Master Thesis

Quality of Life of People with Dementia in Nursing Homes in the Netherlands: the Influence of the Intra-, Interpersonal and Organizational level

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Abstract

This research aimed to investigate factors influencing quality of life (QoL) of people with dementia (PwD) living in nursing homes (NH) in the Netherlands. The factors were identified using the Socio-Ecological Model (SEM), which allowed to look at factors from different levels simultaneously. Moreover, the current study examined the influence of the location of the NH on QoL and as such contributed to the research gap. Additionally, it was examined whether amount of visits by family carer (FC) influenced QoL, and whether this relationship was moderated by rural NHs. Data collected by Trimbos Institute (2019-2020) was used to test hypotheses. Four datasets (PwD, FC, NH's manager and care staff) were merged into one dataset. Only suitable data was used which resulted in a subset for the current study ($N = 261$). A multi-level regression analysis tested the predictors of QoL. Moreover, an interaction effect between amount of visits by FC and location of the NHs is included. Results from the multi-level regression analysis showed that independency on activities of daily living, amount of visits by FC, perceptions of the caregiving role by FC, small scale care, facility size and location of the NH did not significantly influence QoL of PwD. Additionally, no support was found for the interaction effect. Although relationships were congruent with previous research, no significant effects were found. Possible explanations for the unexpected outcomes were addressed. This study contributed to the research field by using an holistic approach. Future researchers are advised to expand on research on QoL according to the SEM. Moreover, it is advised to revise research design methods. Finally, as previous research identified differences in QoL of PwD by NHs' location, it is advised that policy makers and health care professionals reconsider health care policies.

Key words: Quality of Life, People with Dementia, Socio-Ecological Model

List of abbreviations

ADL	Activities of daily living
CPS	Cognitive performance scale
CS	Care staff
FC	Family carer
NH	Nursing home
PwD	People with dementia
QoL	Quality of life
SEM	Social-Ecological Model

Introduction

The global population is ageing and dementia is, consequently, becoming more prevalent. In the Netherlands, the number of people with dementia (PwD) is expected to increase to half a million by 2050 (Alzheimer Nederland, 2019). Hence, there is an urgent need to prepare for the challenges of caring for this population. Since there is no cure for dementia, care for PwD is focused on enhancing PwD's Quality of Life (QoL), especially since PwD often experience a loss in their QoL (Willemse, Heijkants & Prins, 2019). QoL is the perception of individuals on their position in life, in the context of culture, in relation to their goals, expectations, standards and concerns; where the physical, psychological, social and environmental domains are the most important indicators (Skevington et al., 2014).

Previous research identified that QoL of PwD is affected by individual factors, such as depressive symptoms (Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013), whereas social factors such as social engagement contribute to higher QoL (Martyr et al. 2017). Moreover, studies found additional factors related to QoL that are particular for PwD living in nursing homes (NHs). For example, Xu, Kane, & Shamliyan (2013) found that NH's location influences QoL, as rural NHs have more private rooms which increases resident's QoL (Xu, Kane, & Shamliyan, 2013).

While existing literature identified how such NH characteristics impact QoL, research also showed differences in quality of care between urban and rural NHs. For example, rural NHs are more positive about their knowledge on achieving higher quality care than urban NHs (Ploegman et al., 2017). Simultaneously, a disadvantage for residents from rural NHs could be that they receive less visits when their informal carers and children leave rural areas to move to the bigger cities (Hospers, 2019). This could negatively affect PwD's social relations, and consequently their QoL.

