaires including the generation of an item pool is described in these studies and also the statistical method for the validation of the instruments among 297 gerontopsychiatric nursing home residents and their primary responsible care-givers.

Chapter 4, describes the relation between well-being and psychiatric and behavioral problems in the gerontopsychiatric nursing home population. Both instruments developed in Chapters 3 and 4 are used to measure well-being. The research question in this Chapter is: is there a relation between the level of self-rated or observed well-being and the occurrence and frequency of psychiatric and behavioral problems in the gerontopsychiatric nursing home population?

Finally Chapter 5 summarizes and discusses the main findings of our studies. Also implications and directions for future research are presented in this final Chapter.

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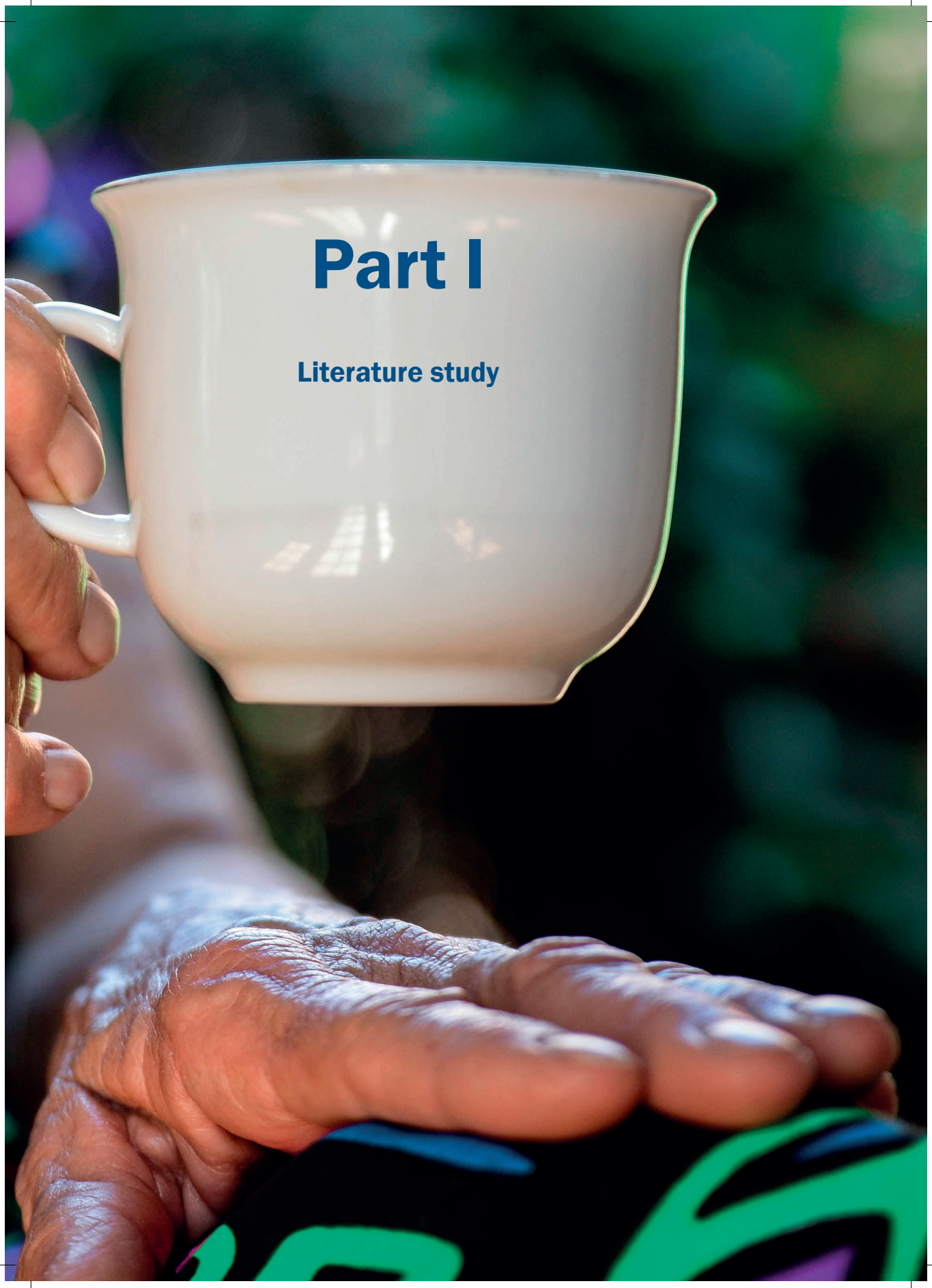
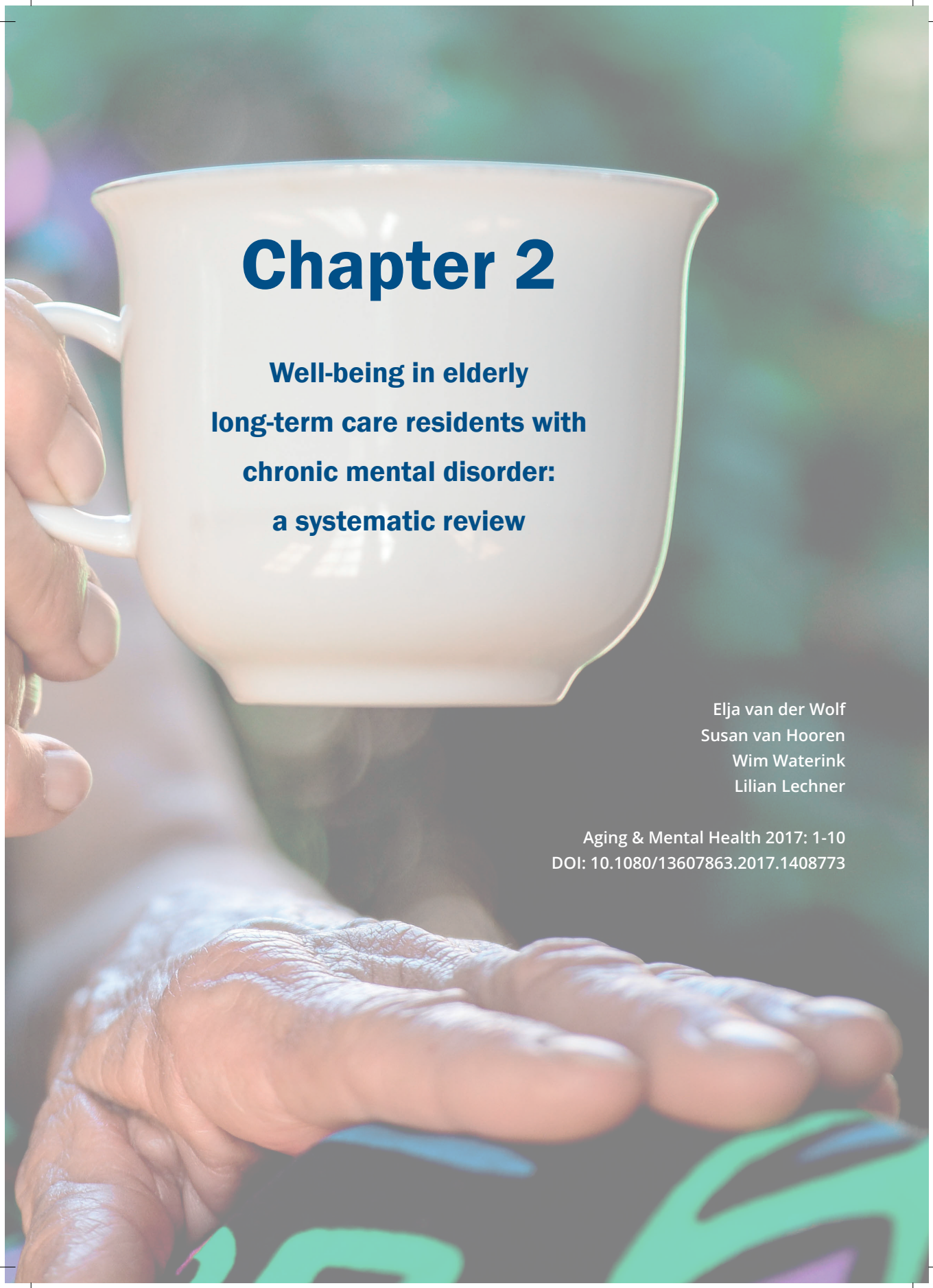


Part I

Literature study



Chapter 2

Well-being in elderly long-term care residents with chronic mental disorder: a systematic review

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Abstract

Objectives: One of the most important objectives of care for older long-term care residents with chronic mental disorders is to facilitate well-being. This review provides an overview of research literature on well-being in this population.

Method: A systematic review was conducted using Pubmed, PsycINFO and PsycARTICLES for all studies up until March 2016. Three reviewers independently assessed the eligibility of the publications and made a selection.

Results: From a total of 720 unique search results, ten studies were deemed eligible. Specialized care, specifically the presence of mental health-workers was associated with increased well-being outcomes. Perceived amount of personal freedom was also related to higher well-being, whereas stigmatization and depression were related to reduced well-being. Residence size, single or group-accommodation or moving to another location did not, however, seem to have an impact on well-being.

Conclusions: Specialized care, aimed at psychiatric disorders and extra attention for depressed residents are useful tools to promote well-being. Additionally, themes like personal freedom and stigmatization should be taken into consideration in the care for older long-term care residents with chronic mental disorder. However, as very little research has been conducted on this topic, conclusions should be interpreted with caution. More research is highly desirable.

Introduction

Long-term care (LTC) facilities are confronted with an increased number of clients with very complex care demands (Hamers, 2011). This is due to both the ageing population and the trend in Western society to keep older people in their own home for as long as possible (Geller, Guzdfski, & Lauterbach, 2008). Older people with chronic mental disorders are among those in need of complex care, since they require a combination of psychiatric and medical support. This group, also referred to as gerontopsychiatric patients (Luzny & Ivanova, 2009; Ponte, Almeida, & Fernandes, 2014) consists of patients of (functional) old age with age-related limitations, and serious psychiatric disorders other than dementia. In this respect they differ from psychogeriatric nursing home residents, for whom dementia is the main reason for nursing home care.

The prevalence of psychiatric disorders is relatively high among LTC residents. In their systematic review Seitz, Purandare, and Conn (2010) found that major depressive disorder occurs worldwide in 5% to 25% (with a median of 10%) of older LTC residents. In another review prevalence of anxiety disorders in nursing homes varied from 3,2% to 20,0% (Creighton, Davison, & Kissane, 2016). Data on other psychiatric disorders among the elderly is scarce and inconclusive, however, according to the National Nursing Home Survey of 2004 there is a 3,6% prevalence of schizophrenia and a 1,5% prevalence of bipolar disorders in USA nursing homes (Seitz et al., 2010).

Attainment and maintenance of well-being or quality of life is one of the most important aims in the care for elderly LTC residents, and thus for the institutionalized gerontopsychiatric population. This is increasingly recognized, both by institutions and by the authorities in Western society, where the biomedical model used to be the predominant model for treatment. Medical care for elderly LTC residents is now more and more focused on enhancing well-being (Brownie & Nancarrow, 2013; Hamers, 2011; Koren, 2010).

If well-being is considered to be one of the main concerns in care, it is important to understand what it is, and how it can be achieved. Well-being is a broad and abstract construct (Diener, Suh, Lucas, & Smith, 1999). In this review, well-being is regarded as a positive judgment or feelings concerning one's life (Dolan, Peasgood, & White, 2008). This definition is deliberately broad and thus allows for literature from different theoretical perspectives.

The level of well-being is often considered to be dependent on the availability of certain determinants or resources (Dodge, Daly, Huyton, & Sanders, 2012; Dolan et al., 2008; Hobfoll, 2002; Ormel, Lindenberg, Steverink, & Verbrugge, 1999). Pinquart and

Sörensen (2000) concluded in their meta-analysis on well-being among the elderly, that socioeconomic status (the result of income and employment status) is related to well-being, as is the existence of high-quality social ties. Self-perceived health, functional status (Cummings, 2002) and marital status (Bilgili & Arpacı, 2014) are also found to be related to life satisfaction or well-being.

Gerontopsychiatric LTC residents tend to fall behind when it comes to the aforementioned determinants. In general, their health is poor. Furthermore, Van den Brink, Gerritsen, Voshaar, and Koopmans (2013) have found that these residents are more often unmarried, younger, and have a higher incidence of problem behavior and cognitive impairment than other LTC residents. These characteristics (plus the psychiatric disorder itself) make gerontopsychiatric LTC residents vulnerable to diminished well-being.

An overview of the knowledge on this subject could help care facilities to pay greater attention to well-being in the gerontopsychiatric population, and to highlight the most effective approaches to promote well-being. However, currently the literature on the relationship between different determinants and well-being in this group is scarce, and difficult to find, due to many differences in terminology. Additionally, for the different types of care setting there is tremendous variation in used terms and forms. This systematic review aims to present an overview of all determinants or resources that are found to be related to the level of well-being in gerontopsychiatric LTC residents. In this way it can offer directions for further research, and provide care institutions with a knowledgebase on how to improve well-being in this population.

Method

Search strategy

The systematic literature search was conducted in three databases: PsycINFO, PsycARTICLES and Pubmed. Articles on the well-being or the quality of life of gerontopsychiatric LTC residents, published in the period up to March 2016 were searched. Titles and abstracts were scanned for the following words: ("well-being" OR "quality of life" OR wellbeing), (psychiatr* OR schizophren* OR "mental health" OR "mental disorder" OR "mental illness" OR bipolar OR depress* OR psychot* OR psychos* OR anxiety OR autism* OR schizoaffect* OR geropsychiatr* OR gerontopsychiatr* OR "double care demanding"), (elderly OR ageing OR aging OR old* OR geriatr* OR aged OR senior), (inpatient* OR "nursing home" OR intramural OR nursery OR "residential care" OR "long-term care" OR facilit* OR "elder care home*" OR "residential home*" OR hospital*). Articles with the

following words in title and/or abstract were excluded: cancer, parent*, HIV, MS, HRQOL, dement*, alzheimer*. Exclusion words were based on irrelevant themes that occurred frequently in the search results. This resulted in 1008 hits. Duplicates were removed, which left a total of 720 articles.

Literature selection

Three authors (EvdW, SvH, and WW) independently screened the titles and abstracts of the remaining 720 articles which were subsequently filtered under the following criteria: subjects were diagnosed with psychiatric disorders (excluding primary diagnoses of dementia or mental retardation), subjects were LTC residents, they were aged 40 and older, well-being or quality of life was measured, studies reported original research data and the full text was written in English or Dutch. Disagreement on selection, which occurred in 72 of the 720 cases, was resolved by discussion until consensus was reached. A total of 584, references were rejected, based on the title and abstract. The main reasons for rejection were: measures of quality of life or well-being were not included (*N* = 62), the research population did not consist of gerontopsychiatric care residents (*N* = 439), or the article was an editorial, review or in another way not-original research (*N* = 83). For the remaining 136 articles, 124 full texts were retrieved (12 full texts could not be obtained due to unavailability in the databases, and unavailable or outdated contact information on the authors, or no response after several attempts to contact). The first Author (EvdW) read the 124 available articles in full, rescreened the abstracts from the 12 unfound articles and made a subsequent selection based on the criteria mentioned above. Two co-authors (SvH and WW) read a random sample of 40 full-texts and made an independent selection. After primary disagreement in 6 out of 40 cases, full consensus was reached after discussion. The 128 studies that did not meet one or more of the inclusion criteria were rejected. Reasons for exclusion were as follows: participants did not live in residential setting, they were younger than 40 years of age, did not have a diagnosed psychiatric disorder, or well-being was not, or only partly measured (e.g. only health-related well-being). A total of eight articles were retained, and selected using this procedure.

A second route in the search strategy was taken by checking reference-lists in all included articles and in relevant reviews that came up from the first search. References that seemed to meet the aforementioned criteria were located and screened by the first author. Reference lists of four of the articles were additionally screened by the two co-authors (SvH and WW). Again, a consensus was reached. This second route resulted in sourcing two additional relevant articles. A total of 10 articles were included in the review. See Figure 1 for a flowchart of the selection-process.

Methodological quality

The methodological quality of the included studies was appraised using two checklists. The first checklist is a guideline by the CBO, a former Dutch institute for health care improvement as published in Collet, De Vugt, Verhey, and Schols (2010), which was used to evaluate the only experimental study in this review (Cooper & Pearce, 1996). All other included studies were not experimental and were thus evaluated using another checklist compiled by Van der Windt, Zeegers, Kemper, Assendelft, and Scholten (2000). Outcomes of the checklists are found in Table 1 and Table 2.

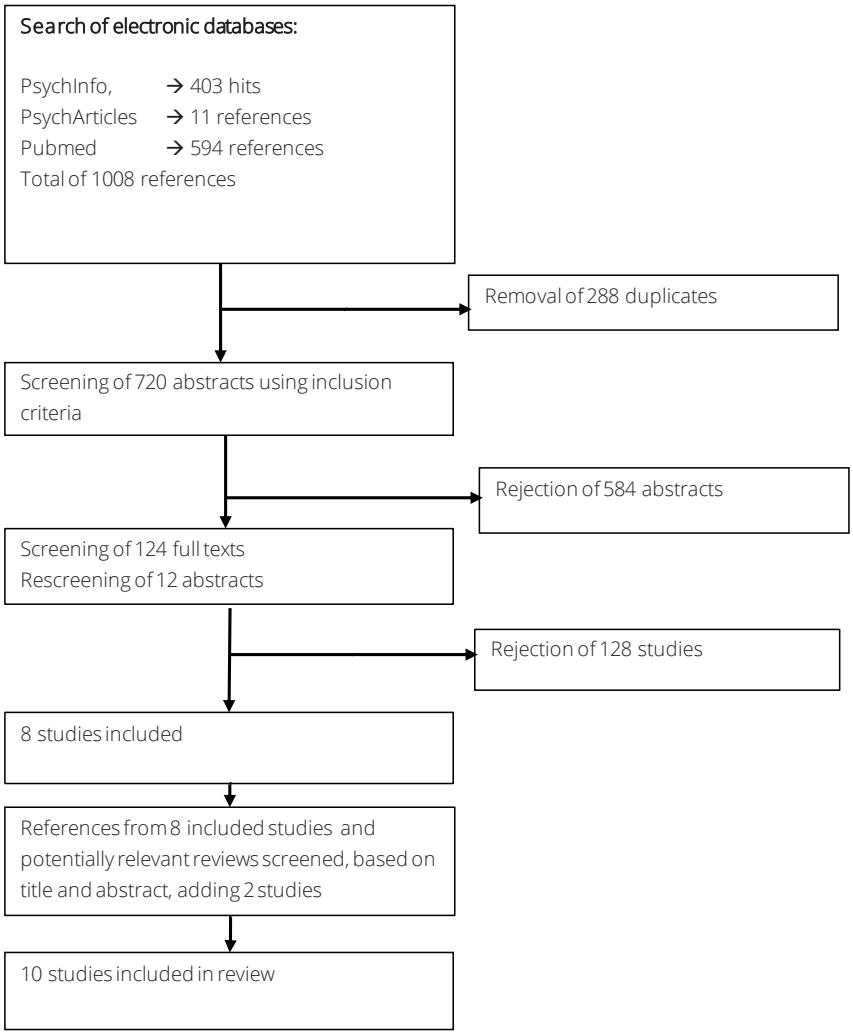

Figure 1. Flowchart showing the selection process

Results

A total of 10 studies were selected for this review (Cooper & Pearce, 1996; Davison, McCabe, Knight, & Mellor, 2012; Depla, De Graaf, & Heeren, 2005; Depla, De Graaf, & Heeren, 2006; Depla, De Graaf, Van Weeghel, & Heeren, 2005; Kallert, Leisse, & Winiecki, 2007; Leisse & Kallert, 2000; Luzny & Ivanova, 2009; Nakagawa & Hayashi, 2013; Smalbrugge et al., 2006). Eight of these studies were cross-sectional studies, and two were longitudinal studies (Table 3).

Participants

All studies included participants with psychiatric diagnoses. Some studies investigated groups with specific diagnoses, such as major depressive disorder (Davison et al., 2012), depression and/or anxiety (Smalbrugge et al., 2006) or psychotic disorders (Kallert et al., 2007; Leisse & Kallert, 2000; Nakagawa & Hayashi, 2013). Other studies included people with a variety of diagnoses (Cooper & Pearce, 1996; Depla, De Graaf, & Heeren, 2005; Depla et al., 2006; Depla, De Graaf, Van Weeghel, et al., 2005; Luzny & Ivanova, 2009). Mean ages varied from 58.5 years to 83.0 years. In more general care settings, mean ages tended to be higher (71.5 – 83.0) than in psychiatric care settings (58.5 – 76.4). In all studies except one, both men and women were included. In six studies women were in the majority, and in three studies relatively more men participated (Cooper & Pearce, 1996; Kallert et al., 2007; Leisse & Kallert, 2000). Nakagawa and Hayashi (2013) solely included female participants.

Settings

Participants lived in a variety of LTC settings. A majority of the studies involved participants living in a general nursing home (Cooper & Pearce, 1996; Davison et al., 2012; Smalbrugge et al., 2006) or in general nursing homes with additional mental health care services, provided by the local psychiatric hospital (Depla, De Graaf, & Heeren, 2005; Depla et al., 2006; Depla, De Graaf, Van Weeghel, et al., 2005). One study involved participants from lower level general care facilities, like assisted living facilities (Davison et al., 2012). In other studies participants from psychiatric nursing homes, or nursing home areas of psychiatric facilities were involved (Kallert et al., 2007; Leisse & Kallert, 2000; Luzny & Ivanova, 2009). Furthermore, some of the studies included participants living in psychiatric hospitals, long-stay-wards of psychiatric centers or other institutions aimed primarily at psychiatric care (Depla, De Graaf, & Heeren, 2005; Depla, De Graaf, Van Weeghel, et al., 2005; Kallert et al., 2007; Leisse & Kallert, 2000; Nakagawa & Hayashi, 2013). In most studies, the participants were recruited from several types of settings. There were some studies that also included participants who lived in other settings, e.g. at home with family, or in a sheltered community residence. These studies were included, but only results relating to the target population (i.e. LTC residents in residential facilities) were investigated in this review.

Table 1. Methodological Quality of Observational Studies

Observational studies	Selection criteria	Response rate> 70%	Validity and reliability of determinants
Davison et al, 2012	0,5	?	1
Depla, De Graaf and Heeren, 2005	1	0	1
Depla, De Graaf, Weeghel and Heeren, 2005	1	?	0,5
Depla et al 2006	1	0	0,5
Kallert et al 2007	0,5	1	0,5
Leisse and Kallert, 2000	0,5	1	0,5
Nakagawa et al 2013	0,5	?	1
Smalbrugge et al 2006	0,5	0	0,5
Luzny and Ivanova, 2009	0,5	0	0,5

1: Yes; 0,5: Partly; 0: No; ?: Unknown

Table 2. Methodological Quality of Experimental Studies

Experimental study	Randomized	Allocation concealed	Comparable baseline characteristics
Cooper and Pearce, 1996	yes	no	yes

	Independence of knowledge about outcome	Validity and reliability of outcomes	Independence of knowledge about determinants?	Adjustment for confounders	Number of participants	Total
	0	1	0	1	0,5	4
	?	1	?	1	1	5
	?	1	?	1	1	4,5
	?	1	?	1	0,5	4
	?	0,5	?	0,5	0,5	3,5
	?	0,5	?	0	1	3,5
	?	1	?	0	0,5	3
	?	1	?	0,5	1	3,5
	0	1	0	0	0,5	2,5

	Blinded providers/ participants	Blinded outcome assessors	Attrition rate reported	Intention to treat analysis	Validation of tools	Total
	no	no	no	no	yes	3

Measurement instruments

All studies applied one or more measurement instruments to assess quality of life or well-being. A total of eight different instruments were used, three of which were adaptations, based on the same original instrument. Firstly, Davison et al. (2012) used a 42-item version of the Ryff multidimensional measure of psychological well-being. This measure is based on the eudaimonic view on well-being and focuses on the relation with self, others and the surroundings. Then, the Philadelphia Geriatric Centre Morale Scale (PGCMS) was applied by Depla, De Graaf, and Heeren (2005); Depla et al. (2006); Smalbrugge et al. (2006). This 17-item instrument placing mood more centrally, is constructed for older people living in institutions. The third instrument that was used was the WHOQOL-BREF, the abbreviated 26-item version of the WHOQOL-100 (Luzny & Ivanova, 2009). This generic questionnaire is developed in the context of four domains: physical, psychological, social and environment (Skevington, Lotfy, O'Connell, & Group, 2004). Fourthly, the Comprehensive Quality of Life Scale (ComQol) was applied by Cooper and Pearce (1996), a 35-item measure of subjective quality of life. Nakagawa and Hayashi (2013) used two different instruments for the measurement of well-being. For objective well-being, the 21-item Quality of Life Scale (QLS) (Heinrichs, Hanlon, & Carpenter, 1984) was used, a disease specific, clinician-rated measure for people with schizophrenia. For the measurement of subjective well-being, an adapted version of the Lancashire Quality of Life Profile (LQoLP) was used, based on Lehman's Quality of Life Profile (Lehman, 1983). This instrument is adjusted and also used in two other versions: the Manchester Short Assessment of Quality of Life (MANSA) (Depla, De Graaf, & Heeren, 2005; Depla et al., 2006; Depla, De Graaf, Van Weeghel, et al., 2005) and the Berlin quality of life profile (Kallert et al., 2007; Leisse & Kallert, 2000). The original LQoLP is developed for chronic psychiatric patients. It includes subjective evaluations of satisfaction on nine life domains: living situation, family, social relationships, leisure activities, work/education, finances, personal safety, health and religion. Beside the subjective evaluations, this instrument includes objective life conditions, and a global well-being measure as part of the measurement instrument (Oliver, Huxley, Priebe, & Kaiser, 1997; van Nieuwenhuizen, Schene, Koeter, & Huxley, 2001). In the versions that were used in the included articles some adaptations were made in the domains. The religion and work domains were omitted in most versions, while the MANSA included both sex-life and fellow-residents as domains. Table 3 provides an overview of all measurement instruments in the included articles.

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Reported outcomes

Type of residence and characteristics of care

The different aspects of residence and characteristics of care were a factor that received considerable attention. Group- versus single living was studied by comparing well-being scores of participants who spent a major part of the day in a communal living room, with those of participants who spend the day in their own flat, located throughout a care facility (Depla et al., 2006). No differences in well-being were found in either psychotic or non-psychotic participants.

The relation between perceived amount of personal freedom and well-being was dependent on several factors (Depla, De Graaf, & Heeren, 2005). For the non-psychotic subgroup there was a positive relation between perceived amount of personal freedom and well-being for some of the PGCMS subscales, but only the relation with one PGCMS-subscale (aggression) remained significant when adjusted for patient characteristics. There was a positive relation with MANSA, the other well-being instrument, but only when adjusted for housing characteristics. For the psychotic subgroup there was no relation with well-being when adjusted for housing or patient characteristics.

The relationship between duration of hospitalization and well-being resulted in conflicting outcomes among 66 women with schizophrenia. Duration was negatively related to objective well-being, measured with the QLS, and positively related to subjective well-being, measured with the LQLP (Nakagawa & Hayashi, 2013). In the same group, Nakagawa and Hayashi (2013) found that the number of admissions to psychiatric hospitals was positively related to subjective well-being, but not to objective well-being.

No adverse effect was found for moving to a new location (Cooper & Pearce, 1996). Fifty-four residents of a large psychiatric hospital, who either moved to smaller scale nursing homes or to supported residential services (a lower level care institution) and a small control-group of 18 non-movers were investigated. After relocation, the supported residential services-group scored higher on both well-being indexes, compared to the nursing home group and the non-movers. There was no difference in well-being between the nursing home group and the non-movers (Cooper & Pearce, 1996). However, these results should be interpreted with caution, since at baseline the supported residential services-group reported higher material well-being. Also, the method of measuring well-being in the supported residential services (self-rating) differed from the method that was used in the nursing homes (by proxy).

