



The relation between autonomy and well-being of nursing home residents with dementia: a systematic review

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Masterthesis – Positive Psychology and Technology

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Enschede, March, 2017

Abstract

As the population is getting older and the number of people with dementia is predicted to increase, it is crucial to identify factors that contribute to their well-being. Research on elderly people suggests that autonomy is related to their well-being. However, these findings are mostly based on studies conducted with older adults in general. Elderly people with dementia tend to be more vulnerable to experience lower levels of autonomy, especially when they live in a nursing home. Therefore, it is of great interest to get a better understanding to what extend autonomy is related to the well-being of nursing home residents with dementia. The aim of the systematic review was to give an overview of studies that focused on the relation between autonomy and well-being of nursing home residents with dementia. Based on previous studies and the Self-Determination-Theory, a positive relation between both variables was expected. Because different views on the concepts of autonomy and well-being exist, the study also tried to analyze how autonomy and well-being were assessed in current research. Furthermore, it aimed to discover the degree of perceived autonomy and well-being of nursing home residents with dementia.

By searching three databases (Scopus, Web of Science and PsycInfo), a total of eight studies, which included information about the relation between autonomy and well-being of nursing home residents with dementia were identified.

All of the included studies showed a positive relation between autonomy and well-being. Autonomy was mainly assessed through residents' independence in Activities of Daily Living and well-being through proxy-reported Quality of Life measurements. Residents had low levels of autonomy and moderate well-being.

The systematic review provides support for a positive relation between autonomy and well-being of nursing home residents with dementia. By this, it extends existing findings about the relation between autonomy and well-being of residents without dementia. The present study also contributes to a better understanding of how autonomy and well-being were assessed and supplies practical implication for future research in this field.

Keywords: Dementia; Nursing home; Autonomy; Well-being

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1. Introduction

Globally, the population is rapidly ageing. With increased age, the risk of chronic diseases, like dementia, raises as well. Currently, 47 million people live with dementia worldwide and the number is predicted to increase to more than 131 million by 2050 (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016). Not many studies about the prevalence of nursing home residents with dementia exist. But in most countries more than half of nursing home residents suffer from dementia and compared to community-dwelling older people the prevalence of dementia is much higher in older people living in nursing homes (Harris-Kojetin et al., 2016; Selbæk, Kirkevold, & Engedal, 2007). For example, in a German study, the prevalence of dementia in people aged 65 and older was 19-fold higher in nursing homes than in the community (Hoffmann, Kaduszkiewicz, Glaeske, van den Bussche, & Koller, 2014). The term nursing home in the present study refers to an international definition. Nursing homes are described as facilities with a domestic-styled environment that provide long-term care and functional support for elderly people who require assistance with daily living activities and who often have complex health needs and increased vulnerability (Sanford et al., 2015).

Dementia is characterized by a gradual cognitive decline that results in limited autonomy of the person affected (American Psychiatric Association, 1994). When older people with dementia are living in nursing homes, the experience of autonomy is especially restricted, due to institutional regulations (Sherwin & Winsby, 2011). Studies conducted in nursing homes show that limited autonomy is related to lower levels of well-being (Ferrand, Martinet, & Durmaz, 2014; Kasser & Ryan, 1999; Schenk, Meyer, Behr, Kuhlmeier, & Holzhausen, 2013; Vallerand, O'Connor, & Blais, 1998). However, less is known and to our knowledge no systematic review exists about the relation between autonomy and well-being of nursing home residents suffering from dementia. More insight in the relation between autonomy and well-being for this specific group is needed, as people with dementia are more vulnerable to experience lower levels of autonomy. Therefore, the objective of the present study is to give an overview of studies that are focusing on the relation between autonomy and well-being of people with dementia living in nursing homes. More knowledge about the relation between autonomy and well-being of people with dementia can be useful for the development of interventions which focus on autonomy in order to increase residents' well-being. As there are no curative treatments for dementia by now,

promoting well-being is an important objective to improve the lives of those suffering from the disease (Algar, Woods, & Windle, 2016).

1.1. Well-being

The concept of well-being became popular with the rise of positive psychology (Seligman & Csikszentmihalyi, 2000), which demands for a science that is more focused on the improvement of optimal functioning of individuals and society instead of a focus on malfunctioning and the treatment of illness. Recent research on well-being is based on two traditions. First, the hedonic approach, in which well-being is simply defined as the experience of pleasure and happiness and second, the eudaimonic approach, which focuses on personal growth, self-actualization and optimal functioning and defines well-being as more than just a feeling of pleasure (Ryan & Deci, 2001). Based on these two views, researchers developed different theories about well-being and determined several factors related to well-being (Ryan & Deci, 2001). In the literature, often quality of life (QoL) instead of well-being is mentioned. It is seen as a broader concept of well-being consisting of various domains (Gerritsen, Steverink, Ooms, & Ribbe, 2004). For example, Kane (2001) did research on QoL of older people living in nursing homes and distinguishes between eleven domains of QoL: security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual well-being, and functional competence.