Despite previous studies that identified various factors on different levels affecting QoL, they have not considered these predictors of QoL simultaneously and how these factors operate together. Thus, the current research used a holistic approach, as guided by the Social-Ecological Model (Mcleroy, Bibeau, Steckler & Glanz, 1988) as a theoretical framework, to look at various factors from different levels *together* influencing QoL of PwD in NHs. Moreover, a direct comparison of QoL of PwD between rural and urban NHs in the Netherlands has not been conducted, even though evidence suggests that differences in rural versus urban environments might impact PwD's QoL. Therefore, this research examined differences in QoL between PwD living in NHs in rural and urban areas. More specifically, the current research examined the

question: ''*How do factors on intra-, interpersonal and organizational level contribute to QoL of PwD in NHs in the Netherlands?''*. This research extended the knowledge on QoL of PwD with its holistic approach and the urban-rural consideration. Moreover, this study contributed to better understanding of QoL of PwD, which helps NHs gain insight on their characteristics or improve their care, ultimately influencing QoL of PwD. Finally, it could help design health policies, contributing to the larger objective of public health.

Theoretical Approach and Existing Literature

While various factors on different levels (i.e. individual, social and organizational) have been identified in previous research to affect QoL of PwD, it remains unclear how these factors simultaneously contribute to QoL of PwD in NHs. Considering that previous research on QoL of PwD from a multidisciplinary perspective remains scarce, the Socio-Ecological Model (SEM) by Mcleroy et al. (1988) lends itself well to understand QoL within broader social and societal contexts. The SEM recognizes individuals as embedded within larger social systems and describes the interactive characteristics of individuals and environments that underlie health outcomes (Sallis et al., 2008). Accordingly, McLeroy et al.'s (1988) SEM enabled the current study to understand QoL as an outcome resulting from factors of different levels.

McLeroy et al. (1988) defined the SEM by showcasing the interrelated systems at five levels: The *Intrapersonal* level relates to characteristics of the individual, such as knowledge, attitudes, behaviour etc.

The *Interpersonal* level are related to the social network, including family, work-group and friendship networks.

The *Organizational* level relates to social institutions with organizational characteristics and regulations.

The *Community* level relates to the relationship among organizations, institutions, informal networks.

The *Policy* level relates to the local, state policies (Mcleroy et al., 1988).
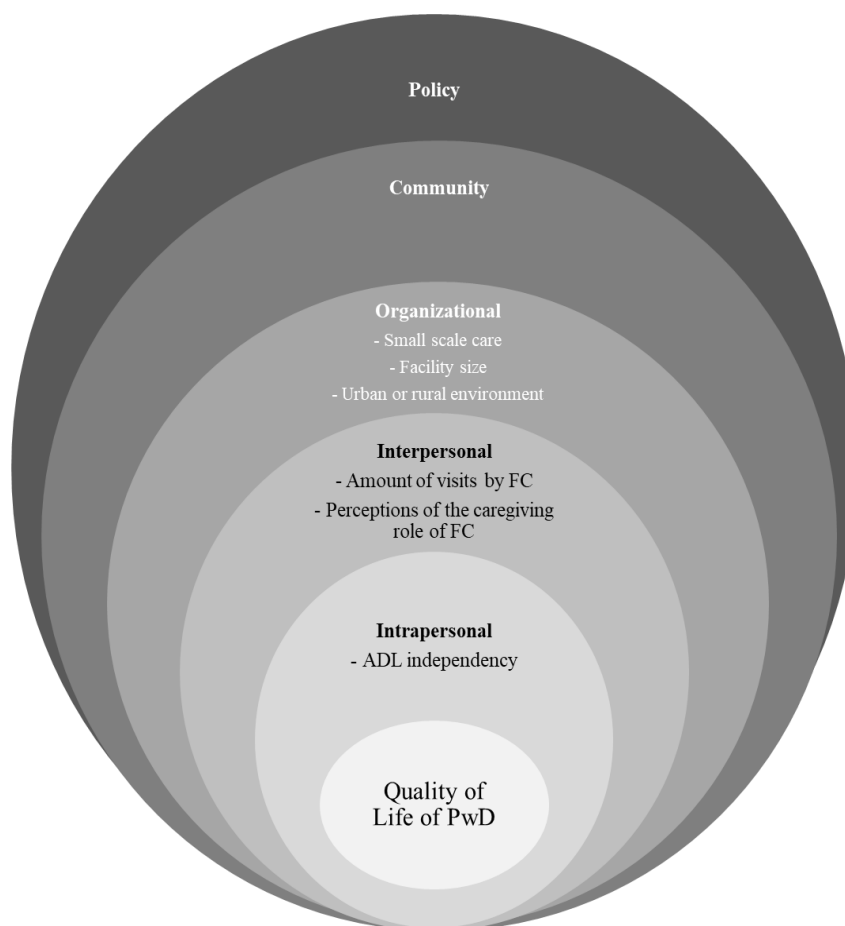
Accordingly, the SEM is used as a framework to guide the current research. In Figure 1, the SEM is depicted demonstrating the different levels of predictors that influence a particular outcome (QoL). The overlapping rings in which the various predictors are classified, illustrate how