Table 3. Characteristics of Included Studies

Study	Design	Participants	Methodo-logical quality	Setting
Davison et al, 2012	Cross-sectional	Country: Australia *N* = 50 Diagnosis: MDD Mean age: 83 (*SD* = 7,2)	4	Four high-level care facilities (nursing homes), 12 low-level care facilities
Depla, De Graaf and Heeren, 2005	Cross-sectional	Country: The Netherlands *N* = 96 (RH) *N* = 78 (HC) Diagnosis: mental disorders, other than dementia Mean age: 76 (= 6)	4	Residential homes operating a supported living programme for at least one year. And Hospital care
Depla, De Graaf, Weeghel and Heeren, 2005	Cross-sectional	Country: The Netherlands *N* = 66 (RH) *N* = 65 (HC) Diagnosis: Axis-1 disorders other than dementia Mean age: 74 (*SD* = 5,9)	3,5	Residential homes operating a supported living programme for at least one year. And Hospital care
Depla et al, 2006	Cross-sectional	Country: The Netherlands *N* = 73 Diagnosis: psychotic and non-psychotic axis-1 disorders, other than dementia Mean age: 75/76	3,5	Residential homes operating a supported living programme for at least one year.
Kallert et al, 2007	Longi-tudinal	Country: Germany *N* = 43 Diagnosis: Chronic schizophrenic patients Mean age: unknown	3	Nursing home area of psychiatric hospital

	Instruments	Factors	Outcomes
	(parts of) Ryff multidimensional measure of psychological well-being	Diagnosis	Both diagnosed MDD and Self rated depression are related to three subscales of well-being: autonomy, environmental mastery and purpose in life.
	PGCMS and MANSA	Type of Setting	On most subscales, patients in psychiatric hospitals showed higher well-being than patients in residential homes.
	MANSA	Stigma Social network and Social activities	In all subgroups (psychotic/non-psychotic; Hospital/ residential home) stigma was associated with lower well-being. Larger social network size was associated with higher well-being in the total sample and in the non-psychotic –hospital subgroup. Social activities were not related to well-being. Only for the psychotic residential home sample there was a negative relation.
	PGCMS and MANSA	Type of Setting MHW-staff availability Perceived amount of personal freedom	There was no relation between group-living and single living for both subgroups (psychotic and non-psychotic). MHW-staff availability was related to decreased agitation (subscale) but only for psychotic participants Perceived amount of freedom was related to decreased agitation for non-psychotic participants.
	Structured QoL interview based on Berlin QoL Profile. Items on 8 subjects + 1 general life satisfaction item	Type of setting	Over a two-year period patients in nursing homes showed significant deterioration in QoL and life satisfaction. This effect remained after adjusting for age and gender.

Table 3. Continued

Study	Design	Participants	Methodo-logical quality	Setting
Leisse and Kallert, 2000	Cross-sectional	Country: Germany *N* = 50 Diagnosis: Chronic schizophrenic patients Mean age: 58,5 (*SD* = 10,4)	2,5	Nursing home area of psychiatric hospital
Nakagawa et al 2013	Cross-sectional	Country: Japan *N* = 66 Diagnosis: schizophrenia Mean age: 68,0 (*SD* = 8,0)	2,5	Longstay wards of large psychiatric centre
Smalbrugge et al 2006	Cross-sectional	Country: The Netherlands *N* = 350 Diagnosis: anxiety and/or depression Mean age: 79,3, (*SD* = 8,3)	3,5	Nursing homes
Luzny and Ivanova, 2009	Cross-sectional	Country: Czech Republic *N* = 297 Diagnosis: several psychiatric conditions Mean age: 73,8 (*SD* = 6,5) residents aged >65.	2	Two psychiatric hospitals in Czech republic

	Instruments	Factors	Outcomes
	Structured QoL interview based on Berlin QoL Profile. Items on eight subjects and one general life satisfaction item	Type of setting	No significant results
	Quality of Life scale, and the Lancashire QoL profile	Observed vs. self-rated QoL. Demographics: Age, age of onset, age first admission, education, duration and frequency of admissions and neuroleptic daily dose Positive and negative symptoms of Schizophrenia (PANSS) Daily life activities (REHAB)	No significant relation between observed and self-rated QoL Observed QoL (or subscales) correlated with age (neg), education (pos), duration of current hospitalization (neg) and age of onset (pos) Also with PANSS subscales: anergia (neg), activation(neg) and lack of judgement/insight. And with alle REHAB subscales (neg) Self-rated QoL correlated with duration of hospitalization (pos), number of admissions (pos) and (PANSS) depression (neg)
	PGCMS	Diagnosis Perceived social support	Patients with depression or combined depression and anxiety had significantly lower well-being than patients with pure anxiety, or no disorder at all. Perceived social support was associated with significantly higher well-being. Gender, age, education level, having a partner, density of urbanization, MMSE score and amount of physical illnesses were not significantly related to well-being.
	WHO-QoL BREF	Diagnosis	No significant differences in WB between gerontpsychiatric- and somatic residents. Qualitative findings: There were complaints about loneliness, lack of social contacts, suffering because of the disease and being hospitalized. Furthermore worries about the future (where to live, health etc.) were mentioned.

Table 3. Continued

Study	Design	Participants	Methodo-logical quality	Setting
Cooper and Pearce, 1996	Longi-tudinal	Country: Australia *N* = 54 Diagnosis: Several psychiatric conditions median Age: 72 range: 42-90	3	Living in a PG-hospital, moving to - Supported resident services - Nursing homes in community - Or staying in PG hospital (control group)

A final aspect with regard to living situation is the difference between general care locations and residences that specifically provide psychiatric care. A higher well-being score was found among residents of a psychiatric hospital, compared to a matched group of residents receiving general care, who lived in residential homes that followed a 'supported living program' (Depla, De Graaf, & Heeren, 2005). Depla and her colleagues explored some of the possible explanations for this result. One possible explanation is the difference in availability of mental health workers (MHW-staff). It was found that for participants with a psychotic disorder the availability of MHW-staff was negatively related to agitation, one of the subscales of the PGCMS. No differences were found however, for residents with non-psychotic Axis I disorders (Depla et al., 2006). Another potential explanation for this difference would be stigmatization in the general health care settings. Depla, De Graaf, Van Weeghel, et al. (2005) found a negative relation between stigmatization and well-being, a relation that remained significant when controlling for several confounders (i.e. age, gender, cognitive impairment, mastery, ADL assistance needs, behavioral problems, network size and social activities). There was no difference however, in the amount of reported stigmatization between the general care settings and the psychiatric hospital.

Diagnosis

The relationship between type or characteristics of diagnoses and well-being was investigated by Davison et al. (2012), Smalbrugge et al. (2006), Luzny and Ivanova (2009) and Nakagawa and Hayashi (2013).

Both Davison et al. (2012) and Smalbrugge et al. (2006) found a negative relation between depression and well-being. Davison et al. (2012) compared depressed elderly (*N* = 50) to a matched non-depressive control-group (*N* = 50). When confounders (duration of residence, health and disability variables) were controlled for, there was still a negative relation between depression and three subscales of well-being: environmental mastery,

	Instruments	Factors	Outcomes
	Comprehensive quality of life scale (ComQol)	Type of setting Short term effect of relocation	Patients that moved to SRS showed significantly greater improvement on the emotional well-being domain (happiness) than patients who moved to a nursing home. No other significant differences.

autonomy and purpose in life. Smalbrugge and his colleagues (2006) compared patients with depression, patients with anxiety, patients with both, and patients without depression or anxiety. These groups were different in size, varying from *N* = 16 (patients with anxiety) to *N* = 243 (patients without depression or anxiety). They found that participants with combined depression and anxiety or pure depression experienced lower well-being than participants with pure anxiety or no depression/ anxiety.

No differences were found in well-being among psychiatric and somatic nursing home inhabitants (Luzny & Ivanova, 2009). In this study, participants from two separate institutions with different approaches (holistic vs. conventional) were compared. Confounders were not accounted for. The response-rate was low (26,3% for the somatic nursing home, and 23,4% in the psychiatric hospital).

In a study including chronic schizophrenic women, some symptoms of schizophrenia, measured with the Positive And Negative Symptoms of Schizophrenia (PANSS), correlated negatively with well-being. Anergia was negatively related with objective wellbeing (QLS-total score), and two other PANSS subscales were related to subjective well-being (LQLP): depression (negatively) and paranoid/belligerence (positively) (Nakagawa & Hayashi, 2013).

Social activities and network

Involvement in social activities such as shopping, exercise class or going on visits was positively related to well-being (Depla, De Graaf, Van Weeghel, et al., 2005). This relationship was however, no longer significant when adjusted for confounders (i.e. gender, age, cognitive impairment, mastery, ADL assistance needs, behavioral problems, social network size and stigmatization). After adjustment, there was even a negative relation between activity and well-being, for the subgroup of psychotic residents in a general care home.

In the same study by Depla, De Graaf, Van Weeghel, et al. (2005) network size was studied, which was measured by the number of people with whom respondents maintained regular and meaningful contacts. Both in the crude and in the adjusted regression analysis, a positive relation was found between network size and well-being.

Other factors
Nakagawa and Hayashi (2013) investigated the relationship between various other factors and the level of well-being. Only the strongest correlations are mentioned here. A negative correlation was found between current age and objective well-being measured with the Quality of Life Scale (QLS). This was not the case for subjective well-being, which was measured with the Lancashire Quality of Life Profile (LQLP). The relation between well-being and daily life activities, measured with the Rehabilitation Evaluation Hall and Baker (REHAB) was also studied, using multiple stepwise regression. Only a negative relation between the REHAB subscale 'community skills' and objective well-being (QLS) was found (Nakagawa & Hayashi, 2013).

Discussion

The aim of this review is to provide an overview of aspects that are linked to well-being among older, psychiatric long-term care patients. Primarily it is notable that only a few studies have been conducted on well-being in gerontopsychiatry. Considering that well-being is one of the main healthcare outcomes, a mere ten studies on this topic is a disappointingly small number. Roughly one study per subject was readily available and the population tested in these studies was heterogeneous in the type of residences, psychiatric disorders and the definitions of well-being that were being tested. This limits the possibilities of general conclusions.

The studies that were included suggest that specialist care aimed at psychiatric disabilities and the availability of mental health workers are positively related to well-being (Depla, De Graaf, & Heeren, 2005; Depla et al., 2006). Depression (Davison et al., 2012; Smalbrugge et al., 2006), and also some symptoms of schizophrenia (Nakagawa & Hayashi, 2013) appear to be negatively related to the level of well-being. Stigmatization perceived by the residents is linked to lower well-being, whereas larger social network size, and (perceived) personal freedom are related to a higher sense of well-being (Depla et al., 2006).

Strengths and limitations
Although a systematic and broad literature search was performed in this review, it always remains possible that articles were overlooked. Also, negative results are not always published, and may therefore be omitted.

Various diagnostic groups were examined. These groups may differ in their characteristics and outcomes, however, due to the small number of studies it is not feasible to discuss diagnostic groups separately. For the measurement of well-being, as many as eight different instruments were used within ten studies, using not entirely similar theoretical constructs of well-being. Also, in some cases when one instrument was used, more methods were applied to measure differences in well-being between two groups within one study (i.e. via interviews or with proxy measurements) (Cooper & Pearce, 1996). Comparability of results on these measures is therefore limited.

When it comes to methodological quality, a general problem in research with this population is the response rate. When data collection is performed through interviews with residents, response rates tend to be low. Due to refusal, cognitive impairment or severity of mental or physical health problems, reported response rates in the included articles vary between 23,4% and 59%. Only Leisse and Kallert (2000) reported they had included all schizophrenic inpatients in a specific nursing home. It remains unclear what approach was used for this high response rate. Due to the relatively low response rate of most studies, the results may have been biased, since it is probable that the non-responders differed in some respects. They may have been more cognitively impaired, have a higher level of anxiety or they may have been more paranoid, or low in socially desirable behavior.

Another methodological problem is the fact that in four of the included studies the possible influence of confounding factors was overlooked (Cooper & Pearce, 1996; Leisse & Kallert, 2000; Luzny & Ivanova, 2009; Nakagawa & Hayashi, 2013). In the studies by Depla et al., it was shown that confounders such as age, gender and marital status can have a substantial influence on the results. These two methodological issues, the low response rates in the included studies, and the disregard of confounders in some studies, compromise generalizability of the results.

Eight out of ten studies were cross sectional, which means that the direction of the relations that were found remain unclear. This applies strongly to depression for example, where not only the relation may be reciprocal, but in addition it might be argued that depression is part of well-being. Feelings of depression are considered to be an element of well-being in the WHOQOL among others.

Finally, it is clear that not all factors that could potentially influence well-being in the gerontopsychiatric population are investigated. Conclusions in this review are limited to the topics studied so far, which may be an arbitrary selection of the possible noteworthy factors.

A strength in this study is the diversity of countries and continents where the included studies were conducted. Most articles were from Europe: The Netherlands, Germany and Czech Republic, but studies were also performed in Australia and Japan. No studies from the US were found on well-being in gerontopsychiatric LTC residents. A possible explanation is the fact that gerontopsychiatric residents in the US generally live in mainstream nursing homes, among cognitively disabled residents (Grabowski, Aschbrenner, Rome, & Bartels, 2010). They may not be seen as a distinct group and therefore not be investigated separately. Also the stronger emphasis on temporary care in US nursing homes (Fullerton, McGuire, Feng, Mor, & Grabowski, 2009) may be a reason for the absence of studies, since the focus of this study is on long-term care.

Implications and recommendations for care facilities

Due to the small number of studies on well-being for gerontopsychiatry, implications are few, and should be stated with some caution. However, it seems that settings with specialized mental health care meet the needs of gerontopsychiatric LTC residents better than general care settings, and are the preferred setting for this population.

Stigmatization, the feeling of being treated differently, or in a negative way because of a psychiatric disorder is negatively related to well-being. A social environment that is accepting of psychiatric disability is therefore recommended for this population.

Special attention is needed for depressed elderly in LTC settings. Depression appears to be strongly related to well-being, stronger than other mental disorders such as anxiety. Treatment of depression should therefore be a priority in care for gerontopsychiatric LTC residents.

Lastly, the perceived amount of personal freedom, as well as the size of social networks appear to be positively related to the level of well-being. Exercise of personal freedom within the boundaries of responsible care should be encouraged by care workers. In addition, assistance in the maintenance or growth of social networks, might promote well-being in the gerontopsychiatric population.

Recommendations for further research

The first recommendation regarding future research on well-being in gerontopsychiatric LTC-residents would be to develop and validate an instrument specifically for the measurement of well-being in this population. This would improve comparability and might prevent drop out, caused by cognitive demands that are too high. Also, to better address the problem of low response-rate, the development of a specialized by proxy instrument is recommended, of which the outcomes are related as closely as possible to a self-rated well-being scale.

More research on the relation between determinants and the level of well-being in gerontopsychiatric LTC residents, is highly desirable. Replication of the existing studies could allow for firmer conclusions to be drawn on the topics described in this study.

Determinants that have already been found to be related to well-being among the elderly or among psychiatric inpatients might also be an interesting focus for further research. Examples of such determinants are functional status (Cummings, 2002), quality of the relationship with health care staff (Custers, Westerhof, Kuin, & Riksen-Walraven, 2010), pain (Jakobsson, Hallberg, & Westergren, 2004), psychiatric diagnosis and severity of the disorder (Picardi et al., 2006), and behavioral disturbance (Banerjee et al., 2006). Special focus should be placed on themes like pain or the relationship with health care staff, since these are subjects that might be influenced by treatment or training, and may therefore be good starting points to explore ways in which well-being can be improved in this population.

Furthermore, well-designed experimental- and longitudinal research is recommended, to investigate the direction of the relationship between different topics and well-being, and the effects of treatment or improvement regarding these topics on well-being.

To conclude, this study shows that although the group of older LTC residents with chronic mental disorders is substantial and still growing, and although well-being is one of the main aims of care for this population, there is very limited evidence based knowledge on this theme. The evidence that is available suggests that an accepting and non-stigmatizing environment with specialist psychiatric care, one that encourages autonomy and provides effective treatment for depression, would result in higher well-being. For good quality of care, more knowledge on well-being and potential related factors is essential.

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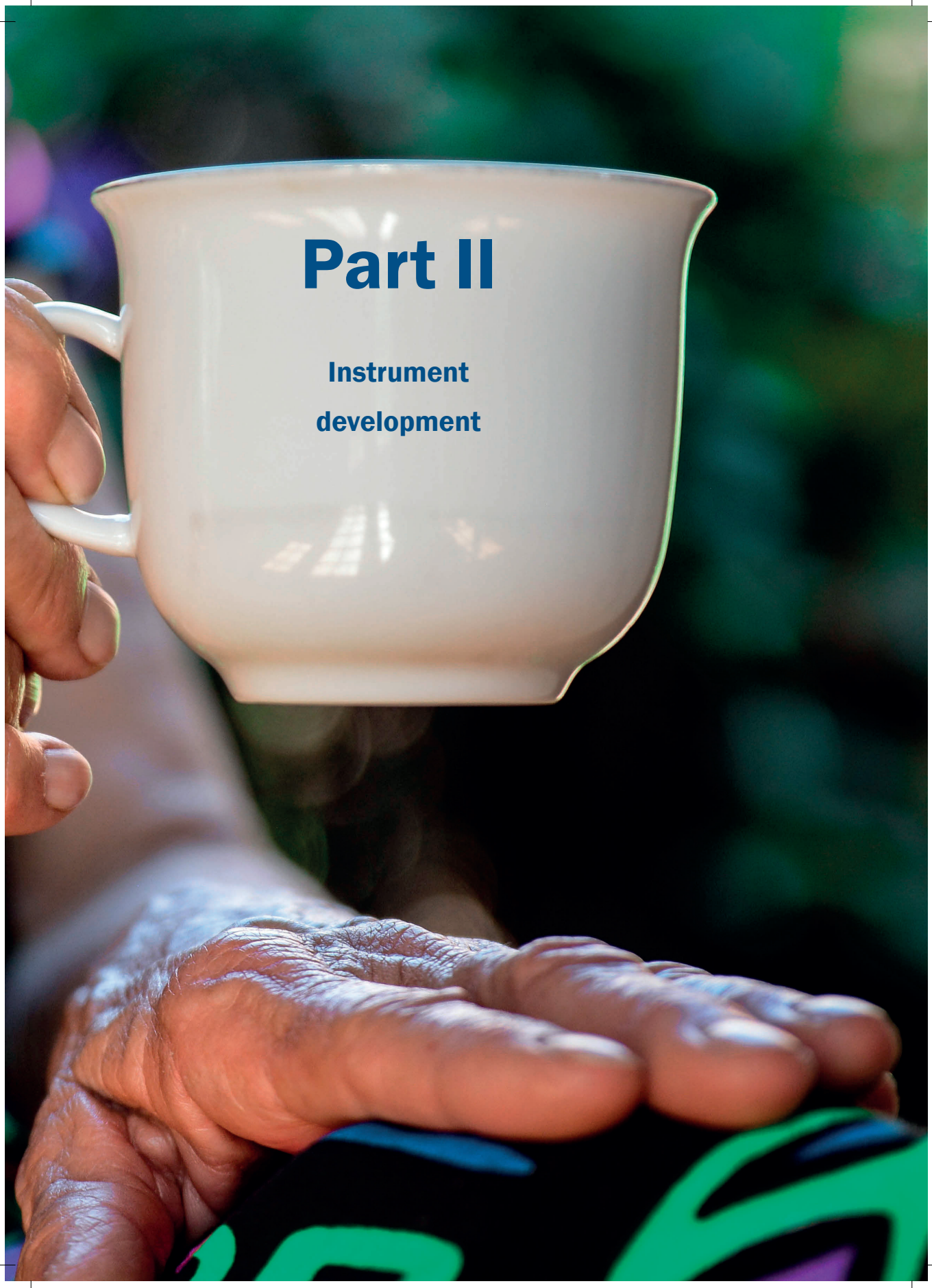
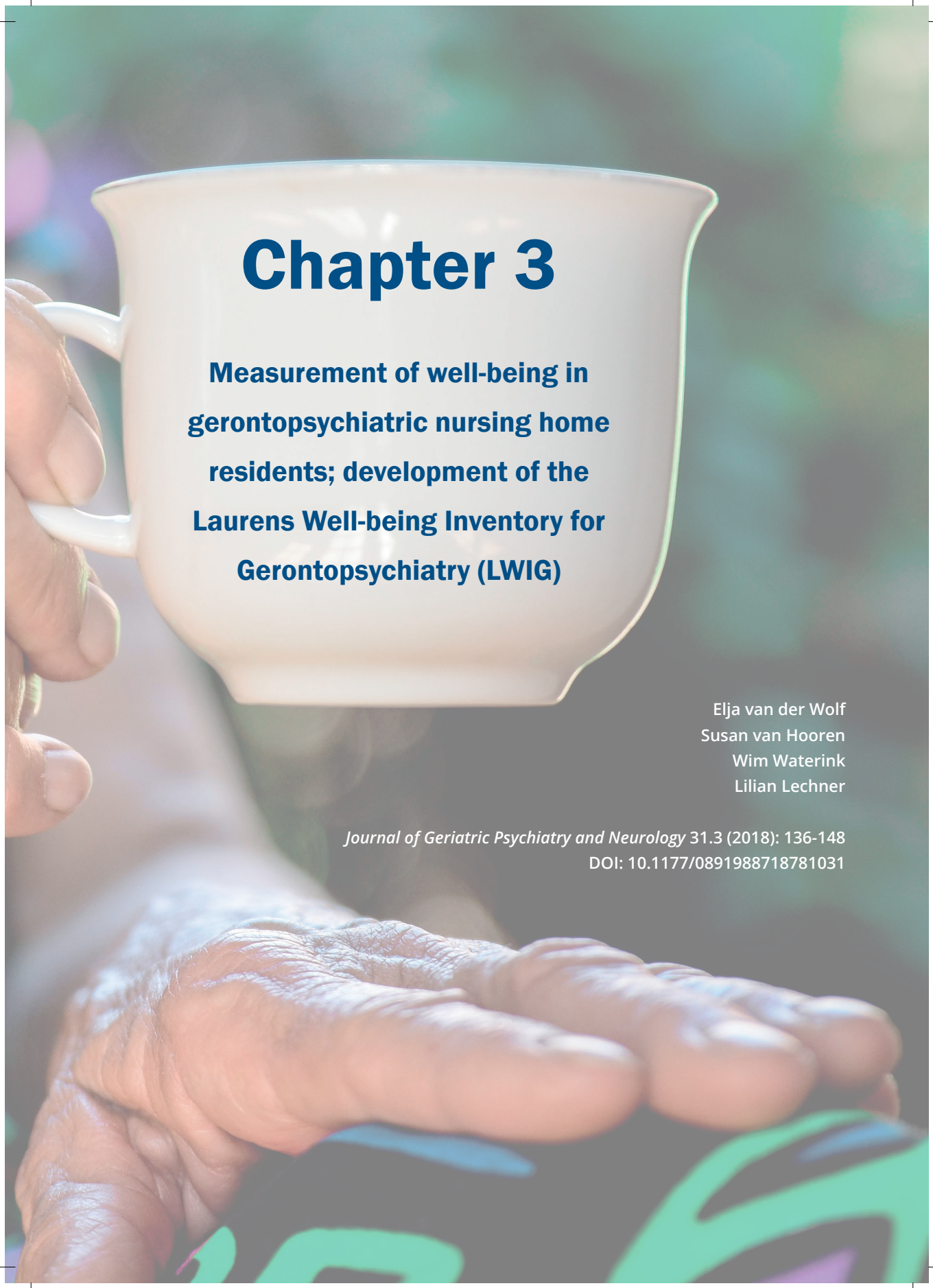


Part II

Instrument development



Chapter 3

Measurement of well-being in gerontopsychiatric nursing home residents; development of the Laurens Well-being Inventory for Gerontopsychiatry (LWIG)

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Abstract

Objectives: The gerontopsychiatric population consists of nursing home residents with combined psychiatric and physical disabilities. A validated measure to assess well-being among this populations is currently not available. This paper is a first step towards the development of a well-being instrument for the gerontopsychiatric population.

Method: Potential measurement items were gathered and selected with the help of both gerontopsychiatric residents and care professionals. In a cross-sectional design, a total of 295 residents and their primary professional caregiver were interviewed. Theoretical and data-driven considerations were applied in the methodological process of scale construction.

Results: The final instrument comprised of 30 items within three dimensions of well-being (physical, social and psychological well-being). Reliability and validity were found to be adequate for all dimensions and subscales.

Conclusion: The LWIG measures well-being in gerontopsychiatric nursing home residents. The first results regarding reliability and validity are promising. More research is needed, especially to examine test-retest reliability and responsiveness to change.

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Introduction

As the aging process progresses, and health, physical functioning, and the number of social contacts may start to decline, retaining a sense of well-being can increasingly become a goal in its own right. In the care for older people this has been recognized and over the years well-being or quality of life has become one of the main outcomes in elderly health care, and thus a topic of considerable research (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007; Brownie & Nancarrow, 2013; Hamers, 2011; Jing, Willis, & Feng, 2016; Windle, Hughes, Linck, Russell, & Woods, 2010). There is, however, a substantial, and growing group of gerontopsychiatric nursing home residents that have as yet not been so thoroughly studied. This group is characterized by one or more chronic psychiatric conditions (not dementia), often combined with one or more medical conditions. In a recent systematic review, it was found that, despite the widely recognized importance of well-being in elderly-care, only 10 studies on the subject of well-being or quality of life for this specific population were available (Van der Wolf, Van Hooren, Waterink, & Lechner, 2017). In the 10 studies on well-being in the gerontopsychiatric population, a total of eight different instruments for the measurement of well-being were used, none of which were validated for the gerontopsychiatric population.

The gerontopsychiatric nursing home population is a heterogeneous group, characterized by both chronic psychiatric problems and a high prevalence of physical disorders (Van den Brink, Gerritsen, Voshaar, & Koopmans, 2013; Woo, Daly, Allen, Jeste, & Sewell, 2003). Due to deinstitutionalization only the most disabled patients live in a nursing home, where they are dependent on care for the activities of their daily life (Collet, De Vugt, Verhey, Engelen, & Schols, 2016). The everyday experiences of this population are influenced by the fact that they live in a residential facility, alongside other psychiatric patients. Despite their relatively young age, the nursing home will likely be their final place of residence, consequently, many gerontopsychiatric patients live in a nursing home for many years (Van den Brink et al., 2013). Also, in some cases a lifetime of dealing with psychiatric illness increases the risk of social isolation or a limited social network (Elisha, Castle, & Hocking, 2006). A relatively large number of residents are divorced, or have never been married (Van den Brink et al., 2013). Since psychiatric, physical disorders (Saharinen et al., 2010) and low functional status (Cummings, 2002) among the elderly are negatively associated with well-being, and both high quality social ties (Pinquart & Sörensen, 2000) and marital status (Bilgili & Arpacı, 2014) are found to be positively associated with well-being, this population is especially susceptible for low well-being. In addition, living in a nursing home may impact on quality of life in a psychiatric population (Kallert, Leisse, & Winiecki, 2007). These vulnerabilities make the study of well-being in this population significant.

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It is well documented in the field of gerontopsychiatry that well-being is of major importance, emphasizing the need for developing a well-being instrument that is validated for this specific population. To the best of our knowledge, no valid questionnaire is available for this purpose. One might argue that an instrument that is developed for a psychogeriatric nursing home population could additionally be used for the gerontopsychiatric population. However, the gerontopsychiatric population differs not only in the type of disorder, a disorder that 'may shape each domain of quality of life' (Brod, Stewart, Sands, & Walton, 1999), but also in demographics and behavior. In general, this population is more often unmarried, and exhibits more behavioral problems or psychiatric symptoms such as agitation, delusions and hallucinations than other nursing home residents (Van den Brink, Gerritsen, de Valk, Voshaar, & Koopmans, 2017; Van den Brink et al., 2013).

In such an instrument, the likelihood of cognitive impairment should be accounted for (Friedman et al., 2001; Fullerton, McGuire, Feng, Mor, & Grabowski, 2009; Van den Brink et al., 2017). The use of a measurement instrument that is complex, or otherwise cognitively demanding may lead to low response rates, as we see for example in a study of Luzny and Ivanova (2009), where the use of the WHOQOL-BREF among a gerontopsychiatric population led to a mere 23.4% response rate. The type of cognitive impairment in this population differs in several aspects from the cognitive problems as seen in demented nursing home residents. Memory loss and language problems play a more important role in common forms of dementia (Jonker, Verhey, & Slaets, 2010), whereas issues like concentration problems, difficulties in decision making and an impaired ability regarding abstract thinking are more often the main issue in the gerontopsychiatric population (Alexopoulos, Meyers, Young, & et al., 2000; Berg & Dellasega, 1996; Fucetola et al., 2000). The instrument should consist of short, concrete and simple questions and answer-scales, in order for it to fit the often limited cognitive capacity of the gerontopsychiatric population.

When it comes to content, the instrument should be based on a clearly defined and operationalized concept of well-being or quality of life. Since the concepts are very much similar, the terms 'quality of life' and 'well-being' will be used interchangeably in this study. The World Health Organization (WHO) describes quality of life as subjective, multidimensional and containing both positive and negative dimension (WHOQOL Group, 1995). Following this description, and based on the definition by Diener et al. of subjective well-being (Diener et al., 2017; Diener, Oishi, & Lucas, 2003) we will use the following definition of well-being: "*a multidimensional concept that concerns the individuals' cognitive and emotional evaluations of their lives*". According to the WHO, dimensions that should be included at minimum, are the physical, social and psychological dimension (WHOQOL Group, 1995). Two models that, when uses together cover and explicate these dimensions are the Social Production Function (SPF) model (Lindenberg, 1986; Ormel, Lindenberg,

Steverink, & Verbrugge, 1999) (for both the physical and social domain), and Ryff's model of psychological well-being (Ryff, 1989; Ryff & Keyes, 1995) (for the psychological domain). A clear definition and operationalization of well-being are important for determining validity of an instrument. Since a definitive 'gold standard' is not available, the validity of a well-being instrument should be established using several measures, that comply with the working definition. Ideally an instrument should correlate highly with other self-rated measures of well-being, and moderately correlate with observed well-being (Fuh & Wang, 2006; Torisson, Stavenow, Minthon, & Londos, 2016). In addition, we expect there may be an association with depressive symptoms, since people with depressive symptoms are expected to have lower well-being scores (Beekman et al., 2002; Van der Wolf et al., 2017).