Despite different views on well-being, its positive effect on the physical and mental health of older people with dementia is widely accepted. For example, those with higher levels of well-being reported lower levels of depression, cognitive impairment, or pain (Lee, McConnell, & Algase, 2015; Torisson, Stavenow, Minthon, & Londos, 2016). On the other hand, people with dementia with lower levels of well-being had more emotional and behavioral problems (Cooper, Bebbington, Katona, & Livingston, 2009). Despite a diagnosis of dementia, research demonstrate that older people are able to experience well-being (Cordner, Blass, Rabins, & Black, 2010). However, there is evidence that cognitive impairments and institutionalization have a negative influence on older peoples' well-being (Cobo, 2014; Missotten et al., 2007). People with dementia reported poorer well-being compared to older people without dementia and people with dementia living in nursing homes had lower levels of well-being compared to people with

dementia living in the community (Abrahamson, Clark, Perkins, & Arling, 2012; Nikmat, Al-Mashoor, & Hashim, 2015).

There are various measurement tools to assess a persons' well-being, also for people with dementia (Algar et al., 2016). For the assessment of well-being a patients' self-report is essential, because well-being reflects a personal experience. However, the results can be biased, due to cognitive impairments and communication deficits of the respondent with dementia. Therefore, family or staff members often act as a proxy and report on half of the patient (Leontjevas et al., 2016). But some studies show that proxies reported poorer well-being compared to self-reports, especially in dementia, which is described as an attenuation bias (Maria Crespo, Bernaldo De Quirós, Gómez, & Hornillos, 2011; Leontjevas, Teerenstra, Smalbrugge, Koopmans, & Gerritsen, 2016).

As cognitive impairments, together with living in a nursing home result in lower levels of well-being, it is of special relevance to support the well-being of residents with dementia and to detect factors which contribute to their well-being. Research suggests that autonomy is related to older peoples' well-being (Ferrand et al., 2014; Kasser & Ryan, 1999; Schenk et al., 2013; Vallerand et al., 1998). However, less is known about this relation in older people with dementia living in nursing homes.

1.2. Autonomy

Definitions of autonomy vary and it is widely accepted as a multidimensional construct (Ayalon, 2016). Based on literature it can broadly be divided into two dimensions: a physical component of autonomy, referring to freedom of mobility and physical independence; and a psychological component, referring to freedom of choices and decision making (Ball et al., 2004; Collopy, 1989; Hofland, 1990). Both dimensions are under strain in older people suffering from dementia, as the cognitive impairment leads to lower physical independence and a limited capacity to make decisions (American Psychiatric Association, 1994). Studies which made use of a decision making involvement scale show that involvement in daily decision making of older people with dementia decreased with increased cognitive and physical impairment (Menne, Tucke, Whitlatch, & Feinberg, 2008; Menne & Whitlatch, 2007). Besides difficulties caused by the disease, for older people living in nursing homes the experience of autonomy becomes more complicated, due to institutional regulations and limited privacy. Private rooms are often limited

and daily activities are scheduled with no space for residents to make their own choices (Sherwin & Winsby, 2011). In a longitudinal study of elderly people who went into a nursing home there was a clear relation between institutionalization and a decrease in perceived autonomy over time (Cobo, 2014). Nursing homes are designed to compensate for physical and cognitive losses. Nevertheless, this compensation can lead to an undermining of capabilities which might still be present, as the institutional regulations leave no room to maintain remaining levels of decisional capacity and physical independence (Sherwin & Winsby, 2011). Those suffering from dementia experience additional challenges. Due to safety reasons, they are more often restricted in the way to independently move around and because of a limited capability to effectively communicate one's need, their choices are often ignored and they are isolated from social activities (Behuniak, 2010; Theurer et al., 2015).