factors at one level influence factors at another level, which ultimately affects the outcome (CDCP, 2002).

Extensive literature research was done to identify important factors affecting QoL. Consequently, these factors were provided by variables from the dataset of the LAD-study conducted by Trimbos Institute (2019-2020). Figure 1 depicts the factors classified according to the SEM. These factors will be reviewed in the literature review below.

Figure 1.

Visualisation of the SEM with predictors of QoL

Policy

Community

Organizational
- Small scale care
- Facility size
- Urban or rural environment

Interpersonal
- Amount of visits by FC
- Perceptions of the caregiving role of FC

Intrapersonal
- ADL independency

Quality of Life of PwD

Quality of Life

The QoL of PwD is an individual, subjective, dynamic, multidimensional, and complex construct. It includes the adaptation to the consequences of dementia. QoL is defined as the perception of individuals on their position in life, in the context of culture, in relation to their goals,

expectations, standards and concerns (Skevington et al., 2014); where the physical, psychological, social and environmental domains are the most important indicators. A unifying theme for measuring QoL of PwD is Lawton's (1983) conceptualization of QoL, which captures the multidimensionality of QoL. Lawton's conceptual framework (see figure 1) for QoL in older people includes four domains: *behavioural competence,* which describes how well a person functions regarding physical health, activities of daily living (ADL), cognition, and social behaviour. The second domain is *environmental quality*, which includes housing quality. The third domain is *perceived quality of life* and entails the evaluation of one's neighbourhood, family, friends, etc. The fourth domain is *psychological wellbeing* (negative and positive affect) (Bökberg et al., 2017).

The current research examined QoL, measured with the QUALIDEM instrument. (Ettema et al., 2007) The instrument extends on Lawton's conceptual model through classifying QoL by nine subscales (appendix C) each relating to the multidimensional theory on QoL by Lawton (Bökberg et al., 2017). The QUALIDEM's structure and content stresses the importance of PwD's ability to adapt to, for example, their own disability, developing and maintaining social relationships and dealing with the environment. These different adaptive tasks represent its relationship to Lawton's four different dimensions overlapping each other.

Figure 1.
Lawton's conceptual model on QoL for PwD
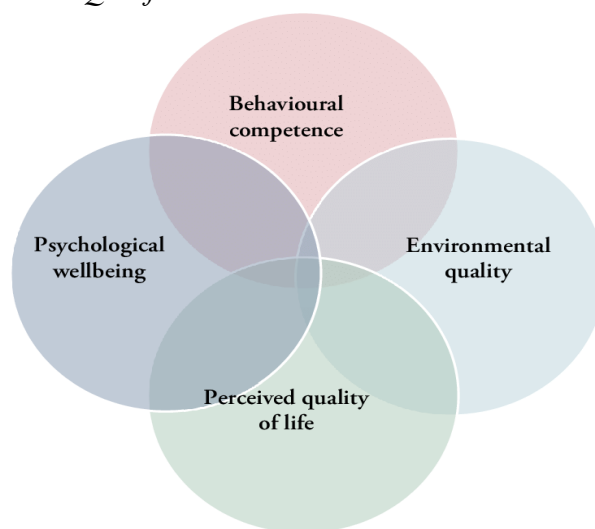
Note. Conceptual model on the dimensions of QoL of Pwd according to Lawton by Bökberg et al. (2017).