A well-designed instrument for the measurement of well-being in gerontopsychiatry can provide a better understanding of well-being in this population and of the factors that are associated with well-being. Also the opportunity to evaluate well-being might support care-workers in their provision of care when they aim for a high well-being for this population. The purpose of this study is therefore to develop an interviewer-administered instrument to measure well-being in gerontopsychiatric nursing home residents, that takes both design- and content related considerations into account. The aim of this instrument is to be applicable in both further research and in the evaluation of well-being in daily care practice in the nursing home.

Method

To develop a measurement instrument, steps were taken based on both data- and theory driven decisions. An item pool was generated and a selection was made out of this item pool using a theoretical model. Experienced care professionals were involved in the generation and in the selection of items. Data collection was carried out in several nursing homes in the Netherlands, after which statistical analyses were performed. Decisions on retaining or rejecting items in this process were made using statistical guidelines, but the content of these items was also examined and discussed from a theoretical perspective before a decision was made.

Generation of an item-pool

In order to gain insight into important aspects of well-being from the residents perspective and to create a first item-pool, both residents and care professionals were consulted to cover the multiple aspects of well-being. Concepts from the SPF model (Lindenberg, 1986) and Ryff's model of psychological well-being (Ryff, 1989) were used to explicate the three dimensions. For physical well-being both comfort and activation were included, for social well-being the

included concepts were affection, behavioral confirmation and status, and psychological well-being was specified with the concepts: self-acceptance, environmental control and purpose in life. Ideas and themes for the items were gathered from three groups of people, with central roles in the care for the gerontopsychiatric population. First, semi-structured interviews were held with a total of eight gerontopsychiatric residents. Open-ended questions based on the aforementioned concepts were used, such as 'when do you consider your day a good day?' or 'what do you do when you want to relax?'. Transcriptions were made, and recurring topics were collected, and added to the item-pool. Second, a brainstorm session was held with two nurses from two different nursing homes, both experienced in working with the gerontopsychiatric population. The three dimensions of well-being and their subsequent concepts were used as the foundation from which, to solicit ideas in all relevant domains of well-being. The nurses were encouraged to name all topics that they considered important for well-being of the residents. The third group that was consulted was a group of eight care practitioners from various disciplines: two psychologists, an elderly care physician, two physical therapists, an occupational therapist, a pastoral worker and a social worker, all experienced in working with the gerontopsychiatric population. A brainstorm session was held, in a comparable format to the brainstorm with the nurses.

Furthermore, two existing well-being instruments i.e. the Social Production Function Instrument for the Level of Well-being (SPF IL) (Nieboer, Lindenberg, Boomsma, & Bruggen, 2005) and the Scales of Psychological Wellbeing (Ryff, 1989) were examined to see if there were still missing themes in the item-pool. Some themes from these instruments were additionally included.

The interviews, brainstorm session and existing instruments yielded a large number of topics and potential items for the measurement instrument, aiming to produce an item-pool broader and more comprehensive than one's own theoretical view of the target construct (Clark & Watson, 1995). When overlapping items and themes were removed, a total of over 300 possible items was left within the three domains, including items for physical well-being such as: 'Do you feel physically well?' and 'Do you sometimes suffer from nightmares?', items for social well-being such as: 'Do you have a close friend within this residence?' or 'do you feel at ease with the nurses?', and items for psychological well-being such as: 'Do you feel confident about yourself?' or 'do you feel supported by your faith or belief system?'.

Scale development

A further selection was made by a small focus group, consisting of two psychologists, one elderly care physician, all experienced in working with the gerontopsychiatric population, and a researcher (the first author). This selection was guided by the following criteria:

the items together should cover a broad focus, all dimensions of well-being and their subsequent concepts should be represented in the items, there should be both positively and negatively formulated items, the items should be broadly applicable for residents with different backgrounds or diagnoses and all items should fit in the general definition of well-being. Items were rephrased by the same focus group into a concise and clear way, using high frequency words as much as possible, to promote comprehensibility. Also the timespan that the item covered was clearly formulated e.g. 'thinking of last week, how often were you anxious or tense?' and, 'thinking of last week, how often did you enjoy music?' This led to a total of 112 items. (For a schematic overview of the scale development process, see Figure 1).

Based on the content of the item, three (slightly) different answer scales with 4 answering options were constructed. Firstly 'not, sometimes, often, always', (e.g. for items using a structure such as: 'how often did you enjoy your meal?'), then 'not, seldom, sometimes, often'(e.g. for items using a structure such as: 'how often did someone ask you what you wanted?'), and lastly 'completely disagree, mostly disagree, mostly agree or completely agree' (e.g. for items using a structure such as: 'there are people around me that have more problems than I do'). All three versions of answer scales were printed in very large font for the participants to use during the interview.

Comprehensibility was tested in interviews with three gerontopsychiatric residents. An independent research assistant was present during the interviews to observe the process critically and make suggestions for improving comprehensibility (Dalemans, Wade, Van den Heuvel, & De Witte, 2009). This resulted in improvement of some items by removing ambiguity in items, removing some ambiguous items altogether, and the improvement of instructions for specific questions. After these steps, the interview instrument comprised of 108 items. With the purpose of item-reduction a pilot was performed among 29 gerontopsychiatric participants in three different nursing homes. Twenty-five participants answered all the items of the initial questionnaire. Observations that were made during the interviews were used in deciding to reject or retain items, e.g. 'the question evokes resistance in the resident' 'the item does not resonate with the resident', 'resident had trouble understanding the question' etc. Using these observations, suggestions for rejection or maintenance of items were made by the same focus group that formulated the items and, independently, by two co-authors (WW and SvH). Differences in the selection were discussed until consensus was reached. Also, the items were categorized according to the three theoretical dimensions of well-being. This was done independently by the members of the focus-group, and two co-authors (WW and SvH). Differences in the distribution were discussed by three authors (WW, SvH and EvdW) until consensus was reached.

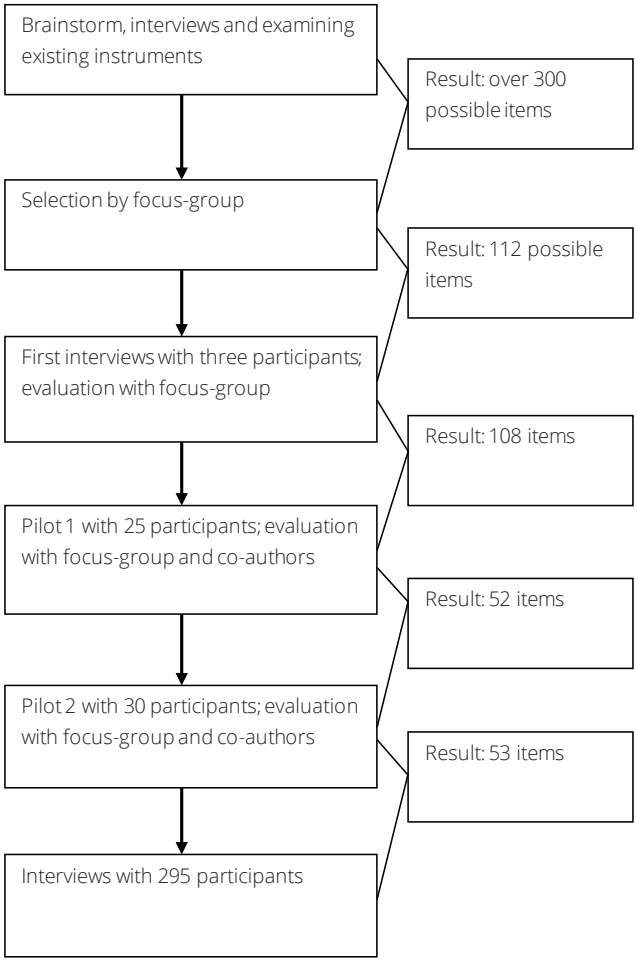

Figure 1. Flowchart showing the procedure of scale development

After this procedure 56 items were dropped, leaving a questionnaire with 52 items, of which 7 in the dimension of physical well-being, 26 in the dimension of psychological well-being and 20 in the dimension of social well-being. With this questionnaire, a second pilot was performed among thirty residents. Another evaluation was held with the same focus-group and with the co-authors. One item was added since the theme had come up during the additional interviews: 'how often are you being bullied?'. This item was added to the social well-being dimension. No other adjustments were made to the measurement instrument.

Participants

A total of 295 residents from 15 locations in The Netherlands participated in this study. Subjects were all residents of a gerontopsychiatric nursing home, or a gerontopsychiatric ward in a general nursing home. All locations included were high-level care institutions in the Netherlands, aimed at long term care. Inclusion criteria were: having a psychiatric diagnosis, living for at least 1 month in the institution, receiving long term care (no revalidation or temporary care), and having the cognitive abilities to participate in the interview. Decisions concerning this last criterion were made by the primary professional caregiver, or by the researcher during the interview. An exclusion criterion was dementia (other than Korsakov's dementia) as a primary diagnosis. There were no age-restrictions.

Measures

Demographic information (i.e. age and duration of stay in the current location) and information on diagnoses were obtained via the electronic client dossiers (ECD). Diagnoses were double checked by the elderly care physician involved in delivering care. Demographic data on educational level and marital status was requested from the participants themselves.

In order to examine construct validity, two instruments for the measurement of well-being were conducted. Cantril's Ladder (Cantril, 1965) was used, a self-rated one-item measure to establish well-being on a ladder scale. In this ladder, zero means 'the worst possible life for you' and 10 means 'the best possible life for you'. Test-retest reliability was moderate, criterion validity was moderate to strong compared to other self-rated well-being instruments, and moderate when compared to peer-ratings of well-being (Larsen, Diener, & Emmons, 1985). The Qualidem (Ettema, Dröes, De Lange, Mellenbergh, & Ribbe, 2007) was used as a validated instrument for proxy-rated quality of life in nursing home residents with dementia. This instrument consists of 37-items like: 'is cheerful', 'enjoys the meal' or 'enjoys helping with chores on the ward', divided into 9 subscales: 'care relationship' (7 items, Cronbach's alpha .83), 'positive affect' (6 items, Cronbach's alpha .89), 'negative affect' (3 items, Cronbach's alpha .71), 'restlessness tense behavior' (3 items, Cronbach's alpha .74), 'positive self-image' (3 items, Cronbach's alpha .64), 'social relations' (6 items, Cronbach's alpha .80), 'social isolation' (3 items, Cronbach's alpha .59), 'feeling at home' (4 items, Cronbach's alpha .73), and 'having something to do' (2 items, Cronbach's alpha .62) (Ettema et al., 2007).

Finally, the Nijmegen Observer-Rated Depression scale (NORD) (Leontjevas et al., 2012) was used as an additional validation measure, since depression is consistently found to be negatively related to level of well-being (Beekman et al., 2002; Davison, McCabe, Knight, & Mellor, 2012; Smalbrugge et al., 2006). The NORD is a 5-item instrument,

administered by the primary professional caregiver. Accuracy is acceptable. For residents without dementia a cutoff score of >1 showed 100% sensitivity and 69% specificity (Leontjevas et al., 2012).

Procedures

Residents and their family received written information about the study a few weeks prior to the researcher visiting the institution. If there was an indication that a resident was not sufficiently mentally competent, informed consent from the legal representative of the resident was requested. Before every interview, residents were (again) informed regarding the content and purpose of the study, and written informed consent was given by all participants. This procedure was approved by the research ethics committee (cETO) of the Open University of the Netherlands.

Following Dalemans et al. (2009), several measures were taken to meet the needs of more disabled participants, to facilitate inclusion of the highest possible percentage of residents. During the interview there was no time-pressure. When the participant seemed tired or lost concentration, a break was inserted or the participant could opt to continue the interview on another day. Visual aid was provided in the form of extra-large printed answer scales. Also hearing problems were accounted for, if necessary the interviewer spoke loudly or brought a large print version of the questionnaire, sat close to the preferred side of the resident, and checked regularly whether the resident was able to hear what was said. Both observer-rated measures were administered by the same interviewers, to the primary professional caregiver of the participant concerned.

All interviews were performed by the first author or by one of five research assistants, all trained psychology-master students. Research assistants received a 2:30 hour training, in which all facets of the interview were explained, and practiced. In addition, during the first interviews of a research assistant, the first author was present to observe, and give feedback regarding the execution of the interviews.

Data analysis

SPSS version 22 was used for most of the statistical analyses. R version 3.4.2 (R Core Team, 2017), package userfriendlyscience (Peters, 2017) was used for calculating confidence intervals and the coefficient omega, and package LAVAAN (Rosseel, 2012) for confirmatory factor analysis. In the analysis procedure, data-driven and a theory-driven approach was used. Both results from the statistical analyses and the theoretical underpinning of the instrument formed the basis for decisions in constructing the instrument.

Firstly, response distributions of the individual items were examined using histograms, for potential imbalance in the response distributions (Clark & Watson, 1995). Items in which more than 80% of the respondents would give the same answer would be removed. Missing values were analyzed and treated according to guidelines (Gold & Bentler, 2000; Tabachnick & Fidell, 2014). The quality of the categorization of the items into the three dimensions of well-being was statistically investigated using confirmatory factor analysis (CFA).

Secondly, unidimensionality was examined for the three dimensions of well-being: physical well-being, social well-being and psychological well-being, and not for general well-being since we did not want to establish unidimensionality of well-being in general, possibly at the cost of the extensiveness of this construct. First, inter-item correlations were checked. Items with 33% or more of their inter-item correlations r< .10 and items with inter-item correlations r>.60 were discussed for removal. This is necessary as unidimensionality is accomplished when inter-item correlations are 'moderate in magnitude, and cluster closely around the mean value'(Clark & Watson, 1995). Then the corrected item-total correlations were checked, and if items with a corrected item-total correlation <.30, they were discussed for potential removal (Field, 2009).

Thirdly, the average inter-item correlation and McDonald's coefficient omega of all three dimension of well-being were calculated. The aim was a range of .15 -.50 for the average inter-item correlation (Clark & Watson, 1995) and reliability, as measured with both Cronbach's' alpha and McDonald's omega was aimed to be >.70 (Nunnally, 1978). The last step in establishing unidimensionality was to perform an unrotated factor analysis, where all items should load >.35 on the first factor of the dimension in question (Clark & Watson, 1995). Items that would load below .35 were discussed for potential removal.

Subscales

To explore the existence of subscales within the three dimensions, exploratory factor analyses were performed using principal axis factoring (Widaman, 1993). The type of rotation was chosen based on the extent of correlation between the factors. The number of subscales was examined via Horn's parallel analysis and checked for interpretability, and a cutoff score of .32 was used for interpretation of items in the factors (Tabachnick & Fidell, 2014). In the case of low communalities (<.30), or items that would not load >.32 on any of the factors, or >.32 on more than one factor, items would be removed (Worthington & Whittaker, 2006), until all items would load >.32 on only one of the factors. Then reliability would be estimated for the subscales, aiming at a range of .15 -.50 for the average inter-item correlation (Clark & Watson, 1995) and both Cronbach's alpha and McDonalds omega >.70 (Nunnally, 1978).

Construct validity
Firstly, content validity was assumed to be well-addressed in the process of development of the instrument, since generation and selection of items has been compiled by, or in consultation with care professionals experienced in working with this population. Where possible, the gerontopsychiatric population has also been involved in the generation of items.

Additionally, for criterion-related validity, all subscale scores were hypothesized to be substantially correlated to the score on Cantril's Ladder. Furthermore, a correlation analysis was conducted with the proxy-instrument Qualidem. In general, correlations between self-rated and proxy instruments for well-being are low to moderate (Fuh & Wang, 2006; Torisson et al., 2016), therefore a weak to moderate correlation was hypothesized for the relation between LWIG and Qualidem outcomes. Finally, as an additional way of assessing validity, the first 126 participants (42.7%) were screened for depressive symptoms using the NORD. Participants that met the criteria for depressive symptoms were compared to the participants that did not meet this criterion, using a t-test, expecting higher well-being scores for the non-depressed group (Davison et al., 2012; Smalbrugge et al., 2006).

Results

Participants
A total of 295 residents with a variety of primary diagnoses were included. Using DSM-V categorization, the population consisted of 41.2 % with schizophrenia spectrum or other psychotic disorders (including 14.3% with a schizoaffective disorder) 12.6% with depressive (or related) disorders, 10.9% with bipolar or related disorders, 11.2% with personality disorders, 12.3% with neurocognitive disorders (6.5% with Korsakov and 5.8% with CVA or acquired brain injury) and 11.9% with other disorders (e.g. substance-related disorders, anxiety disorders or somatic symptom disorders). Age ranged from 38 to 91, with a mean age of 69.3 (SD 11.19). 67.1% of the participants were female, and 32.9% were male.

Most participants (96.5%) had completed at least primary education, 22.5% had also completed vocational training. The largest group (24.6%) finished their middle level applied education. Higher education was completed by 18.3% and 7.4% had attained an academic degree. With regard to marital status, a group of 33.9% had never been married, 29.4% were divorced, and 23.2% were widowed. 13.5% of the participants were married or living together. Participants within this last category did not necessarily live together at the time of the interview, but did consider themselves in a lasting relationship with a significant other.

The duration of current stay in the nursing home is 3.5 years (*SD* = 2.58) on average, with a range of 1 month to 14 years and 5 months. The distribution of length of stay is positively skewed (*z* = 7.38), with a median of 3.2 years. A total of 513 residents that lived in the included nursing homes, fell within the inclusion criteria, and had consenting legal representatives. Of these residents 295 actually completed the interview, a response rate of 57.5%. Reasons for not participating were disinterest, not seeing the relevance or not feeling like participating (28.4%) severe cognitive disorders (22.0%), severe psychiatric symptoms like psychosis, suspiciousness or anxiety (27.5%), hearing- or language problems (8.3%), lack of physical health (7.3%) or unknown reasons (6.5%). Decisions on inability to participate were in some cases made by the primary professional caretaker, in some cases by the interviewer, and in some cases by the residents themselves.

Scale construction

Response distributions of the 53 individual items were initially examined. No extremely unbalanced items were found. On the item with the strongest imbalance, 68.1% of the participants answered with the same response.

Subsequently the amount and distribution of missing values was analyzed. In the 53 items one item had 11.9% missing values, which was explained by the fact that this is the item ('how often are you being bullied?') that was added after the first 30 interviews. Of all other values, only 1.4% was missing, however 27.7% of the cases had at least one value missing. Little's MCAR test was significant (=.002), suggesting that the missing data were missing not at random. According to Tabachnick and Fidell (2013) imputation of missing values is the best solution in case of missing values not at random. Expectation maximization was applied to impute missing values in all three dimensions of well-being. This did not change item means or standard deviations for more than .02.

To study the fit of the proposed three-dimensional model of well-being, a confirmatory factor analysis was performed. Several goodness of fit measures were computed. The χ^2 = 2855.90 with 1322 degrees of freedom. This leads to a relative χ^2 of 2.16. As a 'rule of thumb' a relative χ^2 of <2 indicates a good fitting model (Tabachnick & Fidell, 2014). For the Comparative Fit Index (CFI) and Tucker-Lewis Index (TLI) a score of >.95 is indicative of a good fitting model. The current data show a CFI of .688 and TLI of .675 which is outside this range. However, scores on the root mean square error of approximation (RMSEA): .063 CI [.060 - . 066] and the standardized root mean square residual (SRMR): .077 do fall within the set range for adequate fit, which is <.08 both for the RMSEA (Browne & Cudeck, 1993) and for the SRMR (Hu & Bentler, 1999). The outcomes did not show a perfect model, however the results were sufficiently promising to continue with the current model of well-being. No items were discarded within this step.

Unidimensionality

As a first step towards unidimensionality, the inter-item correlation matrices of the dimensions of well-being were checked. Items with more than 33% low inter-item correlations (<.1) or items with a high inter-item correlation (>.6) were removed in an iterative process. Following these procedures, two items were removed from the dimension of social well-being, one item from the dimension of physical well-being and 5 items were removed from the dimension of psychological well-being. For an overview of the methodological steps that were taken in the process of scale construction, see Figure 2.

For the remaining 45 items the corrected item-total correlations were checked for each dimension, one item within the dimension of social well-being had a corrected item-total correlation slightly <.30 ('how often were you bothered by other residents?', p=.29). However, the difference with the desired value was small, and, from a theoretical content perspective, the item represented an important part of negative social experience within the social well-being dimension. Therefore the theory-based consideration that social well-being is a widely scoped construct led to the decision to temporarily retain the mentioned item at least until the step of subscale development. The average inter-item correlation at this point was .29, 95% CI [.18, .39] for physical well-being, .25, 95% CI [.14, .35] for social well-being and .29, 95% CI [.18, .39] for psychological well-being, values that are within the range of .15 - .50. McDonalds omega was ω_t= .76, 95% CI [.72, .81] for physical well-being, ω_t= .90, 95% CI [.88, .92] for social well-being and ω_t = .92, 95% CI [.90, .93] for psychological well-being, which is within the set range.

As a final step in establishing unidimensionality, three unrotated factor-analyses were performed (Clark & Watson, 1995). The item that scored slightly below .30 in the item-total correlations, and another item that also measured the negative domain of social well-being loaded slightly below .35 in the unrotated factor analysis (i.e. how often were you bothered by other residents?' and 'sometimes I am being bullied' with loadings of .31 and .34 respectively). However, using the same theoretical consideration both items were temporarily retained. All other items loaded >.35 within their subsequent dimension. The instrument at this point consisted of 45 items, 6 in physical well-being, 18 in social well-being and 21 in psychological well-being.

Subscale development

To investigate the existence of subscales within the three dimensions with factor analysis, first sampling adequacy was verified using the Kaiser-Meyer-Olkin measure. For physical well-being KMO =.75, for psychological well-being KMO = .91, and for social well-being KMO = .88, which are all good values, representing adequate sampling (Field, 2009). All KMO

values for individual items were >.72, which is well above the acceptable level of .50 (Field, 2009). For all three dimensions Bartletts test of sphericity was highly significant p <.001, which indicates sufficiently high inter-item correlations for factor analysis.

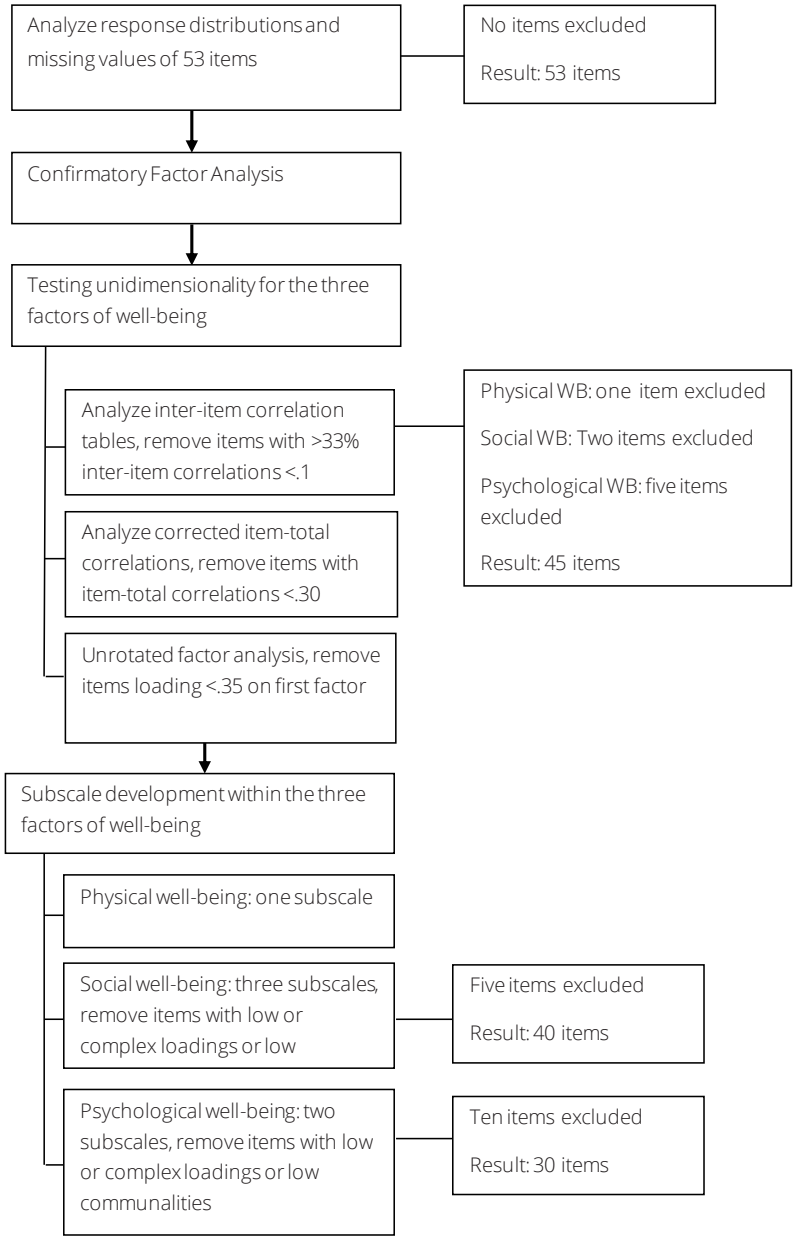

Figure 2. Flowchart showing the methodological steps taken in scale construction

To establish whether one or more factors were present within the dimensions, Horn's parallel analysis was conducted (O'connor, 2000). For physical well-being only one factor was found, for social well-being a three factor solution appeared to be the best fit and for psychological well-being a two factor solution was suggested.

Then for both multi-factored dimensions a factor analysis was performed. First, a factor analysis (principal axis factoring) with oblique rotation was requested for the social well-being dimension. Two out of the three factor correlations were >.32, indicating that oblique rotation would be a better fit than orthogonal rotation (Tabachnick & Fidell, 2014).

In oblique rotation (direct oblimin) the three-factor solution for social well-being was confirmed, resulting in comprehensible factors in a fairly simple structure. To improve factor structure all items loading <.40 on any factor were removed, resulting in the removal of three items in an iterative process. After removal of these items there were no complex items (i.e. loading >.32 on more than one factor) in the factor solution. There were however still some items with low communalities (<.30). Communalities represent the proportion of variance in an item that is predicted by the factors that underlie this item (Tabachnick & Fidell, 2014). Items with low communalities were removed iteratively (Worthington & Whittaker, 2006), resulting in the removal of 2 additional items. After these steps, within the dimension of social well-being, one factor contained six items, one contained four items, and one consisted of three items (see Table 1). Communalities varied from .31 to .53, and 39,8% of the total variance was explained in this three factor solution.

The same process was used for the dimension of psychological well-being. A factor analysis (principal axis factoring) with oblique rotation was used. Both factors correlated strongly r= -.577 suggesting oblique rotation as the preferred option (Tabachnick & Fidell, 2014). The two-factor solution resulted in a reasonably simple and understandable result. Factor structure was improved by removal of the items loading <.40 on any of the factors, which resulted in the removal of three further items. Then items with low communalities (<.3) were removed iteratively, which resulted in the removal of an additional 5 items. After this step loadings in the pattern table had changed, and some items now had low or complex loadings. Another two items were therefore removed. The resulting factors within the dimension of psychological well-being contained seven and four items respectively (see Table 2). Communalities varied from .31 to .60, and 41.7% of the total variance could be explained in this two-factor solution.

Table 1. Pattern matrix of social well-being

	Factor		
	1	2	3
There are nurses with whom I have a good relationship	.717		
There are people with whom I can feel completely at ease	.524		
How often did you receive sufficient attention?	.487		
How often did you receive sufficient respect?	.465		
I see the people that are important to me as often as I would like to	.464		
There are fellow residents with whom I have good contact	.424		
How often did you feel that others saw you as a burden?		.634	
Sometimes I am bullied		.600	
How often did you feel ignored?		.537	
How often were you bothered by other residents?		.491	
How often did you experience a sociable atmosphere when with the other residents?			-.731
How often did you enjoy the communal mealtimes?			-.694
How often did you feel you fitted in with the other residents?			-.641

Extraction Method: Principal Axis Factoring.
Rotation Method: Oblimin with Kaiser Normalization.

Table 2. Pattern matrix of psychological well-being

	Factor	
	1	2
How often did you feel anxious or tense?	.764	
How often did you feel sad or depressed?	.618	
How often did you feel empty or flat?	.609	
How often did you feel bored?	.588	
How often did you worry about the purpose of your life?	.559	
How often did you feel lonely?	.513	
How often did you feel relaxed?	.505	
I am satisfied with how my life has turned out so far		-.783
I have accomplished what I wanted to in life		-.739
I think life is meaningful		-.491
I think I am worth the effort		-.439

Extraction Method: Principal Axis Factoring.
Rotation Method: Oblimin with Kaiser Normalization.