Support for the positive relation between autonomy and well-being comes from the Self-Determination-Theory (SDT) by Deci & Ryan (2000). According to the theory, the fulfillment of autonomy is essential for the experience of well-being and thwarting of it will always result in negative psychological consequences. The theory is supported by many studies in various fields across cultures (e.g. workplaces, schools, healthcare) (e.g. Reis, Sheldon, Gable, Roscoe, & Ryan, 2000; Ryan, Bernstein, & Brown, 2010; Tian, Chen, & Huebner, 2013; Vieira et al., 2011). To our knowledge there are no SDT-based studies with people suffering from dementia. But several studies were conducted with nursing home residents in general and the findings show a relation between autonomy and well-being of the residents (Ferrand et al., 2014; Kasser & Ryan, 1999; Vallerand et al., 1998). For example, in high self-determination nursing homes, characterized as nursing homes which offers more control in daily life by freely making decisions about mealtimes, or decoration of the room, residents had higher levels of well-being compared to residents of low self-determination nursing homes (Vallerand et al., 1998). Within the SDT, autonomy is defined as behavior that is self-endorsed and volitional, which is more in line with the psychological component of autonomy. But also the physical component of autonomy is expected to positively relate to nursing home residents' well-being (Murphy, Cooney, & Casey, 2014).

1.3. The present study

The findings mentioned above demonstrate that nursing home residents with dementia are especially vulnerable to experience lower levels of autonomy and well-being. If autonomy is positively related to well-being it is important to improve residents' autonomy. There is evidence for a positive association between autonomy and well-being of nursing home residents in general. However, less is known about the relation between autonomy and well-being of residents suffering from dementia. Because residents with dementia are particularly vulnerable to perceive limited autonomy and well-being, more knowledge about the relation between both variables is needed. Therefore, the goal of the present systematic review is to give more insight in the relation between autonomy and well-being for this specific group. Based on previous findings and supposed by the SDT, a positive relation between autonomy and well-being is expected. Next to this main objective, three sub-questions were formulated for a deeper understanding of the current assessment and degree of perceived autonomy and well-being of older people with dementia living in nursing homes.

1. What is the relation between autonomy and well-being of older people with dementia living in nursing homes? A positive relation between autonomy and well-being of older people with dementia living in nursing homes is expected.
2. What kinds of measurements were used to assess autonomy and well-being of older people with dementia living in nursing homes?
3. Was autonomy and well-being self- or proxy reported?
4. What is the overall level of autonomy and well-being of older people with dementia living in nursing homes?

2. Methods

2.1. Search strategy

Scientific studies were identified by searching the electronic databases PsychINFO, Scopus and Web of Science. The search terms were the key words dementia, Alzheimer's disease, mild cognitive impairment, autonomy, decision making, independence, freedom, well-being, quality of life, nursing home, long-term care facility and residential home. The full

electronic search strategy for the three databases is represented in table 1. No limit was set on the date of publication. Studies in the English and Dutch language were included.

Table 1. *Electronic search strategy of the databases Scopus, PsycInfo and Web of Science.*

Database	Electronic search strategy
Scopus, PsycINFO, Web of Science	(dementia or alzheimer or "mild cognitive impairment) AND (autonomy or "decision making" or freedom or independence) AND (well-being or wellbeing or "well being" or "quality of life") AND (nursing hom* or "long term care facilit*" or "residential hom*")

2.2. In and exclusion criteria

Inclusion criteria were empirical studies which include information about the relation between autonomy and well-being of older people with dementia living in nursing homes. Exclusion criteria were 1) participants do not have dementia; 2) participants do not live in a nursing home; 3) the study does not report the relation between autonomy and well-being; 4) the study is not in the English or Dutch language.

2.3. Study selection

Selecting studies to include in the systematic review was done by the first author. Figure 1 represents a flow chart of the study selection process. In total, 462 records were identified through database searching. After screening was done by reading title and abstract of the records and 34 duplicates were removed, 34 articles were assessed for full-text eligibility. 26 studies did not meet the inclusion criteria as described. Most studies, in total 15, were excluded, because the relation between autonomy and well-being was not reported. In two studies the participants did not have dementia and two other studies were not in the English or Dutch language. Seven studies had to be excluded, because there was no access to the full text of the article. Finally, eight studies were included in the systematic review. The selected studies are presented in table 2.

Figure 1. Flow chart of study selection.