Socio-ecological predictors of QoL

QoL is affected by different levels. The current research focused on the intra-, interpersonal and organizational levels. Existing research on these levels is discussed in the following paragraphs.

Intrapersonal Level

Intrapersonal influences concern individual characteristics such as emotional state, which appeared to affect QoL of PwD in NHs positively (Crespo et al., 2013). Moreover, mood and especially depressive symptoms are consistently relating to lower self-rated QoL, while behavioural disturbances are related to lower proxy-rated QoL of PwD in NHs (Beerens et al., 2013).

Another important factor is PwD's dependency on activities in daily living (ADL). ADL describes the fundamental activities to manage basic needs, such as eating and personal hygiene. Independency in such activities for PwD in NHs is associated with higher QoL (Henskens, 2019). Moreover, being less independent causes PwD to become more dependent on the care they receive, possibly influencing their QoL (Beerens et al, 2013).

Moreover, PwD's cognitive functioning remains an important factor. For example, improved cognition positively influences QoL for PwD in NHs (Hoe et al., 2009). However, Banerjee et al. (2009) suggest that QoL for PwD in general, was not associated with cognition. Therefore, results concerning cognitive functioning are ambiguous, and it is not clear whether these factors that influence PwD, also impact QoL of PwD living in NHs. While research exists on QoL of PwD living at home, few focused on PwD living in NHs. Hence, factors influencing QoL in NHs in the Netherlands are unclear and warrant more research attention.

Interpersonal Level

Social factors, which are on the interpersonal level, are important for QoL. Individuals with richer social networks are happier, due to the fact that relationships satisfy basic human needs for belongingness which causes positive affirmation (Deci et al., 2002). Specifically, Moyle and O'Dwyer (2012) suggest that a good relationship with family and other persons contributes to QoL, as they reinforce a sense of personal worth and social confidence (Livingston et al., 2008). For PwD at home, the quality of the relationship with the informal caregiver appeared to be the strongest influence on QoL (Quinn et al., 2012). Moreover, frequent contact with family had a

positive influence (Thorgrimsen et al. 2003). For PwD in NHs, informal care is mostly done by family and this relationship positively influences behavioural and psychological symptoms of dementia (Minematsu, 2006).

Other factors contributing to QoL for PwD in NHs are, for instance, if the NH is welcoming to family and friends and if the close family is involved in supporting their relative (Coolen, 2015). Moreover, FC's involvement and their perception on the caregiving role is an important aspect of care for PwD in NHs (Reid, Chappell & Gish, 2007). Their role thus affect QoL of PwD. However, in NHs, contact with family, friends and significant others decreases (Hospers, 2019), causing social isolation. On the other hand, NHs also provide as a space for persons to meet and to participate in social activities (Forsund et al., 2018). Social relationships remain important for QoL, although they could be dependent on the rural-urban setting PwD reside in, as PwD in rural areas might be more socially isolated (Commission for Rural Communities, 2012). Considering these factors from a more holistic approach shows the importance of approaching QoL according to the SEM (Mcleroy et al., 1988).

Organizational Level

Research showed that NH's characteristics, relating to the organizational level, affect QoL. Characteristics include ownership, location, percentage of rooms, staff level and facility size. Although such characteristics do not guarantee the care received, they directly impact processes and outcomes. Harrington et al. (2000) found that increasing the number of care staff (CS) caused fewer QoL deficiencies for NHs residents. The ownership had inconsistent associations with resident's QoL, although most studies indicated that non-profit NHs had better resident QoL (Xu et al. 2013). The same results were found for facility size; the more beds in the NH, the lower the QoL. Perhaps because the larger the facility size, the less they are able to monitor residents (Harrington et al., 2000). Moreover, small-scale environments support social connection with others (van Zadelhoff et al. 2011). Physical environments, such as unit size and a homelike character influence PwD's well-being in NHs positively (Chaudhury et al. 2018).