Table 3. Reliability of dimensions and factors (N=293)

	Mean (SD)
Physical well-being (6 items)	2.72 (.69)
Psychological well-being (11 items)	2.88 (.66)
1: Affect (7 items)	2.84 (.70)
2: Self-worth (4 items)	2.95 (.84)
Social well-being (13 items)	2.85 (.59)
1: Positive social experience (6 items)	3.03 (.67)
2: Negative social experiences (4 items)	2.95 (.82)
3: Communal living (3 items)	2.34 (.92)

Reliability

Reliability of the dimensions and their underlying factors was examined using both the mean inter item correlation, McDonalds Omega and Cronbach's Alpha. The only subscale that had an Omega <.7 was the social well-being subscale of 'negative social experiences', with both an Omega and a Cronbach's alpha of .68. (see Table 3). Reliability was acceptable for all other dimensions and factors.

Construct validity

Correlations among the dimensions and subscales were all significant, and varied from r = .29 to r = .66 (see Table 4). Correlations between total dimension scores and their subscales were left out of the table, since these values are inflated due to a large overlap in items. Table 5 shows the correlations of the LWIG subscales, Cantril's Ladder and the nine Qualidem subscales. As expected the correlations with Cantrils' Ladder are relatively high, as both instruments measure self-rated well-being. Correlations with the Qualidem subscales vary strongly for each subscale. However all dimensions and subscales had significant correlations with several Qualidem subscales. Correlations were in general weak to moderate.

The third way to establish criterion-related validity was to compare non-depressed and potentially depressed participants based on the NORD, a screening instrument for depression. A t-test was performed that showed significantly lower LWIG scores on all subscales for the group that fell within the criteria for depressive symptoms compared to the non-depressed group (see Table 6).

Mean inter item correlation	McDonalds Omega	Cronbach's Alpha
.29, 95% CI [.18, .39]	.72, 95% CI [.68, .77]	.72, 95% CI [.66, .77]
.33, 95% CI [.22, .43]	.84, 95% CI [.82, .87]	.84, 95% CI [.82, .87]
.37, 95% CI [.27, .46]	.80, 95% CI [.77, .84]	.80, 95% CI [.77, .84]
.45, 95% CI [.35, .54]	.77, 95% CI [.73, .81]	.76, 95% CI [.72, .81]
.24, 95% CI [.13, .35]	.81, 95% CI [.78, .84]	.81, 95% CI [.77, .84]
.32, 95% CI [.21, .43]	.73, 95% CI [.68, .78]	.73, 95% CI [.68, .78]
.35, 95% CI [.25, .46]	.68, 95% CI [.62, .74]	.68, 95% CI [.62, .74]
.52, 95% CI [.43, .60]	.76, 95% CI [.71, .81]	.76, 95% CI [.71, .81]

Table 4. Pearson correlations between dimensions and subscales

	Mean (SD)	Phys. WB	Psych. WB	Ps WB - Affect	Ps WB – self-worth	Social WB	Soc WB positive	Soc WB negative
Physical well-being	2.72 (.69)							
Psychological well-being	2.88 (.66)	.659**						
Ps WB - Affect	2.84 (.70)	.633**						
Ps WB – self-worth	2.95 (.84)	.501**		.531**				
Social well-being	2.85 (.59)	.491**	.551**	.447**	.541**			
Soc WB - positive	3.03 (.67)	.375**	.416**	.285**	.484**			
Soc WB - negative	2.95 (.82)	.350**	.406**	.402**	.292**		.317**	
Soc WB - communal	2.34 (.92)	.416**	.460**	.362**	.468**		.476**	.366**

**. Correlation is significant at the 0.01 level (1-tailed).

Table 5. Pearson's correlations between LWIG scores and Cantrils' ladder and Qualidem subscales

	Physical well-being	Psychological well-being	PsWB - Affect
Cantrils' Ladder	.40**	.64**	.52**
Qualidem subscales:			
Care relationship	.131*	.002	.013
Positive affect	.336**	.282**	.303**
Negative affect	.257**	.269**	.312**
Restlessness tense behavior	.046	.096	.148**
Positive self-image	.386**	.325**	.322**
Social relations	.204**	.210**	.211**
Social isolation	.100*	.018	.055
Feeling at home	.227**	.195**	.173**
Having something to do	.241**	.157**	.227**

*significance at the .05 level (1-tailed) ** significance at .01 level (1-tailed).

Table 6. T-test well-being in depressed or non-depressed residents (N=126)

	Mean LWIG score NORD ≤1 (N=51)	Mean LWIG score NORD >1 (N=75)	*t*
Physical well-being	2.84	2.59	2.00*
Psychological well-being	3.05	2.70	2.87**
Affect	3.00	2.69	2.41**
Self-worth	3.13	2.71	2.87**
Social well-being	2.83	2.55	2.80**
Positive social experience	3.10	2.80	2.39**
Negative social experience	2.81	2.54	1.80*
Communal living	2.32	2.04	1.76*

*significance at the .05 level (1-tailed) ** significance at .01 level (1-tailed)

Discussion

The purpose of this study was to develop an instrument for the measurement of well-being among gerontopsychiatric nursing home residents. This is of significant importance since the gerontopsychiatric population is a population that is susceptible to low well-being, due to several characteristics such as high prevalence of physical disorders, and a high dependence on care for daily life activities (Collet et al., 2016; Van den Brink et al., 2017). This population differs from other nursing home residents when it comes to e.g. age, marital status (Van den

	PsWB - Self-worth	Social well-being	SWB - Positive	SWB - Negative	SWB – Communal living
	.62**	.53**	.44**	.33**	.45**
	-.015	.216**	.192**	.144**	.154**
	.166**	.228**	.236**	.118*	.156**
	.126*	.156**	.047	.208**	.123*
	-.008	.003	.006	.042	-.051
	.232**	.277**	.219**	.231**	.184**
	.145**	.221**	.272**	.069	.143**
	-.041	.176**	.088	.258**	.061
	.170**	.277**	.196**	.201**	.256**
	.008	.041	.079	.032	-.038

Brink et al., 2013) and type of cognitive disorders (Fucetola et al., 2000; Jonker et al., 2010; Van den Brink et al., 2017). Up to now there is no validated instrument for the measurement of well-being in this population. The availability of a validated instrument to measure well-being may make it possible to aim to achieve well-being as a treatment goal.

We conceptualized the construct of well-being as consisting of three dimensions: physical well-being, social well-being and psychological well-being, and developed the instrument based on contributions from the target-population itself and professionals experienced in working with this population. The instrument, now referred to as the Laurens Well-being Inventory for Gerontopsychiatry (LWIG), consists of 30 items, within three dimensions: physical, social and psychological well-being, with zero, three or two subscales respectively. These subscales are for social well-being: positive social experience, negative social experience and communal living, and for psychological well-being: affect, and self-worth. Sum-scores of both the social well-being and the psychological well-being subscales can also be used.

To study the internal structure of the instrument, correlations between dimensions and subscales were evaluated. All dimensions and subscales were found to be inter-correlated. This is in line with the hypothesis that well-being is one construct, although it is broad and consisting of multiple dimensions. The correlations were different in magnitude, there is e.g. a relatively high correlation between the physical and the psychological dimension of well-being, which is mainly due to the 'affect' subscale. Also some of the social well-being

subscales correlated relatively highly with the psychological well-being subscales. One explanation could be the influence of overarching factors like context, or personality traits on the different factors of well-being. Optimism for example, has been shown to positively affect both psychological well-being and not only perceived physical health but also actual physical health (Scheier & Carver, 1992). Also the amount of social activity is found to be influenced by the personality trait positive affectivity (DeNeve & Cooper, 1998), which may be comparable to the 'affect' subscale of the psychological well-being dimension. Another explanation might be found in the Social Production Function model, which argues that both social and physical well-being together are a source for general (psychological) well-being (Gerritsen, Steverink, Ooms, & Ribbe, 2004; Ormel et al., 1999).

The moderate to strong correlations between the LWIG subscales and the established well-being measure Cantril's ladder demonstrate validity of the LWIG subscales. Especially noteworthy is the relatively strong correlation between the self-worth subscale and Cantril's ladder. This might indicate that a feeling of self-worth is of major importance in establishing a sense of well-being in this population.

Validity of the LWIG was further demonstrated in the relation with symptoms of depression. Depression has a significant negative effect on mood which also plays a major role in the level of well-being. Also, depression has consistently been shown to be negatively related to well-being (Beekman et al., 2002; Van der Wolf et al., 2017). The LWIG demonstrated sensitivity in being able to differentiate between participants that are screened as potentially depressed, or as non-depressed. Participants that score >1 on the NORD have lower well-being scores on all LWIG subscales.

LWIG subscales that were expected to be related to Qualidem subscales based on content showed as expected, weak to moderate correlations. Stronger correlations were found between subscales that are, at face value, similar in content. Both the positive and negative affect scale of the Qualidem for example, correlated relatively strongly with the affect scale of the LWIG. Also the care relationship, social relations and social isolations subscale, all social subscales of the Qualidem, correlated relatively strongly with the social well-being dimension of the LWIG. Correlations between observed and self-rated subscales that are related in content are an indication of validity since it indicates that participants' answers are at least partially influenced by objectively observable factors as observed by their primary professional caregivers. However, considering the weak correlations between the self-rated and observed scores, the conclusions should be drawn with some caution. This may have partly been caused by the fact that an observational measure for participants with dementia was used, due to unavailability of a gerontopsychiatric well-being measure. The low correlations do not invalidate the new measure, but they also do not strongly support it.

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Because of the limited length, and the expedient number of dimensions and subscales the LWIG is suitable for use in clinical practice, e.g. to get an overview of individual well-being profiles and to get a measure of levels of well-being in a ward or a nursing home. Also for future research the instrument is relevant. The instrument is based on input by the gerontopsychiatric population and care professionals that work with this population, and it has been found to be sufficiently valid and reliable in this population. Since it measures a timeframe of only one week it is expected to be sensitive to change, and suitable for the measurement of treatment response. This should however be further examined.

Given the strong relation between Cantril's ladder and the self-worth subscale in the LWIG, stimulating a sense of self-worth in treatment might be an effective practical implication in the promotion of well-being. It was found that social factors like trust and reciprocity in resident staff-relations and also friendship with, and encouragement from fellow residents are related to feelings of self-worth (Carpenter, 2002; Rijnaard et al., 2016) To improve self-worth, both external resources such as the relation with and the approach by health care staff and also the training of internal resources, or self- management skills (Steverink, Lindenberg, & Slaets, 2005) such as social skills training and interventions that promote positive thoughts on social connectivity might be studied in relation to feelings of self-worth and well-being in the gerontopsychiatric population.

Strengths and Limitations

Some limitations are to be mentioned in this study. Firstly, a fairly large amount of the population (42.5%) was unable or unwilling to participate in the study, despite the measures that were taken to include more severely disabled residents. Also, some primary professional caregivers were more protective of their residents than others, and restricted the number of residents that could be approached for participation in the study. Desire to participate may also have been limited by the relatively large amount of items that were assessed in the first draft of the instrument. The current, more concise instrument of only 30 items may partly resolve this problem.

The amounts of non-participation are common in research with the gerontopsychiatric population (Depla, De Graaf, & Heeren, 2005; Smalbrugge et al., 2006), and can be a source of bias. Residents that did not participate are expected to be relatively more severely disabled, either physically or mentally, which is likely to negatively influence well-being scores. This may have a negative effect on generalizability of well-being scores. Also, all residents in the gerontopsychiatric population, including the participants in this study, are likely to have cognitive impairments which may hamper the ability to understand, reason and make decisions (Okai et al., 2007). Therefore the development of an additional observational instrument for the measurement of well-being is important to get a more

complete picture of the level of well-being in this population, by measuring well-being from different perspectives. For optimal comparability, this observer-rated instrument should be based on the same conceptual framework as the LWIG, and it should be rated by observers with a high quality relation with the resident (Huang, Chang, Tang, Chiu, & Weng, 2009).

A second limitation is the fact that a relatively large amount of data was missing. Sometimes participants refused to give an answer to questions, other times they did not know, or could not decide on an answer. Since we were working with a relatively fragile population, we did not want to press too hard for an answer. Missing data was imputed which naturally creates a possibility of small errors. However, comparisons between data with imputed- and data with missing data showed that the effects of imputation were very limited, whereas the choice to impute the missing values significantly improved the number of analyzable cases.

Another limitation is the unavailability of a true gold standard for the concept of well-being, although much theoretical and empirical research has been conducted on this concept. We have aimed to compensate for this by the involvement of gerontopsychiatric residents and professional caregivers in the development of the items and by the use of several established measures for validation.

Furthermore, the results in this study are based on single measurements, and test-retest reliability is therefore not measured. Both test-retest reliability and sensitivity to change are essential topics especially when a true gold standard is not available. These topics should be a priority in further validation of the LWIG in future research.

Lastly, the subscale of negative social experience fell just outside the adopted scope with regard to both Cronbach's Alpha and McDonald's Omega. Since the subscale is considered to provide unique and relevant information it was decided to keep the subscale in its current format. However, in future research this subscale might need adjustment or additional items to improve reliability.

The considerable contribution of the target population and care professionals experienced in working with the target population in the development of the instrument is an important strength of this study. Another strength is the large number of nursing homes from different parts of the Netherlands that participated. The inclusion of data from many different nursing home settings makes the results more likely to be generalizable to multiple settings.

Conclusion

This study is a first step in the development of a well-being instrument for the gerontopsychiatric nursing home population. To the best of our knowledge, no such instrument exists for this specific population, whereas a substantial proportion of the nursing home population is comprised of gerontopsychiatric residents (Fullerton et al., 2009). This instrument may serve as a stimulation to focus on well-being in research into-, and care for this population. More research is necessary to further establish the internal structure of the instrument, and to examine test-retest reliability and sensitivity to change.

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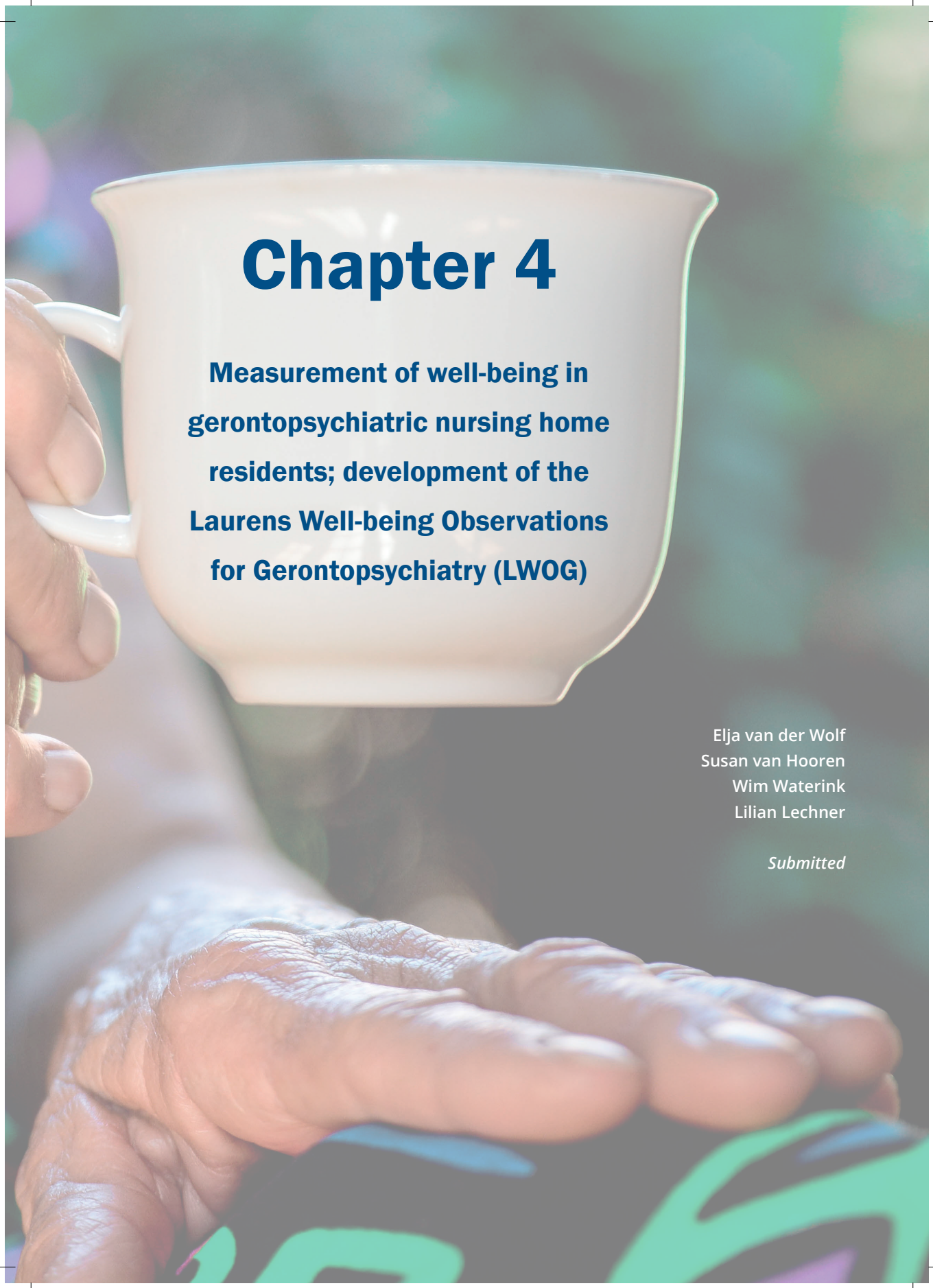

Chapter 4

Measurement of well-being in gerontopsychiatric nursing home residents; development of the Laurens Well-being Observations for Gerontopsychiatry (LWOG)

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Submitted

Abstract

Objectives: In this study, a first step has been taken toward developing an observation scale for the measurement of well-being in the population of gerontopsychiatric nursing home residents, consisting of older residents with combined psychiatric and physical disabilities. This scale aims to complement a previously developed self-reporting instrument for this population, i.e. the Laurens Well-being Inventory for Gerontopsychiatry (LWIG).

Method: An item pool was developed with the help of residents and care professionals. In a cross-sectional design, first responsible nurses were interviewed regarding the well-being of 265 gerontopsychiatric nursing home residents. Unidimensionality and the presence of underlying factors in the data were examined using Pearson correlations and factor-analysis.

Results: The final instrument consisted of 12 items within two factors. The first factor contains positively formulated items concerning social themes. The second factor consists of negatively formulated items, on psychological themes. Reliability was found to be adequate, with Cronbachs Alpha and McDonalds Omega scores well above .70. Validity was also acceptable, correlations with the Qualidem and LWIG subscales were sufficiently high.

Conclusions: First results of the Laurens Well-being Observations for Gerontopsychiatry on validity and reliability are promising. More research is needed on test-retest reliability and responsiveness to change.

Introduction

In the care for older people, awareness has grown that promotion of quality of life and well-being is an essential part of good care. An increasing amount of research has been conducted in order to examine the level of well-being in older people (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007; Brownie & Nancarrow, 2013; Hamers, 2011; Koren, 2010; Pinquart & Sörensen, 2000; Windle, Hughes, Linck, Russell, & Woods, 2010). However, little attention has been given to well-being in the population of gerontopsychiatric nursing home residents (Van der Wolf, Van Hooren, Waterink, & Lechner, 2017). The population of gerontopsychiatric nursing home residents consists of older people with a chronic mental disorder (other than dementia), often combined with one or more physical disorders (Van den Brink, Gerritsen, Voshaar, & Koopmans, 2013). This population differs in several aspects from nursing home residents with dementia. Not only is the type of mental disorder different, but there are also significant differences in demographics and behavior when compared to other nursing home residents. (Van den Brink, Gerritsen, De Valk, Voshaar, & Koopmans, 2017; Van den Brink et al., 2013). In the United States about 18 percent of the long term care population consists of gerontopsychiatric residents (Fullerton, McGuire, Feng, Mor, & Grabowski, 2009), whereas in the Netherlands this population accounts for just over eight percent of the nursing home population (Stuurgroep Gerontopsychiatrie, 2012).

To ensure good care for this population, aimed at the highest possible level of well-being, the availability of an instrument to assess well-being and its related factors is an essential starting point. Van der Wolf, Van Hooren, Waterink, and Lechner (2018) recently developed a self-rated instrument for this purpose. However, in the gerontopsychiatric nursing home population there remains a relatively large percentage of people who are unable or unwilling to adequately respond to questionnaires due to health issues, cognitive problems or a lack of motivation. In research among this population, response rates are around 50% (Depla, De Graaf, & Heeren, 2005; Smalbrugge et al., 2006; Van der Wolf et al., 2018). Apart from the fact that the well-being of a large group of people can therefore not be measured in this way, a low response rate might also lead to biased results, given that the potential reasons for non-response (i.e. the severity of mental or physical complaints) might very well be related to the level of well-being.

One potential method to examine the well-being of the non-responders is the use of an instrument in which well-being is rated by professional caregivers. Rating by professional caregivers has the additional advantage that the risk of biases and heuristics associated with self-report, such as mood of the patient during self-report, or even the weather (Kahneman, Diener, & Schwarz, 1999; Lucas, Diener, & Suh, 1996), are reduced. Proxy-

report, may therefore provide additional important and unique information, even when self-report measures are feasible (Sloane et al., 2005). To the best of our knowledge, there is no proxy well-being instrument validated for the gerontopsychiatric population. The development of such an observer-rated instrument is the aim of this study.

A clearly defined and operationalized concept of well-being is important as a basis for a well-being instrument. As 'quality of life' and 'well-being' are much similar concepts, these terms will be used interchangeably in this study. Following Van der Wolf et al. (2018), and based on both the description by the World Health Organization (WHOQOL Group, 1995), and the definition by Diener et al. (2017) the following definition was used: well-being is "*a multidimensional concept that concerns the individuals' cognitive and emotional evaluations of their lives".* The dimensions of well-being are described as physical well-being, social well-being and psychological well-being (Van der Wolf et al., 2018). In order to achieve the strongest possible correlation between a proxy- and a self-report measure, which would be a strong form of validation for either of the measures, the instruments should be based on the same definition and operationalization of well-being. Furthermore, the degree of concreteness and observability of the required information in the proxy measure (Sneeuw, Sprangers, & Aaronson, 2002), and the quality of the relationship between the observer and the observant (Huang, Chang, Tang, Chiu, & Weng, 2009) are found to be important. However, based on several studies, the relation between proxy and self-report instruments among different patient-groups is still expected to be low to moderate (Fuh & Wang, 2006; Riedel, Spellmann, Schennach-Wolff, Obermeier, & Musil, 2011; Torisson, Stavenow, Minthon, & Londos, 2016; Wolak et al., 2009).

This study was designed to develop and test a proxy instrument for the measurement of well-being in the gerontopsychiatric population. A well-designed proxy-rated instrument, in combination with a self-report instrument can provide a more complete picture of the level of well-being in gerontopsychiatric nursing home residents. Therefore, this proxy-rated instrument is designed to complement the Laurens Well-being Index for Gerontopsychiatry (LWIG) (Van der Wolf et al., 2018). The instrument is intended to be administered by the primary professional caregiver, and designed for use in additional research as well as for use in clinical practice.

Method

The measurement instrument was created in several steps, in which the decisions taken were both data-driven and theory-driven. The steps were in line with the procedure as followed in the development of the LWIG (Van der Wolf et al., 2018).

Generation of an Item Pool

An initial item-pool was created by means of interviews with gerontopsychiatric nursing home residents, and brainstorm sessions with nurses, psychologists, physical therapists, a physician and other disciplines that worked with the gerontopsychiatric population. The interviews and brainstorm sessions were based on the aforementioned definition and dimensions of well-being. This led to an item pool of over 300 items, which is the same item pool that formed the basis for the self-report instrument LWIG. For a more detailed description of the generation of this item-pool, see Van der Wolf et al. (2018). In addition, the Qualidem (Ettema, Dröes, De Lange, Mellenbergh, & Ribbe, 2007), was used as a source for both the content of items and for the design of the proxy-instrument. The Qualidem is an observer-rated, 37-item instrument for the measurement of quality of life among older nursing home residents with dementia.

Questionnaire Development

From the item pool, a selection was made by a focus-group, consisting of two psychologists, one geriatric medicine specialist, all experienced in working with the gerontopsychiatric population, and a researcher (the first author). This selection was based on the following guidelines: items should measure observable characteristics, items should fit in the definition of well-being (they should measure an observable evaluation of life by the resident), and all three dimensions of well-being should be represented by at least 5 items per dimension. A total of 29 items were selected by means of discussion until full consensus was reached. The selected items were reformulated by the same focus-group with the aim of unambiguousness, clarity and conciseness. The short and concise format of the items and the answer scales were based on the format as used in the Qualidem (Ettema et al., 2007). The timespan covered by the items was a period of two weeks. This is more than the one week scope of the LWIG items, because the target nurses who were required to answer the questions are not continuously present in the nursing home. A two week reflection period increases the likelihood of sufficient working days on which to base a more solid judgement.

A four-point answer-scale was chosen to avoid a central tendency bias, and to deviate as little as possible from the 4-point scale structure of the LWIG. The options were provided with a short concrete explanation, which is in line with the Qualidem (Ettema et al., 2007). The following option and explanations were used: 'never', 'seldom' (once or a few times a week), 'sometimes' (almost) daily) and 'often' (more than once a day).

The instrument consisting of 29 items was tested in a pilot among the first responsible nurses (i.e. the nurse that bears primary responsibility for the care of this resident within his or her team of nurses) of 28 gerontopsychiatric residents, 19 female and 9 male, from

three different nursing homes to examine both comprehensibility and ambiguousness. Based on observations by the researcher and remarks by the respondents, and after consultation with the aforementioned focus-group, some of the items were adjusted. Two items were adjusted because of the risk of socially desirable answers, (e.g. 'the resident received compliments'). One item was adjusted because the topic of the question was not sufficiently observable for the nurses ('was positively engaged in his or her own meaning or spirituality'). Three items were adjusted because they appeared to be unclear or ambiguous (e.g. 'made his or her own choices'). Two items were added: 'responded positively to jokes or humor', and 'tried to make the best of the situation'. The adapted version of the instrument consisted of 31 items, of which 6 items focused on physical well-being, 10 items focused on social well-being and 15 items focused on psychological well-being.

Participants

All participants were residents living in a gerontopsychiatric nursing home, or a gerontopsychiatric ward in a general nursing home. Only high-level care institutions in the Netherlands, aimed at long term care were included. Dementia (other than Korsakov's dementia) as a primary diagnosis was a criterion for exclusion. Inclusion criteria were: being diagnosed with a psychiatric disorder, as classified according to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), living one month or longer in the institution and receiving long term care (no revalidation or temporary care). For validation purposes, the participants also had to partake in an interview measuring self-rated well-being, therefore a final inclusion criterion was that the participant had the cognitive abilities to partake in the interview as judged by the interviewer or by the first responsible nurse. There were no age-restrictions.

Measures

Diagnostic data, and some demographic data were gathered via the electronic client dossiers (ECD). Diagnoses were double checked by the involved specialist geriatric medicine. Demographic data generated from ECD's were date of birth and duration of stay in their current location. Other demographic data on educational level ('Less than elementary school', 'primary school completed', 'primary school and two years follow up education', 'vocational education', 'middle-level applied education', 'higher education' and 'academic education') and marital status ('married or living together', 'single', 'divorced', 'widowed') was requested from the residents themselves.

To establish construct validity, three other measures to assess well-being were used: the Qualidem (Ettema et al., 2007), the Laurens Well-being Inventory for Gerontopsychiatry (LWIG) (Van der Wolf et al, 2018) and Cantril's Ladder (Cantril, 1965).

The Qualidem is a validated instrument for proxy-rated quality of life in nursing home residents with dementia. This instrument consists of 37-items like: 'is cheerful', 'enjoys the meal' or 'enjoys helping with chores on the ward', divided into 9 subscales: 'care relationship' (7 items, Cronbach's alpha .83), 'positive affect' (6 items, Cronbach's alpha .89), 'negative affect' (3 items, Cronbach's alpha .71), 'restlessness tense behavior' (3 items, Cronbach's alpha .74), 'positive self-image' (3 items, Cronbach's alpha .64), 'social relations' (6 items, Cronbach's alpha .80), 'social isolation' (3 items, Cronbach's alpha .59), 'feeling at home' (4 items, Cronbach's alpha .73), and 'having something to do' (2 items, Cronbach's alpha .62) (Ettema et al., 2007).

The LWIG (Van der Wolf et al., 2018) was used to measure self-rated well-being. This is a 30-item measure, with six subscales within three dimensions: physical well-being, social well-being and psychological well-being. It contains questions like 'in the last week, how often did you feel anxious or tense?', 'in the last week, how often did you feel you fitted in with the other residents?' or statements like 'I think I am valuable', and it utilizes a 4-point answer scale for all items. Reliability of the LWIG is sufficient, with McDonalds Omega's of the subscales varying from .68 to .84. Validity is also adequate as the scale correlates sufficiently with other well-being measures, and it distinguishes between depressed- and non-depressed patients (Van der Wolf et al., 2018).

Lastly, Cantril's Ladder was used, a self-rated one-item measure to establish well-being on a ladder scale. In this ladder, zero means 'the worst possible life for you' and 10 means 'the best possible life for you'. Inter-scale correlations with other QoL measures were low to moderate, varying from r = .13 with the Affect Intensity Measure to r = .62 with the Satisfaction With Life Scale (Larsen, Diener, & Emmons, 1985) and it has a moderate test-retest reliability: .40 across 2 years, among an older sample (Atkinson, 1982).