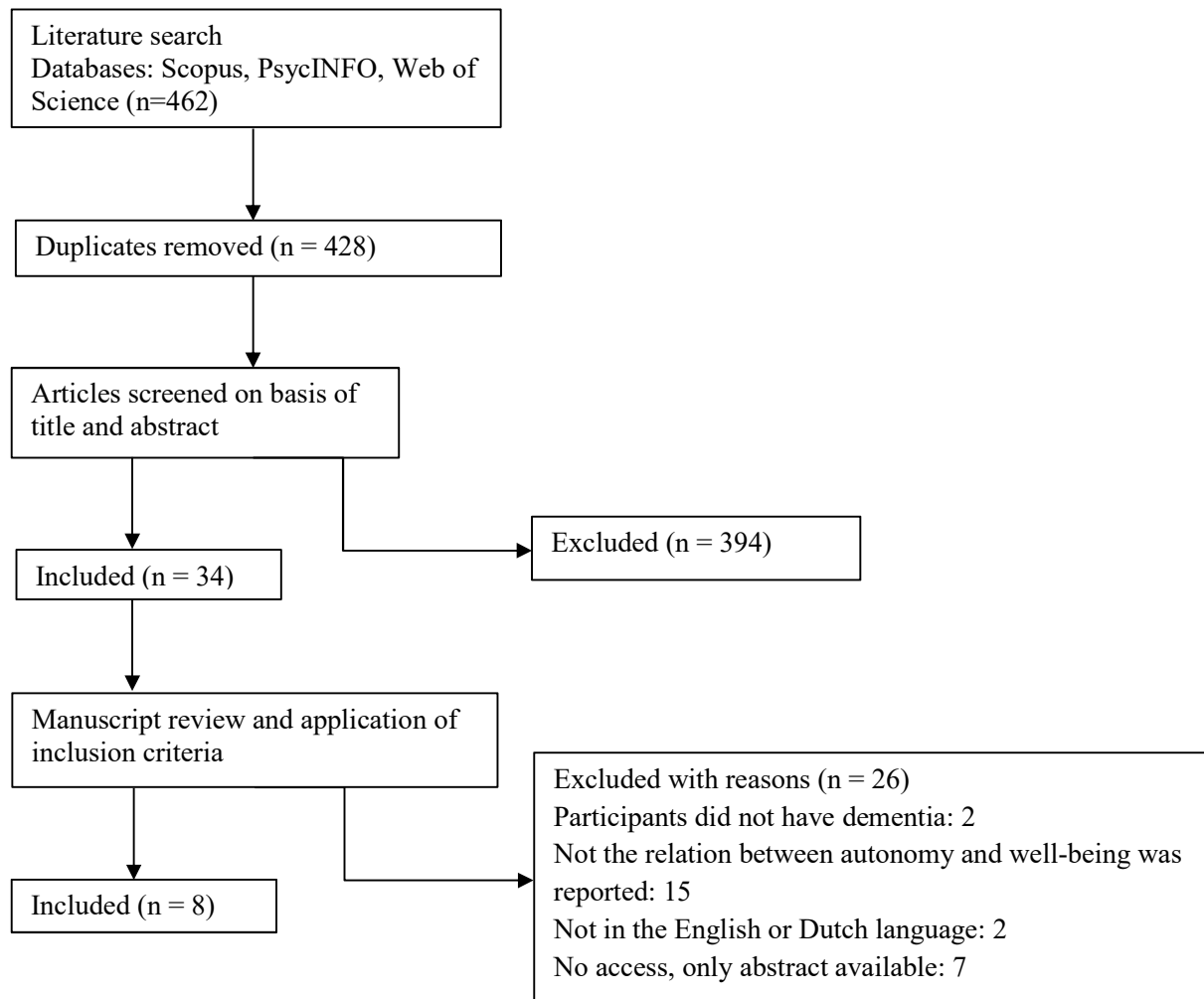


Table 2. Studies included in the review.

#	Title	Author	Journal
S1	Quality of life for people with dementia living in residential and nursing home care: The Impact of Performance on Activities of Daily Living, Behavioral and Psychological Symptoms, Language Skills, and Psychotropic Drugs	(Ballard et al., 2001)	International Psychogeriatric Association
S2	Change in quality of life of people with dementia	(Beerens et al.,	Journal of

	recently admitted to long-term care facilities	2014)	Advanced Nursing
S3	Factors associated with quality of life in dementia patients in long-term care	(M. Crespo, Hornillos, & De Quirós, 2013)	International Psychogeriatric Association
S4	A meaningful daily life in nursing homes - a place of shelter and a space of freedom: A participatory appreciative action reflection study	(James, Blomberg, & Kihlgren, 2014)	BioMed Central
S5	Ideals regarding a good life for nursing home residents with dementia: Views of professional caregivers	(Kalis, Schermer, & Van Delden, 2005)	Nursing Ethics
S6	Quality of life in older people with dementia: A multilevel study of individual attributes and residential care center characteristics.	(Marventano et al., 2014)	Geriatrics & Gerontology International
S7	Quality of life (QoL) in community-dwelling and institutionalized Alzheimer' s disease (AD) patients	(León-Salas et al., 2013)	Archives of Gerontology and Geriatrics
S8	The impact of subject/respondent characteristics on a proxy-rated quality of life instrument for the Japanese elderly with dementia	(Yamamoto-Mitani et al., 2004)	Quality of Life Research

2.4. Data extraction and analysis

To answer the research questions, all included articles were analyzed on 1) participants' characteristics; 2) types of measurements and methods to assess autonomy and well-being; 3) whether the questionnaires were rated by residents or proxies; 4) findings related to the relation between autonomy and well-being.