Another important aspect is the NH's rural or urban location. Most studies focused on differences in quality of care between urban-rural NHs. Of course, QoL of PwD is, in large part, dependent on the quality of care received (Bökberg et al., 2017). For example, rural NHs are more positive about achieving quality care than urban NHs (Ploegman et al., 2017). Residents in American rural NHs appeared to receive better care (Philips et al., 2004), possibly due to NHs in

rural areas feeling more emotionally attached to the neighbourhood, but also to the social network creating more person centred care (Philips et al., 2004; Ploegman et al., 2017). As such, these studies identified potential sources of the differences in quality of care.

Furthermore, living in rural NHs might reduce dementia deficiencies due to low levels of noise and air pollution, and the presence of green space (de Souto Barreto et al., 2014). Hence, this possibly influences QoL as well. At the same time, the outflow of younger people from rural areas is coupled with the influx of those who move to the country on retirement, and the combined effect is that many people are ageing in rural environments without the local support of their adult children (Barr and Russell, 2007). Hence, a disadvantage for PwD in rural NHs is that they might receive fewer visits due to this outflow (Hospers, 2019). This negatively affects their social relations, and consequently their QoL. The same could be suggested for quality of care, as highly educated people move to urban areas. This causes rural NHs to experience difficulties in finding highly educated staff (PBL, 2016). However, even though the environment is recognized as an important factor for QoL of PwD, research on differences between rural-urban NHs and their impact on QoL remain scarce. Moreover, most research is conducted in the USA and Australia and as such, little is known about the topic in Europe and the Netherlands, where no research on this topic has been conducted as yet.

Current Proposed Research

This research aimed to further expand knowledge on QoL of PwD living in NHs in the Netherlands. To offer a more holistic overview of the topic and predict QoL of PwD in NHs in urban-rural environments, the following research question was examined: ''*How do factors on intra-, interpersonal and organizational level contribute to QoL of PwD in NHs in the Netherlands?''*. This research was conducted within the context of an internship at Trimbos Institute, and used existing data from the Living Arrangements for PwD (LAD-) to answer the research question. Based on previous research, eight hypotheses were included in the research model (see figure A2 and A3, Appendix A). An important note is that the current research did not include factors from the community and policy level, since factors from these levels were not available from the existing dataset.

Intrapersonal level:

H1: *ADL dependency* negatively predicts *QoL of PwD in NHs* (Henskens, 2019).

Interpersonal level:

H2: *FC's amount of visits* positively predicts *QoL of PwD in NHs* (Coolen, 2015).

H3: *Perceptions of the caregiving role* positively predicts *QoL of PwD in NHs* (Reid et al., 2007; Moyle & O'Dwyer, 2012; Quinn et al., 2012).

Organizational level:

H4: *Small scale care* positively predicts *QoL of PwD in NHs* (Chaudhury et al. 2018; Xu et al., 2013).

H5: *Large facility size* negatively predicts *QoL of PwD* in NHs *(*Van Zadelhoff et al. 2011).

H6: *Rural NHs* positively predicts *QoL of PwD (*Ploegman et al., 2017; Xu et al., 2013).

Moreover, as the relationship between *amount of visits* by FC and *QoL* of PwD could be moderated by rural NHs, the following hypothesis was analysed:

H7: The relationship between *frequency of visits* and *QoL of PwD* is moderated by *rural NHs (Coolen, 2015; Hospers, 2019).*

Methods

The current study is examined with cross-sectional data collected for the fifth measurement cycle (2019 – 2020) of the Living Arrangements for people with Dementia (LAD-) study, conducted by Trimbos Institute. As such, the current research is a quantitative study employing a secondary data analysis. The LAD-study monitors and evaluates changes in themes relevant for PwD in NHs and related variables since 2008 (Prins et al., 2019).