Procedures

The ethical committee from the Open University approved the research proposal concerning this study, and considered judgement by a Medical Ethical Committee not necessary (ref no: U2013/03517/CBO). After nursing home management approval, residents and their family were informed about the study by a letter, a few weeks before the researcher would visit the institution. Written informed consent was given by the residents and, when nursing home staff indicated that the resident was not mentally competent concerning this decision, informed consent was additionally given by the residents legal representative. All questionnaires were conducted by means of interviews, performed by the first author or by one of five trained research assistants (psychology-master students). The items that were developed in this study and also the Qualidem were administered to the first responsible nurse of the residents. The LWIG and Cantril's Ladder were conducted on the residents themselves.

Data Analysis

For statistical analyses SPSS version 22, and R version 3.4.2 (R Core Team, 2017) were used. In R the packages userfriendlyscience (Peters, 2017) was used for the calculation of confidence intervals and the McDonalds Omega, and the package LAVAAN (Rosseel, 2012) was used for confirmatory factor analysis. Decisions in the construction of the instrument were mainly based on results from statistical analysis. However, theoretical considerations regarding the content of questions could also be a motivation for decisions on removing or retaining items.

Firstly, the individual items were examined for potential imbalance in the response distributions using histograms (Clark & Watson, 1995). Items that yielded the same response in more than 80% of the cases would be removed. The number and distribution of missing values was examined. In case of non-random missing values and if the sample size would become too small if listwise deletion would be used, imputation of missing values would be applied (Tabachnick & Fidell, 2014). The fit of the results with the initially proposed three dimensional model of well-being was statistically examined using confirmatory factor analysis (CFA).

Unidimensionality

Assuming that the proposed three dimensional model would be confirmed in CFA, the next step would be to examine the unidimensionality of the three dimensions of well-being. If the predesigned three-dimensional model was not confirmed, the model would be simplified, and well-being would then be regarded as one construct, for which unidimensionality would be examined. In a unidimensional data-set, the inter-item correlations should be moderate in magnitude and 'cluster closely around the mean inter-item correlation' (Clark & Watson, 1995). Therefore, inter-item correlations were aimed to be $r>.10$ and $r<.60$. Items with 33% or more of their inter-item correlations $r< .10$ and items with inter-item correlations $r>.60$, potential removal was discussed. The corrected item-total correlations were aimed to be >.30 (Field, 2009). Finally, in an unrotated factor analysis all items should load >.35 on the first factor (Clark & Watson, 1995). Items loading <.35 were removed in an iterative process.

Subscales

An additional factor analysis was performed to investigate the existence of factors in the data. The number of factors was determined using Horn's parallel analysis. Rotation type was chosen based on the strength of the correlation between the factors. Items that loaded <.32 on any factor, or had communalities <.30 and items that loaded >.32 on more than one factor would be discussed for potential removal (Tabachnick & Fidell, 2014).

Validity and Reliability
Reliability of the factors was aimed to be in a range of .15 -.50 for the average inter-item correlation (Clark & Watson, 1995) and Cronbach's Alpha and McDonalds Omega >.70 (Nunnally, 1978).

Construct validity was explored by comparing the to the outcomes of the other proxy-instrument, the Qualidem (Ettema et al., 2007), where high correlations were expected as it measures the same construct in a similar way. Outcomes were also compared to the self-report measures LWIG (Van der Wolf et al., 2018) and Cantril's ladder (Cantril, 1965). Low to moderate correlations for the relations between outcomes of the constructed instrument and both the LWIG and Cantril's Ladder were expected (Fuh & Wang, 2006; Torisson et al., 2016).

Results

Participants
A total of 513 residents living in the participating locations fell within the inclusion criteria, and had consenting legal representatives. Of these residents only those were included that also participated in the self-report questionnaire (LWIG). This was accomplished in 293 participants, a response rate of 57.5%. Since several items were changed after the pilot among 28 participants, the data from the pilot were excluded. This left a total of 265 valid measures from 15 different nursing homes in The Netherlands.

The total group of 265 residents had a variety of primary diagnoses. Using DSM-V categorization (American Psychiatric Association, 2013), the population consisted of 41.1% with schizophrenia spectrum or other psychotic disorders (including 13.2% with a schizoaffective disorder) 12.5% with depressive (or related) disorders, 11.7% with bipolar or related disorders, 11.7% with personality disorders, 12.1% with neurocognitive disorders (including 6.4% with Korsakov, 5.7% with CVA or NAH) and 10.9% with other disorders (e.g. substance-related disorders, anxiety disorders or somatic symptom disorders). Age ranged from 38 to 91, with a mean age of 69.6 (SD 11.2). A majority of 66.8% of the participants was female. The mean duration of current stay was 3.5 years (SD 2.6), ranging from 1 month to 14 years and 5 months.

Scale Construction
Firstly, response distributions of the individual items were examined. No extremely unbalanced items were found. On the item with the strongest imbalance, 66.0% of the interviewed nurses answered with the same response.

A missing value analysis showed that a total of 0.45% of the values were missing. Little's MCAR test was significant (=.029), suggesting that the missing data were not at random. According to Tabachnick and Fidell (2014) when only few values are missing, imputation is not necessary. Listwise deletion was applied.

CFA was performed to examine the fit of a three dimensional model of well-being. Outcomes were all outside the required scope. The χ^2 = 1344.04 with 431 degrees of freedom. This leads to a relative χ^2 of 3.12. As a 'rule of thumb' a relative χ^2 of <2 indicates a good fitting model (Tabachnick & Fidell, 2014). For the Comparative Fit Index (CFI) and Tucker-Lewis Index (TLI) a score of >.95 is indicative of a good fitting model. With a CFI of .593 and TLI of .561, the current data do not fit within this range. Also, scores on the root mean square error of approximation (RMSEA): .095 CI [.089 - .101] and the standardized root mean square residual (SRMR): .114 fall outside the set scope for adequate fit, which is <.08 both for the RMSEA (Browne & Cudeck, 1993) and for the SRMR (Hu & Bentler, 1999). Because all values were outside the required scope, the theoretical model of well-being consisting of three dimensions was rejected.

Since the proposed three-dimensional model was rejected, a simplified model, in which well-being was regarded as one construct was used. A potential factor structure within this construct was investigated with exploratory factor analysis. For an overview of the scale development process, see Figure 1.

Unidimensionality

The inter-item correlation matrix for the 31 items was then observed and items correlating <.1 with more than 33% of the other items, were removed. This led to removal of seven items. Three sets of items had inter-item correlations >.6. One set of items was retained since the content of the items was considered sufficiently dissimilar and relevant. In both other sets of highly correlated items, one of the two items was removed. The item with the highest number of inter-item correlations >.1 was retained. With the remaining items corrected item-total correlations were checked. One item had a corrected item-total correlation below .30, this item was removed. A total of 21 items remained in the instrument.

With these 21 items an unrotated factor analysis (principal axis factoring) was performed, as a final check for unidimensionality. One item loaded <.32 on the first factor and was removed. The instrument consisted of 20 items at this point.

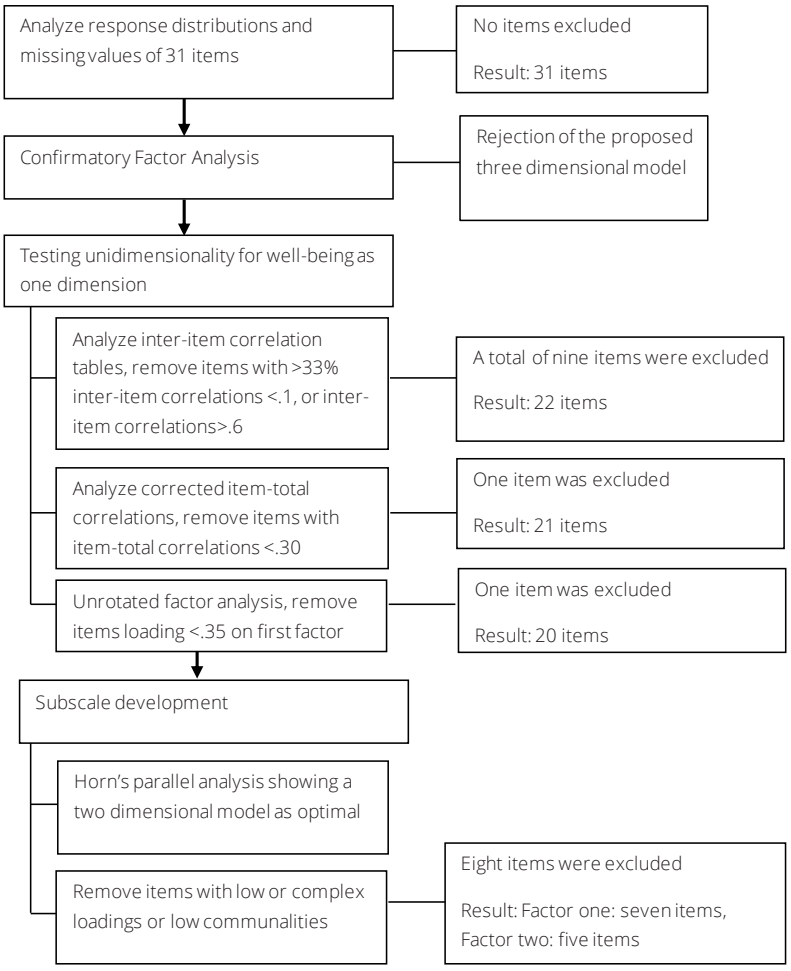

Figure 1. Flowchart showing the methodological steps taken in scale construction

Subscale Development

To explore the resulting dimensions for the existence of factors additional steps were taken. First the assumptions were checked. KMO = .87 ('great', according to Field, 2009) and Bartlett's test of sphericity was significant ($p < .001$). All KMO values for individual items were >.84, which is well above the acceptable level of .50 (Field, 2009).

Horns parallel analysis suggested an optimal factor solution with two factors (O'connor, 2000). Principal axis factoring with oblique rotation resulted in two factors that were comprehensible in terms of content, and simple in structure. The factors correlated >.32, therefore oblique rotation was chosen. All items loaded >.32 on one factor. Based on low

communalities (<.30) seven items were removed in an iterative process. After removal of these items, one item had become complex, i.e. loading >.32 on both factors. This item was removed. The instrument at this point consisted of 12 items, seven in the first factor, and five in the second factor. Communalities varied from .31 to .57, and this factor solution explained 43.6% of the variance. The factor solution is comprehensible, with two clearly different factors in terms of content. The differences between the factors concern two aspects. The first factor contains positively formulated items concerning mostly social themes. The second factor consists of negatively formulated items, concerning mostly psychological themes (see Table 1). Correlations between both factors were low but significant (r = .30, p < .001).

Table 1. Pattern matrix: principal axis factoring (oblique rotation)

	Factor	
	1	2
Responded positively when approached	.774	
Responded positively to jokes or humor	.672	
Enjoyed activities	.612	
Felt at ease in the company of others	.605	
There were nurses with whom the resident has a good relationship	.602	
Tried to make the best of his/her days in this accommodation	.559	
Showed to be content with him/her self	.434	
Was sad or depressed		-.743
Showed that life has become meaningless for him/her		-.702
Complained about physical limitations		-.700
Was anxious or tense		-.678
Indicated feeling unable to do anything		-.651

Reliability

Reliability of the components and of the dimensions was measured using the mean inter-item correlations, Cronbach's Alpha and McDonalds' Omega. Negatively formulated items were recoded so that higher scores are linked to higher well-being. The Cronbach's Alpha and McDonalds' Omega, and their confidence intervals complied with the set criterion of ω>.70 and all mean inter-item correlations fell within the range of .15 - .50 (see Table 2).

Construct Validity

Construct validity of the factors was assessed using results on several well-being measures, i.e. the Qualidem, the LWIG and Cantril's Ladder. Correlations with the Qualidem subscales were all significant (see Table 3).

Table 2. Reliability of dimensions and factors

	Mean inter item correlation	Cronbach's Alpha	McDonalds Omega
Factor 1: Social/positive well-being (7 items)	.38, 95% CI [.25-.46]	.80, 95% CI [.76, .83]	.80, 95% CI [.76, .84]
Factor 2: Psychological/ negative well-being (5 items)	.49, 95% CI [.23-.44]	.82, 95% CI [.79, .86]	.82, 95% CI [.79, .86]
Total well-being (12 items)	.28, 95% CI [.16,.39]	.82, 95% CI [.79, .86]	.82, 95% CI [.79, .85]

Table 3. Correlations LWOG and subscales Qualidem

	LWOG social/ positive	LWOG psychological/ negative	LWOGtotal
Care relationship	.365**	.354**	.442**
Positive affect	.758**	.362**	.693**
Negative affect	.208**	.675**	.548**
Restless tense behavior	.308**	.475**	.485**
Positive self image	.310**	.676**	.610**
Social relations	.619**	.216**	.518**
Social isolation	.300**	.358**	.407**
Feeling at home	.232**	.401**	.391**
Having something to do	.429**	.263**	.429**

**. Correlation is significant at the .01 level (1-tailed).

Correlations with both self-rated scales of well-being, the LWIG and Cantril's Ladder, were low to moderate. The correlations varied in strength and were all significant, except for 1 subscale (see Table 4).

Table 4. Correlations LWOG and self-rated well-being scales

	LWOG social/ positive	LWOG psychological/ negative	LWOGtotal
Cantril's Ladder	.170**	.208**	.232**
LWIG:			
LWIG_phys	.284**	.417**	.433**
LWIG_psych	.232**	.366**	.370**
LWIG_psych_affect	.257**	.384**	.397**
LWIG_psych_selfacc	.129*	.223**	.216**
LWIG_soc	.191**	.228**	.260**
LWIG_soc_positive	.190**	.196**	.239**
LWIG_soc_negative	.147**	.182**	.204**
LWIG_soc_communal	.089	.150**	.148**

**. Correlation is significant at the .01 level (1-tailed). *. Correlation is significant at the .05 level (1-tailed). LWIG = Laurens Well-being Inventory for Gerontopsychiatry

Discussion

The purpose of this study was the development of an observer-rated instrument for the measurement of well-being among gerontopsychiatric nursing home residents, which complements the self-rated Laurens Well-being Inventory for Gerontopsychiatry. Up to now no validated instrument for the measurement of observed well-being has been developed for the gerontopsychiatric population. The availability of such an instrument is of great importance since the measurement of well-being is ideally done from different perspectives to achieve a more complete picture, especially when it concerns older patients with a high risk of cognitive impairments (Sloane et al., 2005).

Development and Internal Structure

In the development of the measure, now referred to as the Laurens Well-being Observations for Gerontopsychiatry (LWOG), the intention was to develop a complementary observational instrument to the self-rated LWIG. Therefore the procedure that was employed in the development of the self-rated LWIG was followed as closely as possible. Unlike the LWIG, CFA in the development of the LWOG showed insufficient confirmation of the three-factor model of well-being. Therefore, the model was simplified by removing the dimensions and considering well-being as being one construct. Using exploratory factor analysis, a social subscale, consisting of seven positively formulated items and a psychological subscale with five negatively formulated items were found within this construct. The fact that the positively formulated items mainly focused on social well-being, whereas the negatively

formulated items were mainly on psychological well-being is a noteworthy result. It might indicate a general tendency by the nurses toward a more negative assessment of the psychological well-being of the resident, and a positive assessment of social well-being. Further research into the nurses general view on residents well-being might be interesting.

With the resulting subscales, two out of the three dimensions (social well-being and psychological well-being) from the LWIG had a comparable equivalent in the LWOG. The physical well-being dimension was not clearly represented in the observational instrument. Nonetheless, correlations between the LWIG and the LWOG are relatively high, giving sufficient reason to use the instruments in addition to each other.

Reliability and Validity

Reliability of both subscales and of the total 12-item measure, was acceptable. Validity was demonstrated in the significant and strong correlations with the Qualidem subscales ($p<.001$). Higher correlations were found between subscales that were, at face value, similar in content. The social/positive subscale of the LWOG for example correlated relatively highly with both the 'positive affect' subscale, and the 'social relations' subscale of the Qualidem. The psychological/negative subscale correlated higher with the 'negative affect', 'restless-tense behavior' and 'positive self-image' subscales of the Qualidem. This last Qualidem subscale contains in contrast to its name, only negatively formulated items. Furthermore, it should be noted that four of the items in the LWOG, two in both subscales, are almost identical to items in the Qualidem. This may influence the correlations between several subscales, i.e. between the social/positive LWOG subscale and the Qualidem subscale 'social relations' (two similar items), and between the psychological/negative LWOG and the Qualidem subscales 'positive self-image' (one similar item) and 'negative affect' (one similar item).

As hypothesized, low but significant correlations were found for both self-rated well-being scales. Correlations with the LWIG were on average stronger than the correlation with Cantril's Ladder. The strongest correlation was found between the LWIG subscale of physical well-being, and the psychological/negative subscale of the LWOG. This may be partly explained by the one item on physical complaints within the observed psychological/negative subscale, it may also however indicate that physical distress is interpreted as psychological distress by the observing nurse, or vice versa, that psychological distress is expressed as physical distress by the residents.

Low correlations were found between the LWOG subscales and the social subscales of the LWIG. This fact remains when looking at the individual items of the social LWIG-subscales that are comparable in content. For example, the item: 'felt at ease in the

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company of others', did not correlate with the self-rated item 'there are people with whom I can feel completely at ease' (r = .04). Also the item 'there are nurses with whom the resident has a good relationship' correlated only very weakly with the self-rated item 'there are nurses with whom I have a good relationship' (r = .13). Residents and nurses thus seem to appraise the level of social well-being differently. One possible explanation for this weak correlation may be the fact that nurses are a large part of the social environment of the resident (Canham et al., 2017). Both the resident and the nurse may therefore be susceptible to giving socially desirable answers, especially since all measures were conducted via interviews, and not in complete privacy. It is also possible that the evaluation of social interaction by the residents is influenced more strongly by their psychiatric disorder than the evaluation of physical and psychological factors (Meyer-Lindenberg & Tost, 2012). This may cause a difference in the interpretation and evaluation of social situations between nurse and resident. Finally, as weak correlations between observed- and self-rated were found as well in a study on need fulfillment among somatic nursing home residents, this might suggest a real discrepancy in the way residents and observers perceive several aspects of well-being (Custers, Westerhof, Kuin, Gerritsen, & Riksen-Walraven, 2013).The evaluation of social situations and interactions by gerontopsychiatric residents, and the relation of these social situations to well-being might be a relevant topic for future research.

Strengths and Limitations

Within this study, a some limitations must be mentioned. Firstly, concerning the measured time period, in the LWOG the items cover a period of two weeks, to ensure that the nurse had sufficient time with the resident upon which to base a solid judgement, even if the nurse was absent for a number of days. This differs from the one-week time period that is used in the LWIG, accounting for possible memory impairment in the participants. The difference in the measured time period might lead to a discrepancy in outcomes of the two instruments. Secondly, even though steps were taken to include the more severely disabled residents, a relatively large part (42.5%) of the total population was unable or unwilling to cooperate with the study. As only the residents that had participated in the self-rating scales were included in this study, the inclusion rate is relatively low, and generalizability is therefore limited. In future research participants that are unable to participate in a self-rating scale should also be included, to increase generalizability of the results. This also gives the opportunity to compare the level of observed well-being between participants that are either able or unable to respond to a self-rated well-being measure. Finally, since a cross-sectional design was used, sensitivity to change and test-retest reliability are not analyzed. In future research these topics should be further studied.

The large number of nursing homes in different regions of The Netherlands, and the large contribution of both the target population and professionals working with this population in the development of the measurement instrument are considered to be strengths in this study.

Conclusion

In this study the first steps have been taken towards the development of an observational instrument for the measurement of well-being among gerontopsychiatric nursing home residents. The instrument is developed to complement the LWIG, a self-rated well-being instrument. Initial results are promising, and the use of both measures in clinical practice might provide a useful indication of well-being from multiple perspectives. More research to examine test- retest reliability and sensitivity to change, and research also including the more severely disabled patients is essential.

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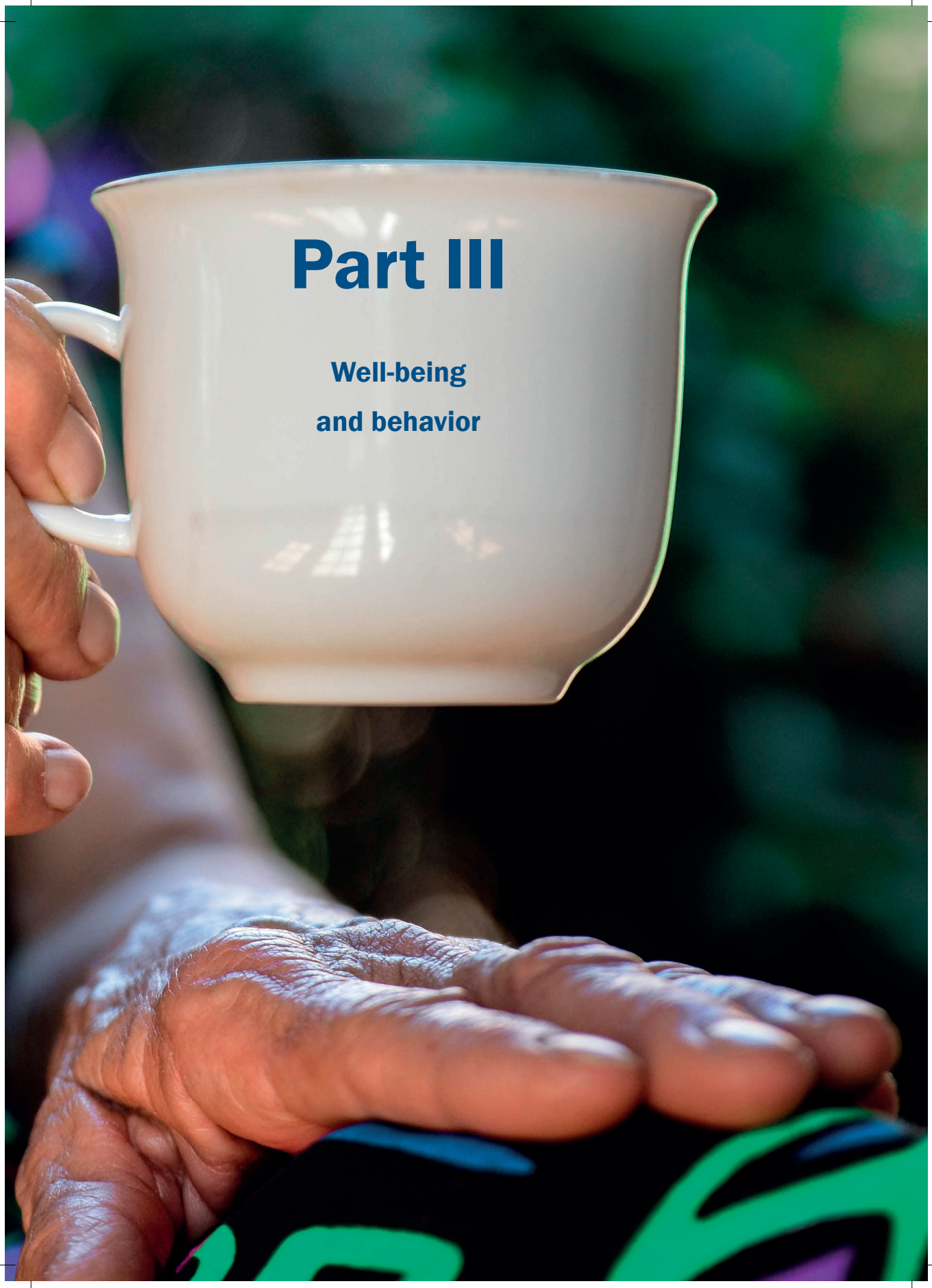
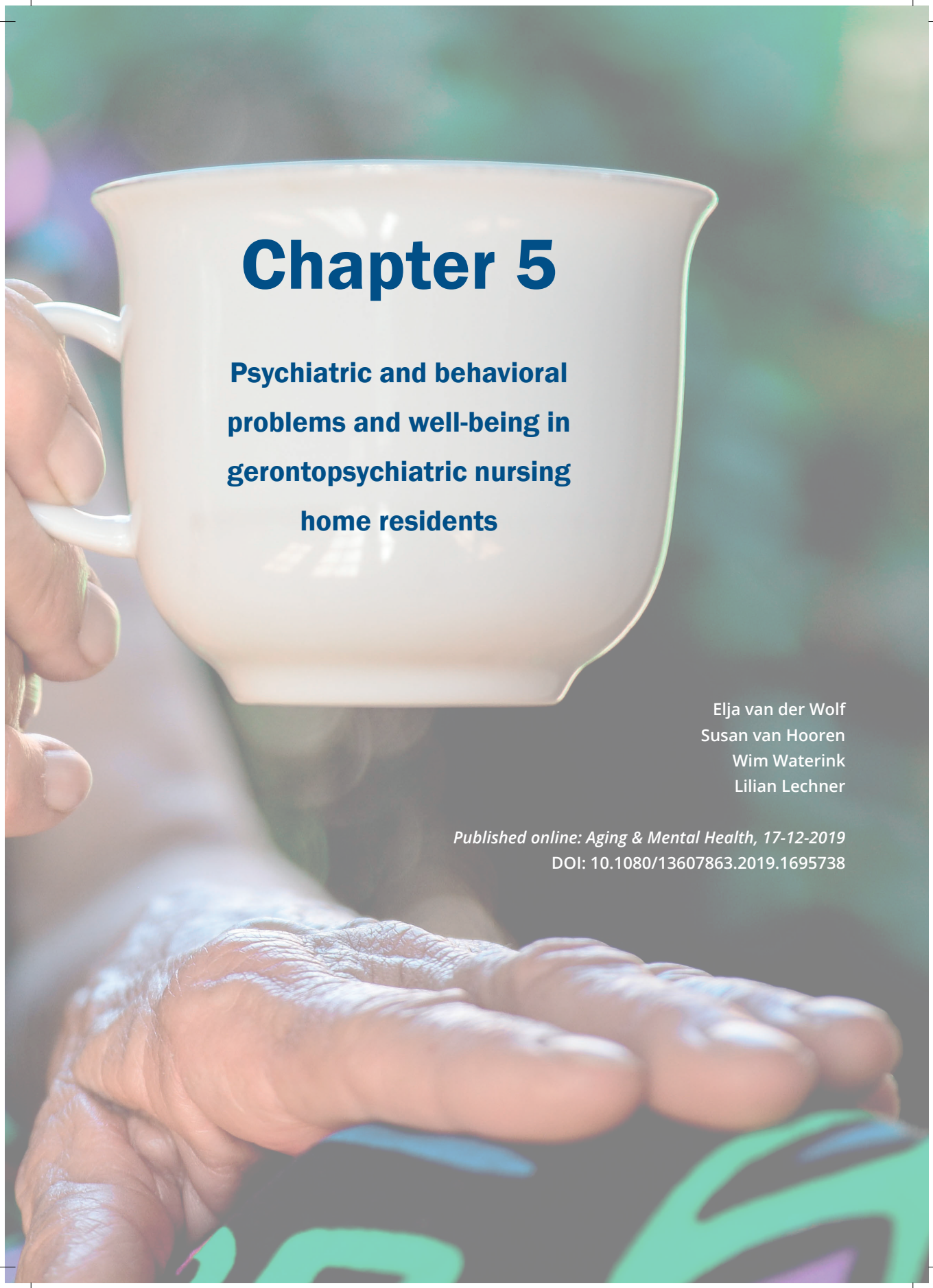


Part III

Well-being and behavior



Chapter 5

Psychiatric and behavioral problems and well-being in gerontopsychiatric nursing home residents

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Abstract

Objectives: Gerontopsychiatric nursing home residents are residents with a chronic mental condition (not dementia), in combination with one or more physical disorders. Psychiatric and behavioral problems are common within this population. The objective of this study is to examine these behaviors and their relationship to the level of both observed and self-rated well-being in the gerontopsychiatric population.

Method: Both gerontopsychiatric residents, and their primary formal caregiver in several nursing homes in The Netherlands were asked to participate in a structured interview concerning psychiatric and behavioral problems and resident well-being. Psychiatric and behavioral problems were measured with the Neuropsychiatric Inventory Questionnaire (NPI-Q) and the Cohen Mansfield Agitation Index (CMAI). Well-being was measured through the self-rated Laurens Well-being Inventory for Gerontopsychiatry (LWIG), and the observer rated Laurens Well-being Observations for Gerontopsychiatry (LWOG).

Results: A total of 126 residents participated in the study with ages varying from 42 to 90. Different types of chronic mental disorders such as schizophrenia spectrum disorder, bipolar disorders and personality disorders were prevalent in the population. Most psychiatric and behavioral problems are associated with lower observed and self-rated well-being. For irritability and affective problem behaviors the relationship with well-being was the most evident.

Conclusion: In daily care practice the relationship between well-being and psychiatric and behavioral problems should be taken into account in care planning and treatment. To further explore the direction and details of this relationship, more research is needed.