3. Results

3.1. Participants' characteristics

Table 3 shows the characteristics of the participants for each study. The sample ranged from 10 to 632 participants. In seven of the eight selected studies, the residents with dementia participated in the study, while one study solely focused on professional caregivers of dementia-care wards. Of the studies in which the residents participated, three also included professional caregivers and in one study both caregivers and relatives participated. In all studies, the residents with dementia were predominantly female and the mean age ranged from 81.7 to 92.0 years. Three different scales were used in the studies to assess the dementia level: The Mini Mental Stage Examination (MMSE) (Folstein, Folstein, & P.R., 1975), the Clinical Dementia Rating

(CDR) (Morris, 1993) and the Karasawan Clinical Dementia Scale (Yamamoto-Mitani et al., 2004). In three studies, the majority of residents had a moderate dementia level and in three other studies they had a severe dementia level. In two studies, no details about the severity of dementia were given. In studies in which caregivers or relatives were included no details about the proxies were reported. Only one study reported demographical data about them: the relatives were predominantly female, with a mean age of 58.85 years and the caregivers were also mainly female, with a mean age of 39.8 years.

Table 3. *Participants' characteristics.*

#	N	female (%)	Age (M)	Instrument	Score	Dementia level
S1	232 residents n caregivers	79.5%	82.5	MMSE	M=8.4 SD=7.2	severe
S2	343 residents n caregivers	74.9%	84.3	MMSE	M=14.1 SD=5.2	moderate
S3	209 residents 197 relatives 92 caregivers	79.4% 62.0% 96.7%	86.1 58.9 39.8	MMSE	M=13.3 SD=5.9	moderate
S4	25 residents	60.0%	92.0	no details		
S5	10 caregivers	no details	no details	no details		
S6	429 residents n caregivers	82.0%	85.8	Clinical Dementia Rating (CDR)	n=64 n=110 n=255	mild moderate severe
S7	108 residents n caregivers	74.0%	79.3	MMSE	M=7.0 SD=6.2	severe
S8	623 residents n caregivers	76.6%	81.7	Karasawan Clinical Dementia Scale	n=92 n=209 n=186 n=136	early middle-stage severe very severe

3.2. Instruments to assess autonomy and well-being

To identify how autonomy and well-being of the older people with dementia were assessed, the instruments used to assess autonomy and well-being was analyzed. The different kinds of instruments are presented in Table 4. In six of the eight included studies (S1, S2, S3, S6, S7, S8), autonomy was defined as 'independence' and was assessed through measurements of residents' level of independence in activities of daily living (ADL). In total, three different scales, which measure residents' independence in ADL were identified in the studies. S2 and S7

made use of the Katz Index of Independence in ADL (Katz ADL), by Katz, et.al. (1963). Three studies (S1, S3, S6) made use of the Barthel Index of ADL (BI), by Mahoney & Barthel (1965). In S8, a Japanese tool: Level of independence in Activities of Daily Living (JMHW), to assess residents' independence was used. S4 and S5 did not measure autonomy, but interviews with residents and caregivers were conducted to assess residents' well-being and the respondents mentioned autonomy as a necessary factor for elderly residents with dementia to experience well-being.

Most frequently, in five studies (S2, S3, S6, S7, S8), well-being was assessed quantitatively through a QoL questionnaire that was specifically developed for people with Alzheimer's disease. In total, four different QoL questionnaires were used. Three studies (S2, S3, S6) made use of the Quality of Life-Alzheimer's disease scale (QoL-AD), by Logsdon, Gibbons, McCurry, & Teri (1999). One was an applied version, developed for people with dementia living in nursing homes, by Edelman, Fulton, Kuhn, & Chang (2005). S7 made use of the ADRQL, by Rabins, Kasper, Kleinman, & Black (1999). A Japanese QoL instrument for older adults experiencing dementia (QLDJ) was used in S8 (Yamamoto-Mitani et al., 2002). Next to quantitative measurements, three studies made use of qualitative methods. Dementia Care Mapping (DCM), an observational method by Kitwood & Bredin (1994), to assess QoL of older people with dementia, was used by S1. In S4 and S5 interviews with caregivers and residents were conducted to assess factors, which are necessary for residents' well-being.

It was also analyzed whether autonomy and well-being were rated by residents or by proxies. Autonomy was always rated by staff members or by relatives. All QoL questionnaires were rated by caregivers, but in S2 they were additionally rated by residents and in S3 the QoL questionnaire was answered by all three: residents, caregivers and relatives. The observations in S1 were done by caregivers and the interviews in S4 and S5 were held with residents and staff members.