Data Collection

For the fifth measurement cycle, data from 678 PwD from 58 NHs in the Netherlands was collected. Data of PwD was collected through their first representative carer. Moreover, data of PwD's family carer (FC), the manager of the NH, and CS of the NH was conducted. The first representative carer of the residents (PwD) and CS were sent an invitation to answer the

questionnaires digitally. They were informed through an accompanying letter stating they have the option to not take part in the study by not completing the questionnaire. The managers of the NH were interviewed by trained research assistants. FCs were sent a paper questionnaire and were given the option to send back the completed questionnaire. No inconvenience was caused for PwD as observations of PwD were done by their first representative carer and therefore does not come in the scope of the Medical Research Involving Human Subjects Act (WMO) (Willemse et al., 2011). The ethics committee of the University Medical Center Utrecht determined that the study meets the required ethical standards (reference number WAG/om/13/055932). All involved participants voluntarily and anonymously participated in the study and cannot be identified, as personal information is never obtained.

Participants

For the current study, four datasets (PwD, FC, CS and manager of the NH) were merged into one dataset. It was ensured that data of each PwD was assigned to their FC and the NH they are living in. Moreover, only suitable data was included. This resulted in a subset of 261 participants pairs (PwD and their FC) from 50 NHs.

Operationalization

The variables of the current study are described in the following paragraph, divided by the levels according to the SEM.

Outcome variable

QoL is measured with the QUALIDEM instrument (Ettema et al., 2007) consisting of 37 items ($\alpha = .78$), answered by PwD's first representative carer. QUALIDEM is rated on a 4-point scale (never–seldom–sometimes–often; range 0–3). QUALIDEM's subscales and items are shown in appendix C. For each subscale, a higher score represents a higher QoL. The severity of dementia as determined by the Cognitive Performance Scale (CPS) (Morris et al., 1994) is taken into account, as the outcome of PwD on CPS (severe dementia or very severe dementia) is considered in the calculation of the each subscales' mean score. For the current study, a mean total score (range 0-27) was calculated by adding the mean scores of each subscale.

Intrapersonal variables

ADL is measured through the KATZ-ADL (1983) 15- item scale (α = .83) that assesses functional status as a measurement of PwD's ability to perform activities of daily living independently. Items are answered by the first representative carer of PwD. It ranks adequacy of performance in six functions: bathing, dressing, toileting, transferring, continence, and feeding. The ADL scores range from 0 (low dependency) to 6 (high dependency). Example of item answers of 'bathing' are: ''can wash himself independently'', ''requires partial assistance to wash below the belt'', ''requires partial assistance to wash both above and below the belt'' and ''must be fully assisted to wash both above and below the belt''. A final mean score is calculated for ADL.

Interpersonal variables

Amount of visits is measured as a continuous variable indicating the amount of times per year that the FC visits their relative (PwD). This question is derived from the variable measuring ''how many times the FC visits the NH'' with an open answer for the amount of visits and four answering options consisting of ''per day'', ''per week'', ''per month'' or ''per year'' and is answered by FC. A final score for amount of visits per year is calculated.

Perceptions on the caregiving role is measured with 15 items (α = .87) from the Family Perceived Caregiving Role (FPCR) instrument (Maas & Buckwalter, 1990) answered by FC. An item example is ''I feel I have control over the care that my relative receives'' with answering options ranging from strongly disagree (1) to strongly agree (7). A final mean score is calculated for the 15 items. A higher score indicates FC have better perceptions on their caregiving role for PwD.

Organizational variables

Small scale care is measured through 17 items (α = .62), answered by the manager of the NH. Examples of items are: 'NH has a homelike environment' and 'family of residents help with chores'. Answering options range from never (0) to always (5). An average score of all items is calculated for each NH. A higher score indicates more small scale care is provided in the NH.

Facility size is measured as a continuous variable indicating the number of residents in the NH, answered by the manager of the NH. A higher amount indicates a larger facility size of the NH.