Introduction

The gerontopsychiatric population consists of older people with both a chronic mental disorder (other than dementia), and one or more physical disorders. Within this population long term care is often needed and provided. On average, one in six to twelve long-term care residents is part of the gerontopsychiatric population. In the Netherlands for example, this was found to be just over eight percent of the nursing home population (Stuurgroep Gerontopsychiatrie, 2012), and in the United States this population accounts for about 18 percent of the long term care population (Fullerton, McGuire, Feng, Mor, & Grabowski, 2009).

The gerontopsychiatric population differs from other nursing home residents in several respects. Gerontopsychiatric residents are often younger, unmarried, a larger proportion is male (Van den Brink, Gerritsen, Voshaar, & Koopmans, 2013) and there is a higher incidence of psychiatric or behavioral problems than in patients with dementia (Collet, De Vugt, Verhey, Engelen, & Schols, 2016; Van den Brink, Gerritsen, De Valk, Voshaar, & Koopmans, 2017; Van den Brink et al., 2013).

Psychiatric and behavioral problems in the gerontopsychiatric population can present in many forms such as irritability, delusions, apathy, constant requests for attention and verbal aggression (Van den Brink et al., 2017). These behaviors are a major focus of attention in nursing homes in terms of both pharmacological and non-pharmacological treatment (Abraha et al., 2017; Chiu, Bero, Hessol, Lexchin, & Harrington, 2015). They lead to an increase in costs and caregiver hours (Herrmann et al., 2006; Neubauer, Holle, Menn, Grossfeld-Schmitz, & Graesel, 2008) and may negatively impact on the health and job satisfaction of nurses (Evers, Tomic, & Brouwers, 2001; Testad, Mikkelsen, Ballard, & Aarsland, 2010).

As well as the negative effects on the care-workers, behavioral problems have often been associated with a decreased level of well-being of nursing home residents (Samus et al., 2005; Ven-Vakhteeva, Bor, Wetzels, Koopmans, & Zuidema, 2013; Winzelberg, Williams, Preisser, Zimmerman, & Sloane, 2005). Providing a pleasant living environment, at the highest possible level of well-being is one of the main objectives in nursing home care (Hamers, 2011). Increasing our knowledge about the relationship between problem behavior and well-being is a crucial first step in improving our interpretation and treatment of problem behavior, and in so doing to strive for the highest possible well-being for the target population.

In this study the relationship between well-being and the incidence of behavioral problems among gerontopsychiatric nursing home residents is examined. Well-being is a broad concept, and the definition has been the focus of much discussion in the literature (Ryan & Deci, 2001). In this article, the following definition of well-being will be used: '*a multidimensional concept that concerns the individuals' cognitive and emotional evaluations of their lives'* (Van der Wolf, Van Hooren, Waterink, & Lechner, 2018).

As shown in a recent review, no research has been conducted on the relationship between well-being and behavioral problems in the gerontopsychiatric nursing home population (Van der Wolf, Van Hooren, Waterink, & Lechner, 2017). Research has however been conducted in the population of nursing home residents with dementia. Results from this population are not entirely applicable to the gerontopsychiatric population as the prominent cognitive problems have a large impact on the behavior of residents with dementia. The results can however give some insight in the possible relationship between well-being and behavioral problems, considering several similarities between the populations that are relevant to both (problem) behavior and well-being, such as the living environment with others that are not family, dependency on care and (relatively) older age. In the population with dementia, a negative relationship between behavioral problems and well-being has been found, both in cross-sectional (Samus et al., 2005; Vogel, Mortensen, Hasselbalch, Andersen, & Waldemar, 2006; Winzelberg, et al., 2005; Zimmerman et al., 2005), in longitudinal (Ven-Vakhteeva, et al., 2013) and in a small (n = 31) double blind randomized control study on the effect of psychotropic medication on behavioral symptoms and quality of life (Kristin Martin-Cook, Hynan, Rice-Koch, Svetlik, & Weiner, 2005). These studies show that an occurrence of behavioral problems is related to diminished quality of life.

A correlation between well-being and behavioral problems was, however only found when well-being was rated with a caregiver-rated instrument. Self-rated well-being was not shown to be related to behavioral problems (Vogel et al., 2006; Yap et al., 2008; Zimmerman et al., 2005). Also when well-being was measured through 'detailed observations of the residents behavior' during a 5 hour-period, no relation with behavioral problems was found (Ballard et al., 2001).

There are several possible explanations for the difference between the relationship of behavioral problems when using self-rated as opposed to caregiver-rated well-being measurement instruments. Primarily this difference could be indicative of a reduced ability of people with dementia to assess their own well-being due to cognitive impairment and denial of problems (Clare, 2002; Tatsumi et al., 2009). Another possible explanation is that behavioral problems might, justly or unjustly, be interpreted by nurses as a sign of reduced

well-being, influencing the caregiver-rated well-being score. Finally, an underlying factor, such as caregiver burden or feelings of depression in the caregiver, might influence the results on both the observer-rated well-being and the problem-behavior instruments, as both concepts are often measured by the same observer. This may cause a slightly over inflated correlation (Logsdon, Gibbons, McCurry, & Teri, 2002; Zimmerman et al., 2005). Both observer-rated and self-rated well-being may therefore have strengths and limitations in the measurement of well-being and its correlation with psychiatric and behavioral problems.

In this study using interviews with the formal caregiver, we examined the link between self-rated well-being and observed well-being with the occurrence and frequency of behavioral problems within the gerontopsychiatric population (through interviews with the formal caregiver). We hypothesize that behavioral problems are associated with lower observed well-being. As cognitive impairment plays a smaller role in the gerontopsychiatric population than in the population described above, we hypothesize there will be a (weak) relationship between behavioral problems and self-rated well-being.

Method

Design and subjects

Subjects were all residents of a gerontopsychiatric ward, in one of four selected nursing homes in The Netherlands. One of these facilities was a general nursing home with several gerontopsychiatric wards, the other three were specialized nursing homes for the gerontopsychiatric population. Data were collected in the period from April 2014 to April 2015 in a cross sectional study design. Inclusion criteria for the participants were: living at least one month in the institution, receiving long term care (no revalidation or temporary care) and having one or more DSM IV diagnoses. Exclusion criteria were dementia (other than Korsakov's dementia) as a primary diagnosis or inability to participate in the interview due to cognitive or physical limitations. This was assessed by the first-responsible nurse (i.e. the nurse that, within the team of nurses, bears primary responsibility for the care of this resident) or it was established by the researcher during the interview, if it appeared that the resident was unable to understand or answer the questions. There were no age-restrictions.

Procedure

Both residents and their first-responsible nurse were interviewed by the first author or by one of three trained research assistants for data collection. A letter describing the content and purpose of the study, was sent to the residents and their family member or legal

representative, one or two weeks in advance. Information on the content and purpose of the study was provided again before the interview, and informed consent was given by all participants. Informed consent was also sought from the legal representative of the resident if the first-responsible nurse deemed it necessary. This procedure was approved by the research ethics committee (cETO) of the Open University of the Netherlands (ref no: U2013/03517/CBO).

Measures

Well-being

For the measurement of well-being, two instruments were used that were recently developed specifically for the gerontopsychiatric population. One instrument measured self-rated well-being: the Laurens Well-being Inventory in Geronto-psychiatry (LWIG) (Van der Wolf et al., 2018), and one instrument measured well-being by proxy: the Laurens Well-being Observations for Gerontopsychiatry (LWOG) (Van der Wolf, Van Hooren, Waterink, & Lechner, 2019).

The LWIG is a self-rated 30-item well-being measure. It contains six subscales within three dimensions: physical well-being, social well-being and psychological well-being. This study focused on the three dimensions of well-being and not on the six subscales for purposes of conciseness. A 4-point answer scale is used for all items. The range of the total scale is 30 to 120, with a higher score indicating a higher level of well-being. Reliability of the LWIG is sufficient, McDonalds Omega's of the subscales vary from .68 to .84. Validity is adequate as the scale correlates sufficiently with another self-rated well-being measure, i.e. $r > .40$ ($p<.01$) with Cantril's ladder (Cantril, 1965; Van der Wolf et al., 2018). Although self-rated and observer rated well-being is generally only weakly correlated, the LWIG subscales were significantly related to most of the observer-rated Qualidem subscales (Ettema, Dröes, De Lange, Mellenbergh, & Ribbe, 2007; Van der Wolf et al., 2018).

The LWOG is a 12-item observer-rated well-being instrument. It consists of two subscales, a social, positive subscale with items like 'there are nurses with whom the resident has a good relationship' and a psychological negative subscale with items like 'was anxious or tense'. The instrument uses a 4-point answer scale, and the range of the total scale is 12 to 48, with a higher score indicating a higher level of well-being. A sufficiently high reliability of the LWOG was found with McDonalds Omega's of the total scale and subscales varying from .80 to .82. Validity of the LWOG is demonstrated, with adequate correlations, r varying from .39 to .69 ($p<.01$) with the observer-rated Qualidem subscales (Ettema et al., 2007), and with the self-rated well-being measure, Cantril's Ladder ($r = .23$, $p < .01$) (Van der Wolf et al., 2019). The relation with the LWIG subscales was also examined by Van der Wolf et al (2019). It was found that all subscales of both instruments were significantly

related, with stronger relations between the psychological negative LWOG subscale and the physical (r = .42, p < .01), the psychological (r = .37, p < .01) and the social (r = .23, p < .01) LWIG subscales. The relations between the social positive LWOG subscale and the LWIG subscales were lower, but also significant: r = .28 , p < .01 for the physical scale, r = .23, p < .01 for the psychological subscale and r = .19 , p < .01 for the social subscale (Van der Wolf et al., 2019).

Behavioral problems

Agitation and aggression was measured using the Cohen Mansfield Agitation Inventory, Dutch version (CMAI-D) (Cohen-Mansfield, 1991; Cohen-Mansfield, Marx, & Rosenthal, 1989). This is a 29-item instrument, measuring the frequency of agitated behavior, through the observations of the primary formal caregiver. A total agitation score and three subscales (i.e. aggressive behavior, physical non-aggressive behavior and verbal agitation) are computed (Zuidema, De Jonghe, Verhey, & Koopmans, 2007a). The items are rated on a 7-point scale, ranging from never (1) to several times an hour (7). The range of this scale is 29 to 203, with higher scores indicating more frequent occurrence of agitated or aggressive behavior. Good validity and reliability has been reported (Cohen-Mansfield & Libin, 2004).

Behavioral problems can also occur in the form of neuropsychiatric symptoms like apathy, delusions and hallucinations. These symptoms were measured with the Neuropsychiatric Inventory Questionnaire (NPI-Q), an abbreviated version of the NPI (Cummings et al., 1994; Kaufer et al., 2000). The NPI-Q is a caregiver-rated instrument, and examines 12 neuropsychiatric symptoms. Items consist of a screening question, with a yes/no answer scale, followed by a severity assessment using a 3-point answer scale varying from mild (1), moderate (2) to severe (3). This scale ranged from 0 (no neuropsychiatric behaviors) to 36 (severe neuropsychiatric behaviors). Reliability and validity of the NPI-Q have been established (De Jonghe, Kat, Kalisvaart, & Boelaarts, 2003; Kaufer et al., 2000). Subscales in different compositions have been established for populations with dementia (Canevelli et al., 2013). Because in the current study a different target group was examined, and to be able to include groupings of related behaviors in the model, the factor structure was determined in the data itself, using principal components analysis.

As the components were not highly correlated ($r \leq .22$), orthogonal rotation was chosen. Based on Kaiser's criterion, a clear and understandable 4- component solution was found, explaining 55.6% of the variance. The first component consisted of irritability, agitation and anxiety, three behavioral symptoms that are all stress- or tension related. This component was named the 'tension-component. The second component contained disinhibition, euphoria and aberrant motor behavior, three symptoms that are related to disturbed

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inhibition. This component was named the 'disinhibition-component. The third component consisted of nighttime behavior, depression, apathy and appetite, all depression related symptoms. This component was called the 'depression-component. The last component consisted of delusions and hallucinations, and was named the 'psychosis-component.

Potential confounders
The correlation between behavioral problems and level of well-being can be confounded by several patient characteristics. To be able to control for confounders, data on several characteristics were collected. Level of functioning was evaluated by the physician, using the Global Assessment of Functioning Scale (GAF) (Endicott, Spitzer, Fleiss, & Cohen, 1976). ADL dependency was measured through interviews with the first-responsible nurse, using the Barthel Index (Mahoney and Barthel, 1965). This is a 10-item index with items on dependency concerning tasks like bathing, feeding and toilet use. It was found to be reliable in different ways of administration (Intraclass-correlation = .89) and on testing by different observers (Intraclass correlation .95 to .97) (Sainsbury, Seebass, Bansal, & Young, 2005).

Electronic client dossiers (ECD) were consulted to collect diagnostic data and some demographic data (i.e. age and duration of stay in current residence). Diagnoses were checked and confirmed by the appointed elderly care physician. Other demographic data on educational level (low education: 'Lower than elementary school', 'primary school completed' and 'primary school and two years follow up education', medium education: 'vocational education' and 'middle-level applied education', and high education: 'higher education' and 'academic education') and marital status ('married or living together', 'single', 'divorced', 'widowed') was requested from the residents themselves.

Data analysis
SPSS version 22 was used for all statistical analyses. Assumptions of linearity were visually inspected using scatterplots. All correlations among the independent variables were .49 or lower, suggesting that multicollinearity is not a problem (Tabachnick & Fidell, 2014). Durbin-Watson scores (for the LWIG) varied from 1.71 to 2.01, suggesting independent errors (Field, 2009). Using scatterplots, the relationship between the dependent and independent variables were visually checked. No non-linear relationships were observed. No outliers were found (IQR > 3).

Due to the fact that some of the collected data was part of a pilot-study in the development of two well-being scales (LWIG and LWOG), the data of 28 of the participants is missing on some specific items. This is the case for one LWIG item ('I am sometimes being bullied') and for two LWOG items ('responded positively to jokes or humor' and 'tried to make the best

of the current situation'). As 28 participants is a substantial percentage of the total group of participants, exclusion of these data would largely impact the power of the results. Therefore imputation of the missing data was considered. Participants for whom the data were missing were randomly selected, and were consequently not expected to differ as a group from the other 98 participants. Using independent samples t-tests the well-being scores of the 28 participants with missing data were compared to the 98 participants that had no missing data. No significant differences were found, confirming this expectation. Furthermore, results on the specific items with missing values were visually compared to the other items in the instrument using histograms. No striking differences were found. Data were therefore imputed using expectation maximization (Gold & Bentler, 2000). For all other variables, only data on age was missing for two participants, there were no other missing values.

Multiple linear regression was performed, with the scores of the subscales of both well-being measures as dependent variables and the different scales of the measures on problem behavior, CMAI and NPI, as independent variables.

The first step was to examine the potential relevant covariates, correlations (for continuous variables) and analysis of variance (ANOVA) (for categorical variables). Only those variables that had a significant relationship with one or both of the well-being measures were added as covariates. A series of linear multiple regressions were then performed, with the different subscales of the well-being instruments as the dependent variable. Forced entry was used as method, and the variables were included in two blocks: relevant covariates in the first block, and psychiatric and behavioral problems in the second block. Cohens f^2 was used as an effect size, defined as small ($f^2 \geq .02$), medium ($f^2 \geq .15$) and large ($f^2 \geq .35$) (Cohen, 1977; Soper, 2019).

Results

Participant characteristics

From the total population of 225 nursing home residents, a total of 126 residents agreed to participate in the study, a participation rate of 56%. The participating population comprised of 88 women and 38 men, with ages varying from 42 to 90 (mean 66.8). Schizophrenia spectrum disorder was the most common primary diagnosis (50%). Other disorders were depressive disorders (11.1%), bipolar or related disorders (11.1%), personality disorders (5.6%), neurocognitive disorders (9.5%) and other disorders (12.7%). Mean GAF score was 32.3 (*SD* = 8.29), varying from 15 to 60. Duration of stay in de the current institution varied from 2 months to 14.4 years (mean 4 years). Concerning marital status, 36.3% were

unmarried, 35.5% were divorced, 16.9% of the participants were widowed and 11.3% were married or living together. For an overview of results on dependent and independent variables, see Table 1. Since gender was found to be an important covariate with significant differences on self-rated well-being, data in the table were subdivided by gender.

Behavior and well-being

Self-rated well-being

The relevant covariates were sex, ADL dependence, level of education and level of functioning. Forced entry analysis was used with the relevant covariates in the first block, and psychiatric or behavioral problems, measured with the CMAI and the NPI in the second block. For the results on the self-rated well-being subscales, see Table 2. For all three subscales the first model is significant, mainly due to sex (men have higher well-being scores than women) and for the psychological subscale also ADL dependence (more dependence is related to lower psychological well-being) is a significant predictor of the well-being score. The second model is significant in all three subscales with small to medium effect sizes, even though the change in R^2 is not. None of the covariates add significantly in the second model. For physical and social well-being only the NPI depression component has a significant negative relationship with well-being. For psychological well-being, there is a positive relationship with the NPI disinhibition component, and a negative relationship with the NPI tension component. None of the CMAI subscales was significantly related to well-being.

Observed well-being

For observed well-being the results of the hierarchical multiple regression are found in Table 3. The models were structured in the same way as the models for self-rated well-being. For the psychological-negative subscale of the LWOG a large proportion (45%) of the variance is explained by psychiatric and behavioral problems. The effect size is large, Cohen's f^2 =1.0. The strongest contributors for this relationship are the NPI tension and depression components and the verbal aggressive subscale of the CMAI. However, also the NPI psychosis component was related to lower well-being, whereas the NPI disinhibition component and the CMAI physical aggression subscale were related to higher levels of observed well-being. The results differed for the social-positive subscale of the LWOG. Only 12% of the variance was explained by psychiatric and behavioral problems with a medium effect size. For this subscale there was a positive relationship with the NPI disinhibition component, and a negative relationship with the NPI tension component. The results are similar to the results on self-rated psychological well-being.

Table 1. Results on well-being and behavioral measures

	Mean total (*SD*) (*N*=126)	Mean women (*SD*) (*N*= 88)	Mean men (*SD*) (*N*= 38)	Difference gender[1]
Self-rated well-being (LWIG)				
Total LWIG score (range 30 to 120)	81.2 (16.7)	78.6 (15.4)	87.2 (18.4)	t(124)=2.70**
Physical well-being (range 6 to 24)	16.0 (4.2)	15.5 (3.9)	17.3 (4.7)	t(124)=2.26*
Psychological well-being (range 11 to 44)	30.9 (7.6)	30.0 (7.4)	33.2 (7.9)	t(124)=2.21*
Social well-being (range 13 to 52)	34.3 (7.7)	33.2 (7.3)	36.7 (8.1)	t(124)=2.40*
Observed well-being (LWOG)				
Total LWOG score (range 12 to 48)	35.9 (6.0)	35.7 (6.2)	36.2 (5.6)	NS
Social-positive subscale (range 7 to 28)	21.8 (3.9)	21.9 (3.9)	21.4 (3.9)	NS
Psychological-negative subscale (range 5 to 20)	14.1 (3.8)	13.8 (3.7)	14.8 (4.0)	NS
Neuropsychiatric symptoms (NPI-Q)				
Total NPI-Q score (range 0 to 36)	8.5 (5.7)	9.0 (5.5)	7.4 (6.2)	NS
Tension component (range 0 to 9)	3.2 (2.6)	3.3 (2.6)	2.9 (2.7)	NS
Disinhibition component (range 0 to 9)	1.4 (1.8)	1.4 (2.0)	1.4 (1.6)	NS
Depression component (range 0 to 12)	2.7 (2.5)	3.0 (2.5)	2.0 (2.6)	t(124)=-2.15*
Psychosis component (range 0 to 6)	1.2 (1.6)	1.3 (1.6)	1.1 (1.7)	NS
Agitated behavior (CMAI)				
Total CMAI score (range 29 to 203)	47.7 (14.5)	47.1 (14.2)	49.1 (15.4)	NS
Verbal aggressive behavior (range 4 to 28)	11.6 (6.2)	11.5 (5.9)	11.9 (7.0)	NS
Physical non-aggressive behavior (range 7 to 49)	11.7 (5.4)	11.5 (5.2)	12.2 (5.7)	NS
Physical aggressive behavior (range 8 to 56)	12.3 (5.0)	12.2 (5.2)	12.4 (4.3)	NS

LWIG = Laurens Well-being Inventory for Gerontopsychiatry; LWOG = Laurens Well-being Observations for Gerontopsychiatry; NPI-Q = Neuropsychiatric Inventory-Questionnaire; tension component contains irritability, agitation and anxiety, disinhibition component contains disinhibition, euphoria and aberrant motor behavior, depression component contains nighttime behavior, depression, apathy and appetite, psychosis component contains delusions and hallucinations; CMAI = Cohen Mansfield Agitation Index; Results are based on imputed data.

[1]Independent samples t-tests were used to test for differences between women and men; *p < .05; **p < .01

Table 2. Hierarchical multiple regression of behavioral problems on self-rated well-being scores

	LWIG physical		
		B (*SE*)	β
Block 1			
Constant		2.61 (.38)	
Sex		-.23 (.14)	-.15
Barthel score		.03 (.01)	.21*
GAF		.01 (.01)	.05
Level of education		.00 (.04)	.01
R^2	.09*		
Block 2			
constant		2.83 (.44)	
Sex		-.15 (.14)	-.10
Barthel score		.01 (.01)	.11
GAF		.01 (.01)	.09
Level of education		.00 (.04)	.01
tension component		-.07 (.09)	-.08
disinhibition component		.19 (.11)	.17
depression component		-.31 (.11)	-.28**
psychosis component		-.02 (.08)	-.03
CMAI verbally aggressive		-.02 (.05)	-.05
CMAI physical not-aggressive		-.00 (.09)	-.00
CMAI physical aggressive		-.01 (.12)	-.01
ΔR^2	.10		
R^2 (f^2)	.18* (.11)		

LWIG = Laurens Well-being Inventory for Gerontopsychiatry; NPI=Neuropsychiatric Inventory; tension component contains irritability, agitation and anxiety, disinhibition component contains disinhibition, euphoria and aberrant motor behavior, depression component contains nighttime behavior, depression, apathy and appetite, psychosis component contains delusions and hallucinations; CMAI=Cohen Mansfield Agitation Index.
*p <. 05, **p < .01, ***p < .001

	LWIG psychological			LWIG social	
	B (*SE*)	β		*B* (*SE*)	β
	2.86 (.37)			3.24 (.33)	
	-.28 (.13)	-.19*		-.27 (.12)	-.21*
	.02 (.01)	.20*		-.00 (.01)	-.03
	.00 (.01)	.04		.01 (.01)	.08
	.01 (.04)	.02		-.06 (.03)	-.17
.08*			.08*		
	2.59 (.44)			3.40 (.39)	
	-.21 (.13)	-.14		-.22 (.12)	-.17
	.02 (.01)	.16		-.01 (.01)	-.12
	.01 (.01)	.10		.01 (.01)	.11
	.01 (.04)	.03		-.07 (.03)	-.18*
	-.18 (.09)	-.23*		-.09 (.08)	-.14
	.26 (11)	.24*		.11 (.10)	.11
	-.15 (.11)	-.13		-.23 (.10)	-.24*
	-.02 (.08)	-.03		.05 (.07)	.06
	-.02 (.05)	-.05		-.03 (.04)	-.07
	.11 (09)	.13		.00 (.08)	.01
	.06 (.12)	.05		.03 (.10)	.03
.11			.09		
.19* (.14)			.18* (.12)		

Table 3. Standard multiple regression of behavioral problems on observed well-being scores

	LWOG psychological-negative		LWOG social-positive	
	B (*SE*)	β	*B* (*SE*)	β
Block 1				
Constant	2.39 (.41)		2.58 (.30)	
Sex	-.18 (.15)	-.11	.09 (.11)	.07
Barthel score	.03 (.01)	.23*	-.00 (.01)	.01
GAF	.00 (.01)	.02	.01 (.01)	.17
Level of education	.06 (.04)	.13	.00 (.03)	.00
R^2	.08*		.04	
Block 2				
constant	2.91 (.37)		2.85 (.35)	
Sex	-.06 (.11)	-.04	.12 (.11)	.10
Barthel score	.01 (.01)	.08	-.00 (.01)	-.04
GAF	.01 (.01)	.10	.01 (.01)	.20*
Level of education	.06 (.03)	.13	-.01 (.03)	-.02
Tension component	-.28 (.07)	-.33***	-.16 (.07)	-.25*
disinhibition component	.19 (.09)	.16*	.20 (.09)	.23*
depression component	-.37 (.09)	-.31***	-.12 (.09)	-.14
psychosis component	-.13(.06)	-.15*	.04 (.06)	.06
CMAI verbally aggressive	-.19 (.04)	-.39***	-.01 (.04)	-.03
CMAI physical not-aggressive	.07 (.07)	.07	-.04 (.07)	-.05
CMAI physical aggressive	.20 (.10)	.16*	-.06 (.09)	-.07
ΔR^2	.45***		.13*	
R^2 (f^2)	.53*** (1.00)		.17* (.16)	

LWOG = Laurens Well-being Observations for Gerontopsychiatry; NPI = Neuropsychiatric Inventory; tension component contains irritability, agitation and anxiety, disinhibition component contains disinhibition, euphoria and aberrant motor behavior, depression component contains nighttime behavior, depression, apathy and appetite, psychosis component contains delusions and hallucinations; CMAI=Cohen Mansfield Agitation Index.
*p < .05, **p < .01, ***p < .001

Discussion

This study aimed to examine how psychiatric and behavioral problems are related to well-being among gerontopsychiatric nursing home residents. Specifically, we aimed to investigate if the strength of this relationship is associated with the method of measurement, comparing the results from a self-rated well-being measure with the results of an observer-rated measure, conducted by the first-responsible nurse. We hypothesized a moderate relationship for caregiver-observed well-being and behavioral problems, and a weak relationship for self-rated well-being and behavioral problems.

Firstly, as there is ambiguity in the term nursing home, and the term may have a different meaning in different countries (Sanford et al., 2015), it is important to discuss the type of residence in the context of this study. A nursing home in The Netherlands is a high level care facility, where people can live in a homely environment, and where nearly all medical care can be provided within the nursing home. People generally stay here until their death. The gerontopsychiatric population lives in special units, or a specialized nursing home, and is not placed in wards with people with dementia or with purely somatic complaints. This approach differs between European countries and the USA. In the USA the gerontopsychiatric population is generally admitted to standard nursing home care, and lives in wards with people with dementia or somatic disorders (Fullerton et al., 2009; Grabowski, Aschbrenner, Rome, & Bartels, 2010). A unique specialty in The Netherlands is the elderly care physician, a physician who is employed by the nursing home (Sanford et al., 2015).

Several differences were found between self-rated and observer-rated well-being and their relationship with problem behavior. Firstly, although all self-rated well-being subscales were associated with one or more behavioral problems even after controlling for other relevant resident characteristics, the relationship to behavioral problems was greater for observed well-being than for self-rated well-being. There were also some behaviors that were associated with lower observed well-being (i.e. the NPI psychosis component and CMAI verbal aggression), that were not related to lower self-rated well-being.

The NPI depression component was related to both lower self-rated physical and social well-being and to lower observed psychological-negative well-being. This is in line with a previous study on depression and well-being in the gerontopsychiatric population (Smalbrugge et al., 2006). The NPI tension component was related to lower self-rated psychological well-being and to lower scores on both of the observed well-being subscales. Since happiness is enhanced by prosocial and positive behavior (Sin and Lyubomirsky, 2009; Warner and Vroman, 2011), it is conceivable to assume that the opposite is also true,

that negative behavior works as a reinforcement of somberness and low mood. This line of thought is supported by a small study among nursing home residents with dementia (Kristin Martin-Cook et al., 2005). Also, the negative relationship to items within the NPI tension component (i.e. agitation, irritability and anxiety) are in line with the outcomes of another study among long term care residents with dementia (Samus et al., 2005).

Interestingly, the NPI disinhibition component, was related to higher observed well-being and to a higher score on the psychological subscale from the LWIG. The NPI disinhibition component contains items on disinhibition, euphoria and aberrant motor behavior. When looking at correlations of the separate items with both the self-rated psychological well-being subscale and the observed well-being subscales, the strongest positive correlation was found for the euphoria item. It is also possible that abnormally elevated mood adds to well-being. The fact that both self-rated and observed well-being are positively related to this subscale, provides a strong indication that there is indeed a positive association between the behaviors in the NPI disinhibition component and well-being.

Another unexpected positive relation was found for the CMAI physical aggression subscale, which was related to higher observed psychological well-being on the LWOG. The expression of physical aggression may be caused by disinhibition, pointing towards the idea that disinhibited behavior is related to higher well-being, as was argued previously. It is also possible that the low mean score on the physical aggression scale slightly inflated the relation. However, 55.6% of the participants was rated with one or more of the physical aggressive behaviors at least once a week. More research on the relation between physical aggression, disinhibition and well-being in the gerontopsychiatric population is strongly recommended.

In general one could say based on these positive relations, that some problem behaviors that may be experienced as a problem for the environment of the resident, may not actually be a problem for the residents themselves. They might even result from, or lead to a higher level of well-being of the resident. In research on long-term care residents with dementia however, this relationship was not found. Both disinhibition and aberrant motor behavior were associated with lower quality of life scores, and euphoria was not significantly related to quality of life (Samus et al., 2005). The prevalence of euphoric behavior is found to be higher in the gerontopsychiatric population (29.4%) than in the population with dementia. Samus et al. (2005) do not give prevalence rates of the NPI symptoms, but Zuidema, Koopmans, & Verhey (2007) studied a similar population, and found a 7% prevalence rate for euphoria. A small prevalence rate may explain the absence of a significant relationship in a population of residents with dementia.