It can be concluded that autonomy was predominantly assessed by residents' level of independence in ADL. Well-being was mainly measured quantitatively through QoL questionnaires for patients with Alzheimer's disease. Only three studies made use of qualitative measurements, with observations and interviews. In most of the cases, the questionnaires were proxy-reported by caregivers, two studies used self-report and in one study interviews were held with the residents and caregivers.

3.3. Residents' level of autonomy and well-being

To get insight in residents' degree of autonomy and well-being, the scores of both variables in the different studies were analyzed. The results are also presented in table 4. In all studies that measured autonomy (S1, S2, S3, S6, S7, S8), the scores were in the lower range on the different scales. This means low independence in ADL of the residents. In all studies that quantitatively measured well-being (S2, S3, S6, S7, S8), the overall scores were in the midrange. This indicates moderate well-being levels of the residents. In two studies well-being was reported by residents and proxies (S2 and S3). In both cases resident-reported well-being was significantly higher compared to proxy-rated well-being (S2: $t = 2.1$, $p = 0.04$ S3: $F(2,132) = 21.86$ $p < 0.001$). In S8 well-being was measured separately for males and females. The results show that females ($M = 59.9$, $SD = 17.7$) scored higher than males ($M = 56.8$, $SD = 17.2$). However, the difference was not significant. In S1, in which the Dementia Care Mapping method was used, the majority of residents (56.0%) were observed to have good well-being. But 25.0% also had poor well-being and 8.3% had very poor well-being. Based on the results of the different scales, it can be concluded that the residents' had low levels of autonomy and moderate levels of well-being. Well-being reported by the residents themselves was significantly higher than proxy-reported well-being.

Table 4. *Instruments, ranges and scores of autonomy and well-being.*

#	Instrument autonomy	Range	Score	Instrument well-being	Range	Score	Respondent
S1	Barthel Index of Activities of Daily Living (BI)	0-20	M=12.6 SD=5.4	Dementia Care Mapping (DCM)	very good good fair poor very poor	1.9% 56.0% 9.3% 25.0% 8.3%	caregiver
S2	Katz Index of Independence in Activities of Daily Living (Katz ADL)	0-6	M=2.8 SD=1.7	Quality of Life-Alzheimer's Disease scale (QoL-AD) (range)	13-52	M=32.1 SD=5.6 M=32.8 SD=6.1	caregiver self
S3	Barthel Index of Activities of Daily Living (BI)		no details	Adaption of the Quality of Life-Alzheimer's Disease Scale (QoL-AD)	1-4	M=2.5 SD=0.7 M=2.0 SD=0.8 M=2.0 SD=0.8	caregiver relative self
S4	Interviews						
S5	Interview						
S6	Barthel Index of Activities of Daily Living (BI)	0-100	M=33.8 SD=29.3	Quality of Life in Alzheimer's disease (QOL-AD)	13-52	M=27.6 SD=5.1	caregiver
S7	Katz Index of Independence in Activities of Daily Living (Katz ADL)	0-6	M=1.5 SD=2.0	ADRQL	0-100	M=64.8 SD=18.2	caregiver
S8	Level of independence in ADL (JMHW)	almost independent homebound	n=132 n=323	Japanese Quality of Life Instrument for Older Adults Experiencing Dementia (QLDJ)	0-100	female M=59.9 SD=17.7 male	caregiver

bedbound	n=112	M=56.8 SD=17.2
completely bedbound	n=56	

3.4. Relation between autonomy and well-being

Based on the SDT and previous studies, a positive relation between autonomy and well-being of older people with dementia in nursing homes was expected. In six studies (S1, S2, S3, S6, S7, S8) the relation between autonomy and well-being was measured with correlation analysis. All studies found a significant association between both variables ($0.08 \leq r \leq 0.51$; $0.0001 \leq p \leq 0.05$). Higher scores on QoL were related to higher scores on independency in ADL and lower scores on QoL were related to lower scores on independency in ADL. However, the associations between QoL and independence were only found in proxy-reported QoL. Two studies (S2 and S3) also measured resident-reported QoL and in those studies no significant correlation between autonomy and resident-reported well-being was found. S2 measured changes in well-being over a period of three months. A decline in proxy-reported well-being was associated with greater dependence at baseline ($\beta = 0.4$, $p = 0.009$) and with an increase in dependence between baseline and follow-up ($\beta = 0.7$, $p < 0.001$). In studies that used interviews with residents or staff members to assess determinants of residents' well-being, autonomy was mentioned by residents and staff members as necessary factor for residents with dementia to experience well-being (S4 and S5).