The rural-urban environment of the NH is measured through the amount of inhabitants of the municipality the NH is located in, according to the Central Bureau for Statistics (2020). The variable is an ordinal variable, with five degrees of urbanisation: 'extremely urbanised' (1), 'strongly urbanised' (2), 'moderately urbanised' (3), 'hardly urbanised' (4) and 'not urbanised' (5). '1' indicates that the municipality has 250.000 inhabitants or more, and '5' indicating 50.000 till 100.000 inhabitants. This item is answered by the manager of the NH.

Control Variable

Length of stay of PwD is answered by the first representative carer of PwD and is measured as a categorial variable. The question of the item is: ''For how long has PwD been residing in the NH?''. There are five answering options: ''less than 6 months'', 6 months – 1 year'', ''1 - 2 year'', ''2 - 5 year'' and ''more than 5 year''.

Data Management and Data analysis

For this study's data analysis, the datasets were merged in the statistics software program SPSS version 27 (IBM Corp., 2020), while ensuring that each PwD was assigned to their FC and NH they are living in. For hypothesis testing, a mixed effects multi-level regression analysis was conducted in STATA 16.1 (StataCorp LLC, 2019). This model was chosen due to the hierarchical structure of the data. Within the model, observations on the level of PwD were nested within the level of NH and as such accounted for possible dependencies between observations caused by living in the same NH. This study's analysis examined what variables predict *QoL*, controlling for *length of stay*. The current research aimed to reach insight into how the predicting variables on different levels of the SEM relate to the outcome variable *QoL*. The predictor variables included were *ADL dependency, perceptions on the caregiving role of FC, amount of visits by FC, small scale care, facility size and urbanisation of the NH*. Moreover, an interaction effect between *amount of visits by the FC* and *urbanisation of NHs* is tested in the model. We tested for possible relationships between the above described dependent and independent variables, with a significance level (alpha =.05). The analysis enabled us to measure how each predictor explained a significant amount of variance in QoL of PwD. The control variable *length of stay* consisted of five categories and were recoded into four dummy variables. For the variable u*rbanisation*, STATA 16.1 enabled us to specify indicators for each category of the variable, with the category ''extremely urbanised'' as the reference group.

<p style="text-align: center;">**Results**</p>

Quality of the Data

Before conducting the main analysis, regression assumptions were checked. The assumptions of independence of observations, linearity, homoscedasticity, multicollinearity, outliers and leverage points and normality were met and are described in appendix B.

Descriptive statistics

In table 1, characteristics of the sample are described. In table 2, the division of PwD living in NHs in rural or urban environment is described. In figure 2, mean scores on QoL per urbanisation degree of the NH are depicted. Moreover, before conducting the hierarchical regression analysis in STATA, a preliminary analysis was conducted to showcase the mean scores, standard deviations and correlations of all variables (see table 3).

Table 1.

Sample characteristics (N=261)

	N	*%*
Gender		
Male	100	38.3
Female	161	61.7
Age group (yr)		
18 – 35	1	0.4
36 – 50	29	11.2
51 – 61	88	34.0
61 – 70	92	35.1
71 – 80	29	11.2
> 80	22	8.1

Table 2.

PwD living in NHs in per urbanisation degree (N=261)

Degree of Urbanisation	N	%
Extremely urbanised	41	15,7%
Strongly urbanised	102	39,1%
Moderately urbanised	22	8,4%
Hardly urbanised	83	31,8%
Not urban (rural)	13	5%

Table 3.

Mean scores on QoL per Urbanisation

Degree of Urbanisation	Mean score on QoL
Extremely urbanised	15.160
Strongly urbanised	14.516
Moderately urban	15.076
Hardly urbanised	15.037
Not urban (rural)	15.409