On all subscales, men rated their well-being higher than women. This is in line with previous research (Pinquart & Sörensen, 2001). After adding the behavioral subscales the relation between gender and well-being is no longer significant. It might be that this difference between men and women is mainly explained by differences in behavior, such as the higher score of women on the NPI depression component, as depressive symptoms are strongly related with well-being (Smalbrugge et al., 2006). It might also be the case that men and women experience and value their own problem behavior differently, or that their problem behavior is caused by different factors. This would be an interesting topic for future research.

Strengths and weaknesses

This study is, to the best of our knowledge the first study on the relationship between psychiatric and behavioral problems and the level of well-being among gerontopsychiatric nursing home residents. It aims to add to the understanding of how behavior and well-being are related, which is a first step towards improving our interpretation and treatment of behavioral problems, and enhancing resident well-being. The use of well-being scales that are specifically designed for the gerontopsychiatric population is one of the key strengths of this study. Another significant strength is the inclusion of both self-rated and observer-rated well-being measures. Well-being is a broad and highly subjective construct, and to provide a complete picture, multiple perspectives should be included in the measurement (Sloane et al., 2005). An important limitation in this study is its cross-sectional design, as it limits the possibility of drawing conclusions on the direction of the relations. Another limitation is the amount of missing values, mainly in the observed-well-being scales. Exclusion of the cases with missing values would have resulted in the loss of quite a large percentage of the participant numbers, and subsequently loss of power for the analyses. The best solution was to impute the missing values using expectation maximization (Gold & Bentler, 2000), but any solution to a large number of missing values can provide possible bias in the results.

A participation-rate of only 56% is not very high, however in this population participation rates around 50% are common (Depla, De Graaf, & Heeren, 2005; Smalbrugge et al., 2006). The reasons for not participating varied from physical health problems to simply not feeling like participating. It can be assumed that more highly functioning residents participated more frequently, and residents with lower well-being or with more behavioral problems may be underrepresented. This may limit the generalizability of the results.

Furthermore, the factor structure of the NPI-Q as used in this study should be discussed. Factor analysis has been performed often with data from a dementia population, resulting in different factor structures e.g. (Aalten et al., 2007; Chen et al., 2018; Zuidema, De Jonghe,

Verhey, & Koopmans, 2007b). In 2012, a review was done on the studies that performed FA on the NPI up to then (Canevelli et al., 2013), and found some recurring patterns in the factor structure. The psychosis factor as found in this study, was found in all studies included by Canevelli et al. Also the combination of disinhibition and euphoria, and the combination of irritability and agitation/aggression was often found. Compared to the findings in Canevelli's review, one slightly unusual finding in our current study was the fact that anxiety and depression were not in the same factor. In conclusion the factor structure of the NPI as found in this study did not seem to differ greatly from findings in the dementia population.

Directions for future research and care practice:
As this is the first study on the relationship between psychiatric and behavioral problems and well-being in the gerontopsychiatric population, more research is recommended to determine if the research findings of an association of both self-rated and observer rated well-being with several behavioral problems can be verified. In order to study the direction of the relationship, experimental or longitudinal research on this topic would be strongly recommended. As mentioned previously, the relation between gender, self-rated well-being and behavioral problems might also be an interesting topic for future research. In longitudinal research, differences in the causes of behavioral problems and differences in the effects of these problems on levels of well-being might be studied among men and women. More insight into the differences in well-being and behavior between men and women could provide a direction for the development of treatment and care in daily care practice. Finally, future research might focus on some relevant characteristics of the observers, such as burden and feelings of depression, that could potentially influence their assessment of behavioral problems and of well-being.

Based on this study, some recommendations can be made for care practice. If the aims of the care institution are to strive for high well-being among the gerontopsychiatric residents, treatment should focus on depressive and apathetic behaviors, and also the more severe manifestations of irritability, anxiety and agitation. Also, improving the sense of well-being among the gerontopsychiatric population could lead to a decrease in irritable and agitated behavior, which in turn could prevent reductions in health status and job satisfaction of care employees (Evers et al., 2001; Testad et al., 2010). Finally, in this study we see several differences in the rating of well-being by residents themselves compared to the ratings by their primary responsible formal caregiver. A difference that has also been found in this population by Van den Brink et al. (2018) concerning unmet needs. It is important for (formal) caregivers to be aware of these differences, and to remain attentive to the perceptions of the residents themselves when it comes to well-being and its related factors.

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Conclusions

Contrary to findings in long term care residents with dementia (Vogel et al., 2006; Yap et al., 2008; Zimmerman et al., 2005) but in accordance with our hypotheses, we found a relationship between self-rated well-being and several behavioral problems. Consistent with studies in participants with dementia, the relationship between well-being and behavioral problems was strongest when well-being was measured via observation measures. For irritability and affective problem behaviors the relation with well-being was the most evident, a finding that gives direction for care and treatment in daily care practice. More research on well-being and behavioral problems in the gerontopsychiatric population is needed to further explore this relation and strengthen conclusions on this topic.

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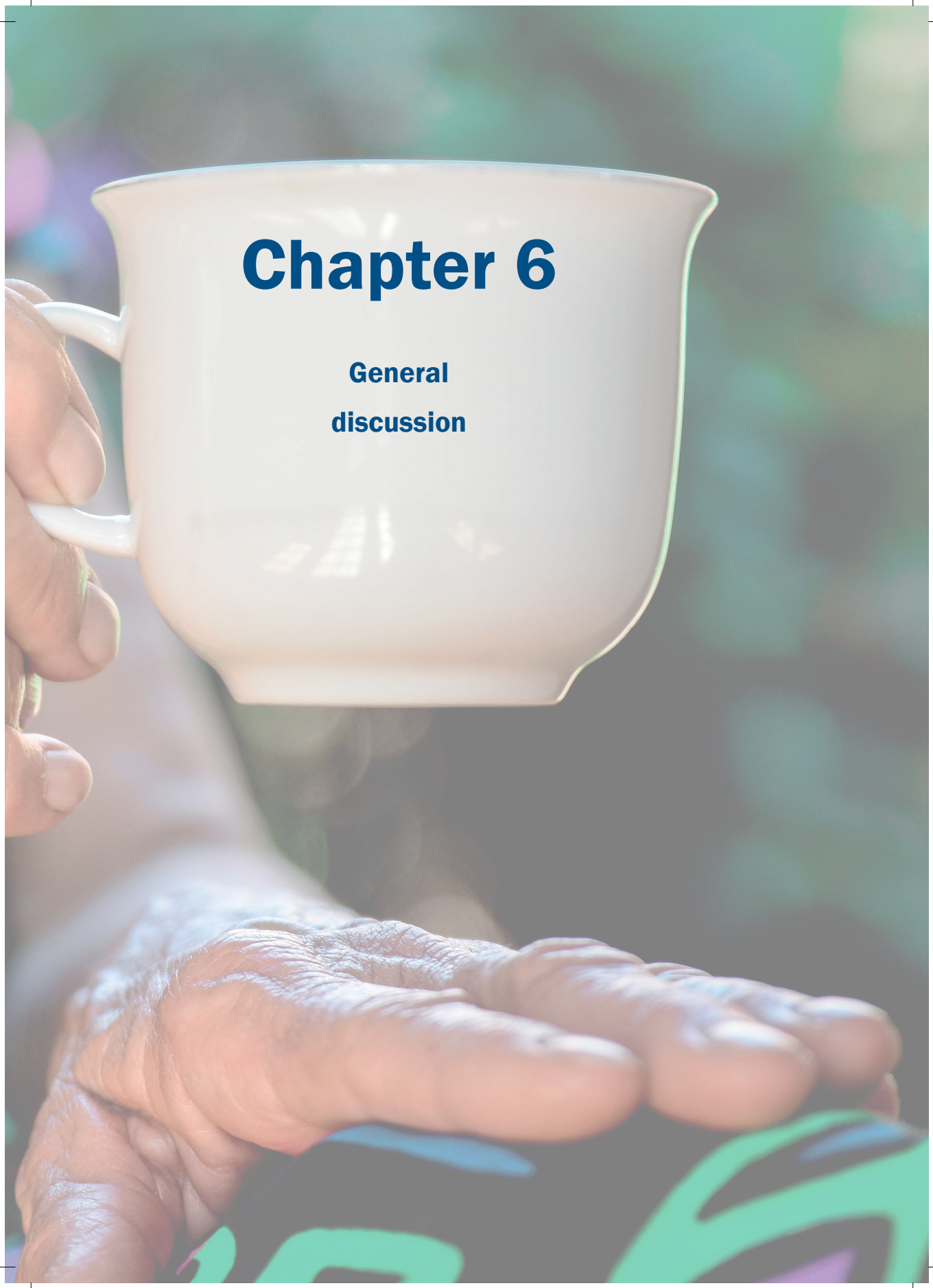

Chapter 6

General discussion

General discussion

The gerontopsychiatric population, comprising of older people with one or more chronic psychiatric conditions combined with physical disabilities, constitutes a substantial part of the nursing home population. Over the years, maintaining an acceptable level of well-being is increasingly seen as an important goal of nursing home care (Brownie & Nancarrow, 2013). To achieve this goal it is important to have evidence-based information on those issues that influence the level of well-being (positively or negatively), additionally to have validated instruments for the measurement of the level of well-being. These instruments and this evidence based information form a crucial basis for the development of tools or forms of treatment to support the gerontopsychiatric nursing home residents in ways that positively influence their levels of well-being.

Relatively little is currently known about well-being in the gerontopsychiatric population. The aims of this thesis were therefore to create an overview of the literature on well-being in the gerontopsychiatric nursing home population, to develop a validated measurement instrument to assess well-being within this population, and finally to gain knowledge on the relation between well-being and behavioral problems within the gerontopsychiatric population.

Main findings:

1. *Development of an overview of the current literature on well-being and its related factors in the gerontopsychiatric population.*
   The review on well-being, presented in Chapter 2 of this thesis, showed that only little has been written on well-being in the specific population of elderly people with psychiatric disorders, living in nursing homes. A total of ten studies on well-being and several related factors were found. These studies lead to the following conclusions: Specialist care aimed at psychiatric disabilities and the availability of mental health workers, larger social network size and perceived personal freedom are linked to higher levels of well-being. Furthermore, depression and some symptoms of schizophrenia and perceived stigmatization are negatively related to well-being. It was also described in Chapter 2 that, in the existing studies, well-being was assessed with several measures of well-being, none of which were specifically validated for the gerontopsychiatric population.

2. *Development of a valid and reliable self-rated measure of self-rated well-being the gerontopsychiatric population.*
   The Laurens Well-being Inventory for Gerontopsychiatry (LWIG) was constructed, driven by both theoretical and data-driven considerations, as is described in Chapter

3 of this thesis. It was administered to 295 gerontopsychiatric nursing home residents. Confirmatory factor analysis confirmed the structure of a model, in which well-being is described to consist of three dimensions: physical, social and psychological well-being. Exploratory factor analysis was performed to explore the structure within these dimensions. Social well-being was found to consist of three factors or subscales, that were named 'positive social experience', 'negative social experience' and 'communal living'. Psychological well-being consisted of two factors, i.e. 'affect' and 'self-worth'. Physical well-being was found to consist of only one factor. The scale contained a total of 30 items.

Reliability was adequate for all dimensions, and for all but one of the subscales, within the dimensions. All dimensions and subscales are intercorrelated, in line with the idea that well-being is one construct, and confirming internal consistency of the instrument. For well-being measures, determining construct validity is complicated, as a true gold standard is not available. It was decided in this thesis to use existing self-rating and observational measures of well-being that were developed and validated for other populations. Correlations with the self-rated Cantril's Ladder (Cantril, 1965) were relatively high, whereas correlations with the Qualidem (Ettema, Dröes, De Lange, Mellenbergh, & Ribbe, 2007a), an observational scale, were low to moderate. The low to moderate correlations were expected, based on other literature on the relation between self-rated and observer-rated well-being (Fuh & Wang, 2006; Torisson, Stavenow, Minthon, & Londos, 2016). Also, criterion-related validity was found to be good, since depressed participants, as screened with the NORD scale showed significantly lower well-being than non-depressed participants. Due to limited length, and simple worded items, the LWIG could be suitable for use in clinical practice and for scientific research purposes.

3. *Development of a valid and reliable observational measure of self-rated well-being the gerontopsychiatric population.*
   An observational well-being measure was developed in addition to the self-rated measure, in order to get an indication of the level of well-being of residents that are unwilling or unable to participate in the self-rating measure. Development of the observational measure, the Laurens Well-being Observations for Gerontopsychiatry (LWOG), as described in Chapter 4, proceeded in the same way, and was based on the same model as the LWIG. A confirmatory factor analysis on data of 265 participants showed adequate fit for a one dimensional model of well-being. Further analysis with exploratory factor analysis resulted in a 12 item measure with two subscales (psychological/negative and social/positive).

Reliability was adequate for the total measure and for both subscales individually, measured with both Cronbach's α and McDonald's ω. Validity was acceptable, as demonstrated with the moderate to strong correlations with the observational Qualidem (Ettema et al., 2007a), a measure developed for the measurement of well-being in nursing home residents with dementia, and low but significant correlations with self-rated well-being measures, the LWIG (Van der Wolf, Van Hooren, Waterink, & Lechner, 2018) and Cantril's Ladder (Cantril, 1965). Because of its adequate reliability, acceptable validity, and brevity, the instrument is suitable for use in clinical practice and for scientific research.

4. *Examination of the relation between the level of self-rated or observed well-being and the occurrence and frequency of psychiatric and behavioral problems in the gerontopsychiatric nursing home population.*
   Chapter 5 of this thesis showed that for observed well-being, controlled for several relevant variables such as sex, ADL dependence and level of education, there is a clear and strong relation with psychiatric and behavioral problems (e.g. irritability, agitation, apathy and depressive behaviors). For self-rated well-being the relation with psychiatric and behavioral problems was found to be comparable to the relation with observed wellbeing, but less pronounced, as was hypothesized - based on existing literature among patients with dementia (Vogel, Mortensen, Hasselbalch, Andersen, & Waldemar, 2006; Yap et al., 2008; Zimmerman et al., 2005). Using multiple linear regression it was found that lower observed well-being was related to more agitated behavior. Lower scores on both observed and self-rated well-being were related to more depressive and apathetic behavior. Higher observed well-being and lower self-rated psychological well-being were however related to higher scores on disinhibited and euphoric behavior.

Interpretation and relation with literature

The model and construction of the well-being measures

The point of departure for this thesis was a theory based model of well-being that formed a framework for the questionnaires (see Figure 1). In this model, well-being is a multidimensional construct that is made up of three universal goals: physical-, social- and psychological well-being. These three universal goals are quite commonly used when well-being or quality of life is described (WHOQOL Group, 1995). In the model, based on the social production function (SPF) model (Lindenberg, 1986; Ormel, Lindenberg, Steverink, & Verbrugge, 1999), combined with Ryff's model of psychological well-being (Ryff, 1989) several more specific goals have been included, such as affection, status and self-acceptance. These more specific goals are instrumental in achieving the universal goals (Ormel et al., 1999), which is why they are called the instrumental goals.

top level	General well-being							
universal goals	Physical well-being		Social well-being			Psychological well-being		
first order instrumental goals	Comfort	Stimulation	Affection	Behavioral confirmation	Status	Self-acceptance	Environmental mastery	Purpose in life
means of production	Absence of physiological needs, pleasant and safe environment	Optimal level of arousal	Positive inputs from caring others	Approval for doing the right things	Control over scarce resources	Positive attitude toward self, acceptance of good and bad qualities	Ability to create contexts suitable to personal needs and values	Holding beliefs that give life purpose, having aims and objectives for living

Figure 1. Combined SPF model with psychological well-being

In the construction of the initial item pool for the development of both the observed (Chapter 4), and the self-rated instrument (Chapter 3), the instrumental goals were used as a starting point. In the statistical analysis, we first examined the presence of the universal goals using confirmatory factor analysis. Next, the organization within the universal goals was examined using explorative factor analysis. By relying on data-driven considerations for the determination of the instrumental goals (or subscales), there was a chance that the internal structure of the instrument at the level of instrumental goals would differ from the original model (Figure 1). The purpose of this being to hone the instrument specifically to the gerontopsychiatric population.

In the self-rating scale (the LWIG), the framework of the three universal goals was confirmed (Chapter 3), and exploratory factor analysis resulted in several factors or instrumental goals within these universal goals (see Figure 2). In the observational scale (the LWOG) however, the three dimensional model was not confirmed (Chapter 4). For the observational scale it was therefore decided to eliminate the three-universal goals altogether, and to use exploratory factor analysis to determine the dimensional structure within this instrument. A two-factor structure was found (see Figure 3).

In the following part of the discussion, the findings concerning well-being will be discussed at three levels, the level of general well-being first, next the level of the universal goals of well-being and finally the level of the instrumental goals.

General well-being					
Physical well-being	Social well-being			Psychological well-being	
	positive social experience	negative social experience	communal living	affect	Self-worth
Absence of physiological needs, feeling fit, being cared for physically	feeling at ease with people, good contact with nurses and other residents. Sufficient respect and attention	feeling ignored or like a burden, being bullied or bothered by others	fitting in with other residents, enjoying group time or communal mealtimes.	Feeling sad, anxious, bored, lonely or relaxed.	Feeling satisfied with oneself, one's life, experience of meaning in life.

Figure 2. Alternative model of well-being, based on dimensional and factor structure of the LWIG

General well-being	
Social well-being (positive scale)	Psychological well-being (negative scale)
Responding positively to social approach, or humor, feeling comfortable around others and with themselves, enjoying activities, and trying to make the best of the situation	Feeling sad, or anxious, experiencing life as meaningless, complaining about physical limitations or feeling unable to do things

Figure 3. Lay out of the dimensional and factor structure of the LWOG

General well-being

The hypothesis, proposed in the original model that well-being is a multidimensional concept, was confirmed in this dissertation. Both the observed and the self-rated instrument contained more than one dimension or universal goal on several main aspects of life. Correlations between these universal goals were positive, and moderate to high in the self-rated well-being measure, and weak to moderate in the observed well-being measure. This indicates that, although multidimensional, the concept of well-being can be seen as one construct.

Observed versus self-rated general well-being

An interesting result in this thesis is the fact that scores on observed well-being were consistently higher within the range of the scale, than those on self-rated well-being. This finding of higher observed scores compared to the self-rated scores is the opposite of what is found among patients with dementia (Beer et al., 2010; Scocco, Fantoni, & Caon, 2005; Vogel et al., 2006).

An often quoted explanation for the fact that people with dementia rate their well-being or quality of life higher than informants is the lack of insight in the disease (anosognosia) by the patients, which is a common feature of Alzheimers disease (Conde-Sala et al., 2014; Dos Santos, Rocha, Fernandez, De Padua, & Reppold, 2018; Perrotin et al., 2015). This lack of insight may however also impact the gerontopsychiatric population, as it is a highly prevalent attribute of schizophrenia (Buckley et al., 2007; Gerretsen, Plitman, Rajji, & Graff-Guerrero, 2014). Since 41 percent of the population included in the studies within this dissertation did have a primary diagnosis of schizophrenia spectrum disorder, it is likely that anosognosia is also prevalent in this population. An important difference between lack of insight in psychotic disorders and lack of insight in dementia however, is that in psychotic disorders the interpretation and attribution of certain phenomenology or hallucinations differs between the patient and their environment, whereas in dementia the lack of insight refers to lack of conscious information about the characteristics of their disease (Gilleen, Greenwood, & David, 2010). If one is not, or only very limited aware of the symptoms, e.g. if a resident is unaware of the extent to which their memory is deteriorating or if they deny the progressive nature of their disease, it is conceivable that the effects of disease or symptoms on self-rated well-being may be relatively small, whereas an observant might rate the well-being according to the observed symptoms. This could very well result in lower observed well-being. If one on the other hand experiences the symptoms (i.e. suspicion or anxiety), but attributes these complaints to an unsafe or dangerous reality instead of a mental disease, this might adversely influence self-rated well-being. This might explain the pattern of results in the gerontopsychiatric population, i.e. lower self-rated well-being scores compared to the well-being scores observed by a relative or caregiver.

Comparison to population samples

In the general introduction of this dissertation it is argued that well-being in the gerontopsychiatric nursing home population is likely to be relatively low, due to several factors. Since no control reference group of healthy older people was included in this dissertation, the LWIG and LWOG scores cannot be compared with a healthy control group.

However, Cummins (1995) developed a general way to compare quality of life scores among different groups. He compared the outcomes of scales that are symmetric Likert scales, ranging from strongly positive to strongly negative around a neutral mean point. In his meta-analysis he included 17 datasets, with populations varying from N=421 to N=71,896. The mean quality of life score of representative population samples from Western countries on such scales was found to be 75.02% of that maximum score, with a standard deviation of 2.74. Although exact numbers are not included, a large study with about 25,000 observations in several wealthy, English speaking countries such as the US, Canada, Australia and the UK did confirm the mean score on Cantril's Ladder around 75% of the maximum score (Steptoe, Deaton, & Stone, 2015).

This value of approximately 75% could serve as a 'gold standard' for research on quality of life or well-being (Cummins, 1995). The LWIG and the LWOG are not based on symmetric Likert scales. However, Cantril's Ladder (Cantril, 1965) was used as a gold standard in Chapter 3 of this dissertation, and is a scale that can be compared in the way Cummins proposes. The mean outcome as a percentage of the maximum score of the population in this study was 67.7% (*SD* = 20.3).

This is a noticeably lower mean than the normative mean, as found by Cummins, suggesting relatively low levels of general well-being in the gerontopsychiatric nursing home population compared to healthy adults, as expected. Also, a striking difference is seen in the size of the standard deviation in the gerontopsychiatric population, which is much larger in comparison to the normative population. Apparently the gerontopsychiatric population is much more heterogeneous when it comes to well-being levels than the normative population. A larger standard deviation, and lower well-being scores are also seen in research on comparable populations of people with mental illness (Bengtsson-Tops et al., 2005; Swinton, Oliver, & Carlisle, 1999) or nursing home residents (Peters, Boter, Buskens, & Slaets, 2012).

One explanation for the much greater standard deviations in combination with the lower well-being scores in the older populations and mentally ill populations might be found in the theory of substitution, which is an important part of the Social Production Function model (Ormel et al., 1999; Steverink, Lindenberg, & Ormel, 1998). The theory proposes that if a certain instrumental goal (e.g. stimulation) is jeopardized due to worse physical health for example, substitution might be found in other activities (e.g. board games), keeping the original level of well-being relatively stable. This might explain the small variation in well-being levels in normative samples. People with a larger amount of alternatives, e.g. a larger social network, more interests and hobbies may be less vulnerable if one of the resources is lost, due to the presence of more options for substitution. On the other

hand, the loss of more resources, or resources that were multifunctional (e.g. a close relationship that provides affection, stimulation and behavioral confirmation) may have a large negative impact on the level of well-being, which may cause substitution to fail (Ormel et al., 1999). This failure of substitution might be seen more strongly in people with psychiatric problems and/or neuropsychological impairments such as cognitive decline, anxiety and depression, as the higher order mental capacities (e.g. energy, self-confidence, concentration, long-term planning and memory) that are needed for substitution, are negatively affected (Ormel et al., 1999).

To conclude, due to several characteristics of the gerontopsychiatric population, and effects of the mental illness, as described in the introduction (Chapter 1) of this thesis, substitution of resources or instrumental goals in well-being may fail more often in this population. This may cause much more variation in well-being scores including a greater prevalence of scores on the very low end of the spectrum.

Dimensional structure, the universal goals

In the following section, the next level of the adapted SPF model concerning the universal goals will be discussed. When comparing the self-rated well-being scale with the observational well-being scale, the dimensional structure shows some similarities and several differences. As can be seen in Figures 2 and 3, the social and psychological dimension of well-being are found in both measurement instruments. The physical dimension was not found to be a separate dimension in the observational instrument, although some items within the psychological dimension are related to physical well-being, i.e. feeling unable to do anything, and complaining about physical limitations. One could therefore argue that in the observational well-being scale the physical well-being dimension is, to some degree, integrated in the psychological well-being scale, which might also explain the high correlation between self-rated physical well-being and observed psychological well-being. The fact that subjective health complaints can be a characteristic of depression, especially in the older population (Gerber et al., 1992), might be an underlying cause for this connection between the physical and psychological components of well-being.

There are several possible reasons for the differences between the dimensions in both instruments. Firstly, the subjectivity of the concept of well-being might play an important role. As Sainfort, Becker, and Diamond (1996) argue, the patient is likely to have more detailed knowledge than the caregiver, on many aspects of their lives such as their social relations, and their affective states. Therefore, the self-rating scale might include items on a more detailed and personal level than the observational scale. This was found in measurement instruments on other subjective concepts too, where a higher degree of subjectivity leads to greater discrepancy between outcomes from patients and caregivers

(Huang, Chang, Tang, Chiu, & Weng, 2009; Sainfort et al., 1996). A higher degree of aggregation in the observational measures was found to partly solve this issue, as higher correlations with self-rated measures were found for observational measures that were lower in detail, and higher in aggregation (Sainfort et al., 1996).

Another factor that might explain some of the differences in dimensions within the two instruments is the relatively small item pool that was used in the pilot studies in the development of the observational measure. This item pool was smaller than the item pool that was used for the self-rated measure. A small initial item pool might result in relevant topics being overlooked, or being excluded due to a small number of items or suboptimal wording of items (Clark & Watson, 1995). If for this reason items are excluded, and too few items on a specific topic remain, this might influence the number and content of the factors that are found in the data.

Also, the structure of the observational scale is not only based on the social and psychological dimension, but also a clear distinction is evident depending on the positive or negative wording of the items. This structure might be influenced by the tendency of people to answer differently to negatively worded items in comparison to positively worded items (DiStefano & Motl, 2006). Items that were negatively formulated were found to form a latent variable in questionnaires on other subjective concepts, such as self-esteem or social physique anxiety (DiStefano & Motl, 2006) and a similar result was found in another well-being measure, the psychological well-being in cognitively impaired persons (PWB-CIP) (Burgener, Twigg, & Popovich, 2005). This tendency may also have played a role in the development of the observational scale, resulting in a factor structure with two factors, based mainly on positively or negatively worded items.

The differences in the internal structure of both instruments limit the possibilities of comparing the different subscales of the two measures. All this considered, there still remain positive aspects worthy of note. The LWIG appears to be a valid and reliable measure of well-being in the gerontopsychiatric population, based on both a solid theoretical background, and tailored to the specific domains and topics that are important for the target population. The LWOG might need fine tuning when it comes to the internal structure. However, reliability and validity are adequate when compared to the existing Qualidem measure (Ettema et al., 2007a) with higher correlations for subscales that are close in terms of content (see Chapter 4). Interrater reliability and sensitivity to change should still be examined, but this first study looks promising for the quality of an observational measure of well-being in the gerontopsychiatric population. Furthermore, although the number of dimensions is not the same, the themes within the dimensions are quite similar, both measures contain the dimensions social and psychological well-being,

and physical well-being is considered within the LWOG psychological well-being dimension. Correlations between the respective dimensions were found to be moderate to weak, consistent with other studies on observed and self-rated well-being (Fuh & Wang, 2006; Torisson et al., 2016). Relatively weaker correlations were found for the social subscales which is in line with studies on people with schizophrenia (Sainfort et al., 1996), and people with dementia (Huang et al., 2009). Thus the results show that the development of these instruments should be seen as a first step towards gaining more insight into the well-being of the gerontopsychiatric population. More research is needed to confirm and further strengthen the psychometric quality, and in addition to gain insight in the possible causes of the small correlations between observed and self-rated dimensions of well-being that are similar in content.

Instrumental goals, the original model compared to current results in the LWIG

In the observational scale there are clear differences from the original model (Figure 1). One of the universal goals was not established as a subscale, and no instrumental goals were differentiated within the universal goals. For the self-rating scale the instrumental goals were identified, however these instrumental goals differed from the original model. Differences might be explained by the specific characteristics of the gerontopsychiatric population living in a nursing home, as will be described in this section.

In the self-rated scale, the universal goal of physical well-being consists of one factor, and items are predominantly on comfort (e.g. 'how often were you cared for in a pleasant way?' or 'how often did you have severe pain?'). Due to increased physical disorders and pain it is likely that comfort is relatively low within this population (Van den Brink, Gerritsen, De Valk, Voshaar, & Koopmans, 2017). The experience of discomfort, due to these characteristics might increase the importance of experiencing comfort as an (instrumental) goal in this population (Zalenski & Raspa, 2006), which explains the focus on comfort in the physical well-being scale.