It can be concluded that the hypothesis is supported, because autonomy and residents' well-being were positively related. Moreover, the longitudinal study shows that autonomy was a predictor of well-being over time. However, the associations were only found in proxy-reported well-being. Next to the statistical relation, interviews demonstrate that residents and staff members rated autonomy as a necessary factor for the experience of well-being.

4. Discussion

The purpose of the current systematic review was to gain more insight in the relation between autonomy and well-being of older people with dementia living in nursing homes. According to the SDT and previous research, a positive relation between autonomy and well-being was expected. Based on the present findings, it can be concluded that autonomy and well-being of persons with dementia living in nursing homes are positively related. One study also shows that autonomy was a predictor of well-being. A decline in autonomy was associated with a decline in residents' well-being over time. Furthermore, residents with dementia and their caregivers mentioned autonomy as a necessary factor for the experience of well-being. By this,

the present study supports already existing findings about a positive relation between autonomy and well-being of nursing home residents in general (Ferrand et al., 2014; Kasser & Ryan, 1999; Schenk et al., 2013; Vallerand et al., 1998). However, it should be mentioned that the relation was only found in proxy-reported well-being. More research is needed to determine whether well-being from the perspective of the resident with dementia is also related to autonomy.

Next to the main objective, the study aimed to provide information about the assessment of autonomy and well-being in nursing home residents with dementia and to discover their degree of experienced autonomy and well-being. In all included studies that measured autonomy it was defined as residents' level of independence in ADL. It should be noted that this is not in line with the definition of the SDT, on which the current hypothesis about a positive relation between autonomy and well-being was based. However, in the literature, autonomy is seen as a multidimensional construct and it can be divided into two dimensions: the physical component of autonomy (e.g. physical independence) and the psychological component (e.g. freedom of decision making) (Collopy, 1989; Hofmann, 1990). Both dimensions are not distinct, rather interrelated, as lower independence and a higher dependence on others go along with a limited capacity to make decisions and regulate behavior in line with inner interests (Davies, Ellis, & Laker, 2000). Therefore, the main finding that autonomy and well-being are positively related in residents with dementia is not limited through another definition of autonomy than defined by the SDT. For more support of the relation between decisional autonomy and well-being more research is needed. This could be done through SDT-based research focusing on residents with dementia, like already done in somatic nursing homes or nursing homes in general (e.g. Custers, Westerhof, Kuin, Gerritsen, & Riksen-Walraven, 2012; Custers, Westerhof, Kuin, & Riksen-Walraven, 2010; Ferrand et al., 2014; Vallerand et al., 1998).

Well-being was mainly measured through QoL questionnaires for patients with dementia. Only one study made use of Dementia Care mapping (DCM), an observational method to assess QoL of people with dementia, and two studies conducted interviews. In the literature, good psychometric properties for the QoL questionnaires can be found (Logsdon et al., 1999). On the other hand, psychometric properties for DCM are less researched and like interviews it is very time consuming (Cooke & Chaudhury, 2013). This may be an explanation for the preference for the QoL scales. However, criticism exists about the influence of patients cognitive and communication abilities on the results. Test results may be biased, because respondents with

dementia might be less able to understand and answer the questions (Crespo, Hornillos, & Gómez, 2013; Leontjevas, Teerenstra, Smalbrugge, Koopmans, & Gerritsen, 2016). Therefore, often proxy-reported measures are used, which is in line with present findings. Only in two of the included studies well-being was also reported by residents. When well-being was rated by residents it was significantly higher compared to proxy-rated well-being. This is also in line with previous research. Different studies show that proxies reported lower well-being compared to the older persons with dementia (Conde-Sala, Garre-Olmo, Turró-Garriga, López-Pousa, & Vilalta-Franch, 2009; Maria Crespo et al., 2011). Therefore, it is assumed that proxies underestimate the well-being of older people with dementia (Leontjevas et al., 2016). To identify whether the differences are a consequence of underestimation by the proxies or a result of the older persons' cognitive disabilities, more research is needed detecting reasons for the different perceptions of well-being. Regarding the present results, together with previous findings, proxy-reported QoL questionnaires seem to be the preferred method to assess well-being of elderly people with dementia. Because of the different perceptions of well-being between the older people and their proxies, it is recommended using both ratings to get reliable and valid results.