Rather than a distinction between types of social needs, as proposed in the original model, exploratory factor analysis yielded a distinction between positively and negatively worded items within the universal goal of social well-being of the self-rated LWIG. Both the absence of negative social interactions and the presence of positive social interactions seem to contribute independently to a higher level of social well-being. A similar finding occurred in the development of the Qualidem (Ettema, Dröes, De Lange, Mellenbergh, & Ribbe, 2007b), where in addition to a 'social relations' scale the 'social isolation' scale was added during the process, including an item on rejection by other residents. One explanation for the appearance of this negative social subscale in both measures is the fact that nursing home residents are forced to live with a group of people that are not family or friends,

in an environment where a relatively high prevalence of depressed, irritable or agitated behavior exists (Van den Brink et al., 2017). This requires considerable adaptability, and under these circumstances the chances of getting involved in negative social exchanges are likely to increase (Rosen et al., 2008). Based on Chapter 3 of this dissertation, one could conclude that these negative social encounters may significantly impact the level of the residents' social well-being. However, the tendency of people to answer differently to positively or negatively worded items may be significant, as was previously discussed (DiStefano & Motl, 2006).

A subscale on *status,* one of the instrumental goals in the original model, is not included in the LWIG. When looking at existing well-being measures for nursing home residents with dementia, there appears to be no questionnaire that has included status or a similar concept as a subscale (Burgener et al., 2005; Ettema et al., 2007b; Logsdon, Gibbons, McCurry, & Teri, 1999; Terada et al., 2002). This does not necessarily mean that status is not important in this population. Status has to do with relative ranking (Van Bruggen, 2001) or a 'distinction in valued aspects such as skills, education, wealth' (Nieboer, Lindenberg, Boomsma, & Bruggen, 2005). Work, skills or financial situation may be less relevant topics in the nursing home, whereas it was found that social relationships are rated among the most important determinants of successful aging (Nosraty, Jylhä, Raittila, & Lumme-Sandt, 2015; Von Faber et al., 2001). Status might therefore be measured in terms of the number of visits someone receives from family or friends, or the quality of relationships with nurses or with fellow residents, in which case it would be implicitly included in the three existing subscales. Or, in terms of the SPF-theory, the loss of status is substituted by more emphasis on the other two instrumental goals within the dimension of social well-being (Ormel et al., 1999).

Finally, the universal goal of psychological well-being. In the original model, Ryff's theory of psychological well-being was used as a source. In the alternative model for the gerontopsychiatric population based on the LWIG (Figure 2), two instrumental goals were found: self-worth and affect.

Self-worth as an instrumental goal is similar to the expected instrumental goal of self-acceptance, that was included in the original model (Figure 1). The 'affect' goal was not part of the original model by Ryff, but in many theories on well-being the ratio between positive and negative affect is considered to be an important part of the well-being concept (Bradburn, 1969; Ryan & Deci, 2001). Affect is also in general included as a well-being subscale in existing well-being measures, differentiating between positive and negative affect (Burgener et al., 2005; Ettema et al., 2007b; Terada et al., 2002). An affect subscale seems therefore to be a valid addition to the model.

Items on environmental mastery are not represented in the scale. According to Ryff and Singer (2000), high scorers of environmental mastery 'have a sense of mastery and competence in managing the environment', and 'are able to choose or create contexts suitable to personal needs and values'. High scorers of autonomy, the component that was combined with environmental mastery in the construction of this scale, are 'self-determining and independent, and able to resist social pressure' (Ryff & Singer, 2000). These are skills that place relatively high demands on the executive functions of the participants. The fact that the gerontopsychiatric population is a population that is at high risk of impaired functioning (especially in the area of executive abilities) (Fucetola et al., 2000; Goodkind et al., 2015) might explain the absence of these factors in the final scale. Comparison with existing measures of well-being among the dementia population in nursing homes, show that items or subscales on autonomy, or mastery of the environment are not commonly included (Burgener et al., 2005; Ettema et al., 2007b; Logsdon et al., 1999; Terada et al., 2002).

Level of well-being and patient characteristics

No differences were found in the level of well-being between residents with different psychiatric diagnoses (Chapter 3 of this thesis). However, in line with Smalbrugge et al. (2006), it was found that residents with a high risk of depression, according to results on the NORD, had lower well-being scores than residents with a lower risk of depression.

In Chapter 5 of this thesis, the aim was to examine the relation of other forms of behavioral problems with the level of well-being. It was found that psychiatric and behavioral problems are mainly related to observed well-being, specifically to the psychological-negative scale of observed well-being. As much as 45% of the variance of this subscale was explained by psychiatric and behavioral problems, such as verbal aggression, irritability and behavioral symptoms of depression. This might be due partly to the fact that both proxy measures were answered by the same nurses. However, the strong relation between well-being and the occurrence of behavioral problems might also indicate that some forms of psychiatric and behavioral problems are interpreted (at least partly) by the caregivers as an expression of low well-being. This is a line of thought that is also reflected in the scientific literature, for example by using a measure for behavioral problems in the measurement of (an aspect of) well-being (Kolanowski, Van Haitsma, Meeks, & Litaker, 2014).

However, the fact that self-rated well-being was only partly and weakly related to psychiatric and behavioral problems is a reason to reconsider this association. In Chapter 5 of this thesis, self-rated well-being was found to be related mainly to behavioral symptoms of depression. A small, but significant relation was found for the universal goal of psychological well-being and the irritability, agitation and anxiety scale in the Neuropsychiatric Inventory Questionnaire (NPI-Q) (De Jonghe, Kat, Kalisvaart, & Boelaarts, 2003). The Cohen Mansfield

Agitation Index (CMAI) (Cohen-Mansfield, 1991), which measures agitation and aggression in a more direct and concrete way however, was not related to any of the self-rated well-being subscales. This indicates that other causes such as lack of self-control (DeWall, Finkel, & Denson, 2011), inability to communicate or psychotic symptoms (Patel & Hope, 1993) might be more strongly related to expressed agitation and aggression than to a low level of well-being in the gerontopsychiatric nursing home population. This finding emphasizes the importance of making a proper assessment of the underlying causes of psychiatric and behavioral problems before starting treatment.

Strengths and limitations

This thesis provides a small but relevant step toward increasing scientific research on well-being in the gerontopsychiatric nursing home population. Since this has been an under-studied subject in this population, this thesis adds important and unique information on several main aspects of life for this population.

The final sample size (295 residents) can be seen as a major strength in this thesis, as several elements can make it difficult to gather a significant sample size in the gerontopsychiatric population. The population usually presents as a subpopulation in a general nursing home, therefore a relatively large number of nursing homes need to participate in the study in order to access sufficient numbers from the target population. Additionally, nurses often have a busy work schedule. Planning interviews with regard to research can therefore sometimes be quite a challenge. Finally, the gerontopsychiatric population is not always willing or able to participate in research. As an additional result, the participants were recruited from as many as 14 nursing homes, which enhances the generalizability of the results. Another important strength is the fact that in the development of the measurement instruments people from the target population, experienced nurses and practitioners were closely involved. This ensured that the questions that were included were based primarily on the daily experience of the target-population.

There are some limitations in this thesis that need to be addressed too. In the development of both the LWIG and the LWOG, the test-retest reliability and sensitivity to change was not measured, since the data were all cross-sectional. Both test-retest reliability and sensitivity to change are important issues to address in future research, as the LWIG and the LWOG are intended for use in (experimental) research, and for the evaluation of treatment in the clinical setting. If test-retest reliability or sensitivity to change are insufficiently high, adaptations of the measures might be necessary, as this would significantly compromise the utility of the measures.

Also, in the LWOG, inter-rater reliability was not included as a reliability measure. Because of the degree of subjectivity in assessing someone's well-being, this too is an important limitation, and inter-rater reliability should be examined in future research. If inter-rater reliability is insufficiently high, this might be a reason to have the LWOG completed by two nurses as standard, to reduce the effect of subjectivity.

Another limitation, as was mentioned before, is the relatively small item pool that was used in the initial phases of the development of the LWOG. This may have influenced the reliability of the final measure, and may have been one of the causes of rejection of the three dimensional model in the LWOG, in confirmatory factor analysis. An important goal in this thesis was to develop a self-rated measurement instrument and an observational instrument based on the same model, so that results on the same dimensions could be compared. With the current instruments this is only possible in part.

Directions for future research and implications for clinical practice

Directions for future research

An important direction for future research would be to further examine the reliability, validity and sensitivity to change in both the LWIG and the LWOG. This thesis provides a first step in validation of these measurement instruments, but further research is necessary to confirm the value and aptitude of the instruments.

Also, once the reliability of both measures is more strongly affirmed, it is recommended that they are used to increase knowledge on the relation between activities, situations or treatments and the level of well-being. A particularly interesting subject would be the subject of social well-being. The relation between observed and self-rated social well-being was relatively low (r = .19). Caregivers and the residents respectably thus seem to view social well-being differently. It would be interesting to investigate to what extent social well-being is related to objectively observable factors such as social network size, types of relationships (friends, family, partner) and frequency of social visits, and to what extent the caregivers and residents make different judgements on the effect of these factors on the level of social well-being. Furthermore, it could be studied which additional characteristics of a social relationship are important in defining the quality of the relationship as good in this population.

As agitated or aggressive behavior seems to be only weakly related to self-rated well-being, it would be interesting to study other possible causes of agitation and aggression such as disinhibition, psychotic symptoms or verbal ability, in gerontopsychiatric nursing home residents. More clarity about the causes of behavioral problems might provide tools for approaching or treating these behavioral problems.

Finally, it was found in Chapter 2 of this thesis that virtually no experimental research has been conducted into well-being and its related factors in the gerontopsychiatric population. This means that there is no strong evidence for any causal links between well-being and its related factors. Thorough experimental or longitudinal research into factors that are found to be related to well-being in the gerontopsychiatric population could make an important contribution to clinical practice, although ethical considerations might make such research among the vulnerable gerontopsychiatric population a challenge. The results could support nursing homes in making policies that focus on the highest possible level of well-being, and enable care professionals to work towards that goal in an evidence based manner.

Implications for clinical practice

The use of both the LWIG and the LWOG in clinical practice could add to the focus on quality of life of the gerontopsychiatric population. The instruments could for example be used as a baseline measure and as evaluation for the measurement of the effect of certain interventions or treatment. Making these instruments available to care-personnel and promoting their use, could lead to greater consideration for the well-being of the gerontopsychiatric population as a whole.

Also as clinical practice is more focused on residents as individuals, the interview for the administration of the instruments could be used as a starting point for a dialogue with residents on what is important in life for them, which of their needs are fulfilled in their current situation, and which needs might be focused on in order to increase their well-being. In administering the interviews during this study, the interviewers noticed that many of the participants enjoyed the interview, and the possibility to talk about the subjects that were raised in the questionnaire. Outcomes of the measure could also be discussed with the resident, giving them the opportunity to have a say when it comes to improvement of their own well-being. Also discrepancies in observed and self-rated well-being could provide a starting point for discussion between residents and nurses, with a focus on increased understanding of each other's point of view.

On a larger scale, if future research confirms good reliability and validity of the LWIG and LWOG, the results of these measures in an entire ward or nursing home could be used to create policy with the aim of increasing the well-being of the residents. One could for example look for patterns in well-being levels across a ward, and specifically aim to improve those dimensions of well-being with a specifically low score.

Another option for the implementation of both well-being measures is to complete the measures on an annual basis. In this way, the subject of well-being remains a key objective, and it can be checked annually to determine whether there is a positive or negative trend when it comes to well-being, and which dimensions or subjects might require additional attention. It is important to note that although the level of well-being can be related to the quality of care in an institution, it is important not to confuse the two. The outcome of the well-being measures should not be used as the (only) measure for determining the quality of care.

Concerning behavioral problems, the results in this thesis emphasize the importance of a thorough assessment of the underlying causes of agitated or aggressive behavior. Well-being might be related to the occurrence of these behavioral problems, but there may also be other factors at play as mentioned previously. The only form of behavioral problems that showed a clear relation with self-rated well-being was that of the behavioral symptoms of depression, where the probability exists that depressive symptoms lower well-being, and a lower well-being increases in turn the symptoms of depression. Diagnosing and treating depression therefore remains important in the care for gerontopsychiatric nursing home residents.

There is another important consequence of the finding that self-rated well-being and behavioral problems are found to be only weakly related. The behaviors of residents with decreased levels of well-being may not ne outwardly exhibited but nonetheless present as internalized, less obvious behavioral problems. If the occurrence of behavioral problems are considered a signal for lower levels of well-being, a group of residents with low well-being and no behavioral problems might potentially be overlooked. This may mean that they do not receive the attention that is necessary to increase their levels of well-being. The availability of a valid well-being scale may prove to be a valuable instrument to recognize this group of residents.

Conclusions

This thesis aimed to add relevant insights to the limited amount of research that has been done so far on well-being in the gerontopsychiatric population. Well-being as a multidimensional concept was confirmed in this dissertation, however, compared to the original model, other factors are found to be central within this concept of well-being for the gerontopsychiatric population. Positive and negative social interaction, communal living, self-worth, affect and comfort are found to be important factors in this population, whereas factors like status and environmental control are not found to have a significant effect on well-being.

Although more research on validation is required, the availability of the evidence based observational and self-rating well-being measures that have been developed creates the opportunity to improve the level of well-being in this population. It provides the tools to measure the effects of interventions or treatments in clinical care, and in (experimental) research on well-being.

The study results illustrate that well-being is relatively low in the gerontopsychiatric population, with large differences between the participants. Also observed well-being tends to be higher than self-rated well-being within this population. With regard to behavioral problems, we can conclude that they are not always clearly linked to the level of self-rated well-being. This means that behavioral problems are not necessarily a sign of low well-being, and the causes of these behaviors should always be carefully examined. Also, it is important to note that not all residents with below average well-being show increased psychiatric or behavioral problems.

In conclusion, this dissertation provides an important first step in the development of measurement tools for the measurement of well-being in in the gerontopsychiatric nursing home population, in both clinical practice and in the scientific field. Also it provides some relevant new insight in the relation between behavioral problems and the level of well-being.

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Appendix

Summary

Summary

The research presented in this dissertation was aimed to improve and increase knowledge on and insight in well-being in the population of gerontopsychiatric nursing home residents. This population consists of older people with serious mental illness (other than dementia), in combination with physical disabilities. Worldwide this group makes up a substantial part of the nursing home population, and several nursing homes in the Netherlands have developed specialized wards specifically for this group.

Within nursing homes one of the main aims is to achieve or maintain an optimal level of well-being among the residents. Because of this aim, it is important to have a good understanding of what well-being is, and what influences the level of well-being within this population. Among the elderly in general, well-being was found to be related to, among other things, socioeconomic status, the existence of high quality social ties, self-perceived health, functional status and marital status. The gerontopsychiatric population generally does not do so well when it comes to these characteristics. The level of well-being in the gerontopsychiatric population might therefore be relatively low.

The concept of well-being has been defined and operationalized by many people and in many ways. In this thesis the following definition of well-being was used: well-being is *'a multidimensional concept that concerns the individuals' cognitive and emotional evaluation of their lives'*. It is operationalized using a combination of the Social Production Function (SPF) model by Lindenberg (1986) and the model of psychological well-being, by Carol Ryff (1989). This model describes general well-being in terms of three universal goals: physical well-being, social well-being and psychological well-being. These universal goals are the result of several lower level instrumental goals, that may differ across different populations.

Well-being in gerontopsychiatry, what do we know?
In Chapter 2 of this thesis a systematic review on the existing literature is presented on well-being within the gerontopsychiatric population. It was aimed to create an overview of what is already known about well-being in the target population and also to map where more research might be needed. For this review three databases were used, psycINFO, psycARTICLES and Pubmed. After independently screening the articles that were found using these databases with three of the authors, only 10 studies were found that were relevant for the aims of the review. The possibilities of drawing general conclusions from these 10 studies were very limited considering different definitions of well-being were used and the composition of the populations differed in terms of diagnosis and type of residence. There were however some notable conclusions. Specialist care for the gerontopsychiatric population in addition to regular nursing home care, perceived personal freedom and

(larger) social network size appear to be positively related to well-being. Also depression, and some symptoms of schizophrenia were found to be negatively related to well-being in the gerontopsychiatric population. More research on well-being in the gerontopsychiatric nursing home population is strongly recommended, as it could add valuable information and provide practical tools for improving care for the gerontopsychiatric population.

Measurement of well-being in the gerontopsychiatric population

In the Chapters 3 and 4 of this thesis, the development and validation of a self-rated instrument: the Laurens Well-being Inventory for Gerontopsychiatry (LWIG) and an observer-rated instrument: the Laurens Well-being Observations for Gerontopsychiatry (LWOG), for the measurement of well-being are described. A definition and a model for the concept of well-being were formulated as described above. Based on the definition and model an item pool was developed with the help of gerontopsychiatric nursing home residents, nurses and other experienced care professionals. For the self-rated instrument a total of 295 residents and their formal caregiver were interviewed by trained interviewers. For the observer-rated instrument a total of 265 residents and their formal caregivers were interviewed.

Both the self-rated instrument (the LWIG) and the observer-rated instrument (the LWOG) were found to have acceptable validity and reliability. The internal structure of both instruments was established using a form of factor analysis. The resulting structure was found to be differ between the two instruments. For the self-rated scale, the structure that was found to be partly corresponded with the model that had served as the starting point for the instruments. The structure of the universal goal i.e. physical, social and psychological well-being was confirmed. The instrumental goals (the goals that are instrumental to the universal goals) as described in the original model were not confirmed by the data. Using factor analysis however, new instrumental goals were established, that did form a logical division within the universal goals.

The internal structure of the observer-rated instrument deviated more from the original model. A two-factor structure was found, including a scale with negatively formulated items, mainly on psychological topics, and a scale with positively formulated items, mainly on social topics. There was no subscale on physical well-being but within the negative/psychological well-being subscale, some items were related to physical well-being.

These results form an important first step in the development of a well-being instrument for an under-researched population. More research is necessary to examine test-retest reliability, sensitivity to change and inter-rater reliability (for the LWOG), however these first results are promising.

Well-being and psychiatric and behavioral problems

In Chapter 5, the relation between psychiatric and behavioral problems and the level of well-being in the gerontopsychiatric nursing home population is examined. For this study a total of 126 gerontopsychiatric nursing home residents and their formal caregivers were interviewed. Both the LWIG and the LWOG, described above were used to measure well-being. Psychiatric and behavioral problems were measured using the Cohen-Mansfield Agitation Index (CMAI) and the Neuropsychiatric Inventory Questionnaire (NPI-Q).

Observed well-being was found to be strongly related to psychiatric and behavioral problems. Especially the relation between psychological well-being and the irritability and affective (e.g. signs of depression and apathy) subscales of the NPI-Q and the verbal aggression subscale of the CMAI was found to be strong. For self-rated well-being a relation was found between psychological well-being and the irritability subscale of the NPI-Q, and between physical and social well-being and the affective subscale of the NPI-Q. The relations were however less pronounced for self-rated well-being.

As the study was cross-sectional, no conclusions can be drawn on the direction of the relations. However, improvement of well-being could co-occur with a decrease in affective behavioral problems and irritability, agitation and anxiety. Further research on the direction of the relationship and on factors that may influence the relation between psychiatric and behavioral problems and the level of well-being is recommended.

Overall results were discussed and it was concluded that well-being is a multi-dimensional construct, with several important elements specifically for the gerontopsychiatric population, i.e. Positive and negative social interaction, communal living, self-worth, affect and (physical) comfort. Knowledge on the important elements of well-being can provide tools for both clinical practice and future research into well-being in this population. As well-being was found to be relatively low in this population the improvement of well-being remains an important focus point. The measures that were developed and validated are a crucial to map the current level of well-being for individuals and groups, and also to measure changes in well-being as a result to treatment or other interventions.

Samenvatting

Samenvatting

Het onderzoek in dit proefschrift had tot doel bestaande kennis en inzicht te vergroten in het welbevinden binnen de doelgroep van gerontopsychiatrische verpleeghuis bewoners. De gerontopsychiatrische populatie bestaat uit oudere mensen met een ernstige psychiatrische stoornis (dementie uitgesloten) in combinatie met fysieke aandoeningen of beperkingen. De wereldwijde verpleeghuispopulatie bestaat voor een aanzienlijk deel uit mensen die in de gerontopsychiatrische doelgroep vallen. In Nederland en in veel andere Europese landen zijn aparte verpleegafdelingen opgezet met specialistische zorg voor deze doelgroep.

Een van de belangrijkste doelen binnen de verpleeghuiszorg is het behouden of vergroten van het niveau van welbevinden van de bewoners. Omdat dit zo'n belangrijk doel is, is het cruciaal om het concept welbevinden goed te definiëren, en in kaart te brengen welke factoren het welbevinden kunnen beïnvloeden binnen de verpleeghuispopulatie. Uit onderzoek is gebleken dat voor ouderen een hoger welbevinden vooral is gerelateerd aan een hogere sociaal economische status, sterke sociale banden, zelf-ervaren gezondheid, een goed niveau van fysiek functioneren en een gehuwde burgerlijke status. Gemiddeld genomen zijn dit juist punten waarop de gerontopsychiatrische populatie niet zo hoog scoort, waardoor de kans op een lager welbevinden binnen deze doelgroep relatief groot is.

Over het concept welbevinden zijn verschillende theorieën en definities te vinden in de literatuur. Binnen het huidige proefschrift is gebruik gemaakt van de volgende definitie: '*welbevinden is een multidimensionaal concept, het behelst zowel het cognitieve als het emotionele oordeel van iemand over zijn of haar leven*.' Voor de operationalisatie van het concept is gebruik gemaakt van een model dat gebaseerd is op twee bestaande modellen: het Social Production Function (SPF) model van Lindenberg (1986) en het model van psychologisch welbevinden van Carol Ryff (1989). In dit model is welbevinden het resultaat van drie (universele) doelen: fysiek welbevinden, sociaal welbevinden en psychologisch welbevinden. Deze universele doelen zijn op hun beurt het resultaat van verschillende lagere 'instrumentele' doelen, die per doelgroep kunnen verschillen.

Welbevinden in de gerontopsychiatrie, wat weten we al?

Hoofdstuk 2 van dit proefschrift beschrijft een systematische review van de bestaande literatuur met betrekking tot welbevinden in de gerontopsychiatrische populatie. Het doel van dit review was het in kaart brengen van wat al bekend is over het welbevinden in deze doelgroep, en inzicht te krijgen in onderwerpen waarover meer onderzoek wenselijk is. Voor het verzamelen van literatuur is gebruik gemaakt van drie databases: psycINFO,

psycARTICLES en Pubmed. Na een onafhankelijke screening door drie van de auteurs bleek dat slechts 10 studies relevant waren voor het doel van het onderzoek. Omdat binnen dit beperkte aantal studies zowel de gebruikte definities van welbevinden als ook de samenstelling van de populaties op gebied van diagnose en woonvorm sterk van elkaar verschilden, was de mogelijkheid tot het trekken van algemene conclusies beperkt. Toch leverden de gevonden studies enkele voorzichtige conclusies op. Hoger welbevinden was gerelateerd aan specialistische zorg als aanvulling op de standaard verpleeghuiszorg, aan een groter gevoel van ervaren vrijheid en aan een groter sociaal netwerk. Depressie en bepaalde symptomen van schizofrenie waren juist gerelateerd aan een lager welbevinden. De belangrijkste conclusie vanuit dit review artikel was echter vooral dat de hoeveelheid onderzoek naar welbevinden binnen de doelgroep van gerontopsychiatrische verpleeghuis bewoners nog zeer beperkt is. Meer onderzoek is wenselijk en zou waardevolle informatie kunnen toevoegen, onder andere in de vorm van praktische handvatten voor het verbeteren van zorg voor de gerontopsychiatrische verpleeghuispopulatie.

Het meten van welbevinden in de gerontopsychiatrische populatie

In de hoofdstukken 3 en 4 van dit proefschrift wordt de ontwikkeling en validering beschreven van een zelfbeoordelingsvragenlijst: de Laurens Well-being Inventory for Gerontopsychiatry (LWIG) en een observatievragenlijst: de Laurens Well-being Observations for Gerontopsychiatry (LWOG) voor het meten van welbevinden in de gerontopsychiatrie. De itempool voor de twee lijsten werd ontwikkeld, gebaseerd op de hierboven beschreven definitie en het model van welbevinden. Zowel gerontopsychiatrische verpleeghuisbewoners als ervaren verzorgenden en behandelaars zijn bij de ontwikkeling van de initiële itempool betrokken geweest. Om de betrouwbaarheid, validiteit en interne structuur van de meetinstrumenten vast te stellen zijn in totaal 295 gerontopsychiatrische verpleeghuisbewoners geïnterviewd door getrainde interviewers. Voor de observatievragenlijst waren dit 265 bewoners en hun eerst verantwoordelijke verzorgenden.

Validiteit en betrouwbaarheid waren in beide ontwikkelde meetinstrumenten voldoende. De interne structuur van de meetinstrumenten werd bepaald met behulp van factoranalyse. Dit leverde een verschil in interne structuur op voor de beide meetinstrumenten. Het model dat het uitgangspunt vormde voor de beide meetinstrumenten werd deels bevestigd in het onderscheid tussen fysiek, sociaal en psychologisch welbevinden van de LWIG. De instrumentele doelen (de doelen die instrumenteel waren aan de universele doelen) zoals beschreven in het oorspronkelijke model werden niet bevestigd door de data. Met behulp van factoranalyse werden echter logische nieuwe instrumentele doelen vastgesteld, die met elkaar de universele doelen vormden.

De interne structuur van de LWOG verschilde meer van het originele model, in die zin dat er geen drie maar slechts twee factoren werden gevonden. Een van de factoren was een schaal met negatief geformuleerde vragen, met name over psychologische onderwerpen, en de andere factor bevatte juist positief geformuleerde vragen, die met name over het sociale welbevinden gingen. Er werd geen factor of subschaal gevonden over fysiek welbevinden, maar de negatief/psychologische subschaal bevatte enkele vragen die gerelateerd waren aan fysiek welbevinden.

De resultaten in de beschreven artikelen vormen een belangrijke eerste stap in de ontwikkeling van een welbevinden instrument specifiek voor de gerontopsychiatrie. Meer onderzoek is nodig om de inter-beoordelaars betrouwbaarheid van de LWOG, en de test-hertest betrouwbaarheid en gevoeligheid voor verandering van de beide meetinstrumenten te onderzoeken, maar de eerste resultaten in dit proefschrift lijken veelbelovend.

Welbevinden en psychiatrische- en gedragsproblemen

In hoofdstuk 5 van dit proefschrift is de relatie tussen psychiatrische- en gedragsproblemen en de mate van het welbevinden binnen de doelgroep van gerontopsychiatrische verpleeghuisbewoners beschreven. Voor dit onderzoek werden 126 gerontopsychiatrische verpleeghuisbewoners en hun eerstverantwoordelijke verzorgende geïnterviewd. Zowel de LWIG als de LWOG (zie hierboven) werden gebruikt om het welbevinden van de bewoners te meten. Psychiatrische- en gedragsproblemen werden in kaart gebracht met behulp van de Cohen-Mansfield Agitation Index (CMAI) en de Neuropsychiatric Inventory Questionnaire (NPI-Q).

De relatie tussen geobserveerd welbevinden en psychiatrische- en gedragsproblemen was relatief sterk. Dit gold in het bijzonder voor de relatie tussen psychologisch (negatief) welbevinden en de NPI subschalen ‘prikkelbaarheid’ en ‘stemming’, en de CMAI subschaal ‘verbale agressie’. Voor het zelf-beoordeelde welbevinden werd ook een relatie gevonden met psychiatrische- en gedragsproblemen. Hierbij werd een sterker verband gevonden tussen de LWIG subschaal ‘psychologisch welbevinden’ en de NPI subschaal ‘prikkelbaarheid, en tussen de LWIG subschalen ‘fysiek welbevinden’ en ‘sociaal welbevinden’ en de stemming-subschaal van de NPI. De relatie tussen psychiatrische- en gedragsproblemen en het zelf-beoordeelde welbevinden was echter minder uitgesproken dan tussen psychiatrische- en gedragsproblemen en geobserveerd welbevinden.

Omdat het een cross-sectioneel onderzoek betrof konden helaas geen conclusies worden getrokken over de richting van de gevonden verbanden. Wel kan geconcludeerd worden dat bepaalde vormen van psychiatrische- en gedragsproblemen samenhangen met

het welbevinden. Meer onderzoek wordt aanbevolen naar de richting van het verband, en naar factoren die mogelijk invloed hebben op de relatie tussen psychiatrische- en gedragsproblemen en de hoogte van het welbevinden.

In de discussie werden de resultaten uit het proefschrift besproken. Hierin werd geconcludeerd dat welbevinden een meerdimensionaal construct is, met daarin verschillende elementen die van specifiek belang zijn voor de gerontopsychiatrische populatie. Deze elementen zijn positieve en negatieve sociale interactie, gemeenschappelijk leven, eigenwaarde, affect en (fysiek) comfort. Kennis over deze elementen kan richting bieden aan zowel de klinische praktijk als aan toekomstig onderzoek naar welbevinden binnen deze populatie. Omdat het welbevinden in de gerontopsychiatrische setting relatief laag bleek te zijn blijft aandacht voor dit onderwerp nodig. De meetinstrumenten die zijn ontwikkeld en gevalideerd zijn van groot belang om zowel de huidige stand van zaken als ook eventuele veranderingen in het welbevinden in kaart te brengen.

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Dankwoord

Dankwoord

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