In all included studies, residents' level of autonomy was in the lower range on the different scales. This finding supports the assumption that older people with dementia living in nursing homes tend to experience low levels of autonomy (Behuniak, 2010; Theurer et al., 2015). It demonstrates that nursing homes should improve the fulfillment of autonomy of residents with dementia. Although there was a difference between self- and proxy-reported well-being, the overall scores on the well-being scales were in the midrange. This finding supports previous research that older people are able to experience well-being, despite a diagnosis of dementia (Cordner et al., 2010). However, research also indicate that elderly people with dementia living in nursing homes tend to have lower well-being compared to residents without dementia or older people with dementia living in the community (Abrahamson et al., 2012; Nikmat et al., 2015). Moreover, well-being is suggested to decrease with advanced cognitive impairment and longer institutionalization (Cobo, 2014; Missotten et al., 2007). Therefore, nursing homes should pay attention to the maintaining of residents' well-being. The present study gives some evidence that this could be done through the support of residents' autonomy.

The current systematic review has some limitations that should be addressed. First, not many studies about the relation between autonomy and well-being were found and evidence that

the two factors are positively related is based on the results of only eight studies. Nevertheless, in all of the six studies that measured the relation between residents' autonomy and well-being both factors were positively correlated. In the other two studies, which conducted interviews, autonomy was mentioned as determinant of the experience of well-being. Therefore, despite the inclusion of only eight studies, the hypothesis can be regarded as supported, as all of the included studies showed similar results.

Another limitation of the review is a possible publication bias, because the present study only includes published scientific articles. Additionally, some studies could not be involved, because they were not in the English or Dutch language or there was no access to the full article. The missing and possible unpublished articles also could provide information about the relation between autonomy and well-being, which might be not in line with the result of the present study. This may have led to an overestimation of the conclusion of a positive relation between autonomy and well-being. Furthermore, studies might be missed through the use of the selected keywords. For broader research in this field, future systematic reviews could use different keywords and could also include books or other literature.

Residents' severity of dementia varied between the selected studies. But the present review did not differentiate between stages of dementia. For a fuller understanding of the relationship between autonomy and well-being in residents with dementia, future research could focus on possible differences between severities of dementia and the relation between autonomy and well-being.

Despite the limitations, the existing systematic review gives evidence for a positive relation between autonomy and well-being in nursing home residents with dementia. The study also provides some support that autonomy is a predictor of residents' well-being over time. However, more research is needed to verify this finding. If more evidence for autonomy as a predictor of residents' well-being can be found, it can be supported through interventions that improve autonomy. In the literature, some interventions focusing on the improvement of autonomy of residents with dementia already can be found. Specific movement exercises (e.g. dancing, tai-chi, or yoga) or environment modifications (e.g. wayfinding improvements through large signage with colors) that make the environment easy for the residents to understand and allow access to secure wandering places, were developed to promote residents' functioning and prevent a loss of independency (Barnes et al., 2015; Day, Carreon, & Stump, 2000; Tilly & Reed,

2008). The present study does not provide support for a relation between decisional autonomy and well-being. However, in the literature interventions focusing on this dimension can be found. Currently, a widely held goal of care services for people with dementia is person-centered care in which the resident with his unique needs and preferences is seen as the focus of care. One guiding principle in this approach is the improvement of autonomy through involvement in decision making of the resident with dementia (Manthorpe & Samsi, 2016). The existing programs show that there is already attention for the improvement of autonomy of residents with dementia. This improvement is recommended, as residents with dementia experience limited autonomy, which is also supported by the present study. But more research is required to analyses if autonomy is a predictor of residents' well-being and if these interventions also have a positive effect on their well-being and can be used to improve it.

5. Conclusion

Overall, the present systematic review gives insight in the relation between autonomy and well-being of nursing home residents with dementia and support the hypothesis that autonomy and well-being are positively related in this specific group. Through this finding, the present study enhances already existing results about a positive relation between autonomy and well-being of residents without dementia. Additionally, the systematic review provides some evidence that autonomy is a predictor of residents' well-being. However, more research is needed to further support this finding. The current results about the assessment of autonomy and well-being of nursing home residents with dementia can be helpful for future research in this field. The study shows that autonomy was solely assessed through residents' level of independence in ADL. For a deeper understanding of the relation between autonomy and well-being, future studies should also focus on the decisional component of autonomy. For the assessment of well-being researcher have to be aware of the different perspectives of well-being by the older adults and their proxies. The assessment through self- and proxy-reports is recommended to get valid and reliable test results. If more evidence for autonomy as a predictor of residents' well-being can be found, it can be supported through interventions that improve autonomy. The development of those interventions is required, as nursing home residents with dementia experience limited autonomy and well-being is assumed to decrease with increased cognitive impairment and a longer stay in nursing homes. Maintaining residents' well-being should be in the interest of every nursing

home, as there are no curative treatments for the disease by now and well-being has a positive effect on the psychological and physical health status of elderly people with dementia.

6. References

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