Table 3. *Mean, SD and correlations*

Variables	M	SD	1.	2.	3.	4.	5.	6.	7.	8.	9.	.10	11.	12.
1. Perceptions on the caregiving role	5.56	.95	1.000	-.078	.115	-.025	-.091	.077	-.073	.063	-.016	-.052	.066	-.071
2. ADL	4.19	1.95	-.078	1.000	-.097	**-.153***	.012	.116	.118	-.083	-.081	-.027	**-.127***	-.033
Length of stay														
3. Less than 6 months	.11	.31	.115	-.097	1.000	**-.160****	**-.254****	**-0.228****	-.093	**.127***	.021	**.137***	.056	.042
4. 6 months – 1 year	.18	.38	-.025	**-.153***	**-.160****	1.000	**-.338****	**-.305****	**-.122***	-.028	.035	**.212****	.034	-.042
5. 1 - 2 years	.35	.48	-.091	.012	**-.254****	**-.338****	1.000	**-.482****	**-.193****	-.110	**-.132***	-.059	.078	.021
6. 2 - 5 years	.30	.47	.077	.116	**-0.228****	**-.305****	**-.482****	1.000	**-.174****	.072	.012	**-.194****	-.067	-.043
7. More than 5 years	.07	.25	-.073	.118	-.093	**-.122***	**-.193****	**-.174****	1.000	-.038	**.153***	-.024	**-.148***	.052
8.Small scale care	33.78	9.65	.063	-.083	**.127***	-.028	-.110	.072	-.038	1.000	**.176****	-.090	**.153***	**-.327****
9. Urbanisation	2.713	1.208	-.016	-.081	.021	.035	**-.132***	.012	**.153***	**.176****	1.000	.016	.072	**.265****
Extremely urbanised	.157	.365												
Strongly urbanised	.782	.978												
Moderately urbanised	.253	.835												
Hardly urbanised	1.272	1.866												
Not urbanised (rural)	.245	1.099												
10. Amount of visits per year	124.08	109.68	-.052	-.027	**.137***	**212****	-.059	**-.194****	-.024	-.090	.016	1.000	.051	.108
11. QoL	14.88	1.79	.066	**-.127***	.056	.034	.078	-.067	**-.148***	**.153***	.072	.051	1.000	-.096
12. Facility size	54.87	45.16	-.071	-.033	.042	-.042	.021	-.043	.052	**-.327****	**.265****	.108	-.096	1.000

Note. N=261. * p < .05, ** p <.01

Main analysis

In table 4, the mixed-effects multi-level regression model is depicted with the predictor variables, control variables and outcome variable coefficients. The Wald chi-square test was calculated to test the fit of the model and was significant (χ^2 (17) = 34.96, p < .01), indicating that the predictors explained some of the variance in QoL. Moreover, the estimated variance components at the NH level indicated that dependency of the residents to the NH is not significant as the intra-class correlation residual value was 3.66e-15, with 95% CI (3.66e-15, 3.66e-15) indicating poor reliability. The random effect parameters and as such, possible dependencies between observations that were caused by living in the same NH were not significant (χ2(1) = 4.5e-13, p = .1). Following are the results of the hypotheses for each level tested for the current study.

Intrapersonal level

Among the intrapersonal level of the SEM, *ADL independency* was not significantly related to QoL (B = -.091, p = .110), indicating that higher ADL dependency does not predict a lower QoL.

Interpersonal level

Among the interpersonal level, *amount of visits* (B = .005, p = .133) and *mean score on FPCR* (B = .099, p = .384) were not significantly related to QoL, indicating that a higher amount of visits and better perceptions on the caregiving role of FC do not predict a higher QoL.

Organizational level

On the organizational level, *small scale care* (B = .018, p = .158), *facility size* (B = -.004, p = .203), *strongly urbanised* NHs (B = -.135, p = .807), *moderately urbanised* NHs (B = -.009, p =.374), *hardly urbanised* NHs (B = .626, p = . 223), and *rural* NHs (B = .315, p = .734) were not significantly related to QoL.

Moderation analysis

An interaction effect was included in the multilevel regression model to test for the moderating effect of rural NHs on the relationship between amount of visits by FC and QoL. The

interaction effect of amount of visits and strongly urbanised NHs is not significant (B = -.004, p = .235). For moderately urbanised NHs, the interaction effect is not significant (B = -.009, p = .075). For hardly urbanised NHs, the interaction effect is not significant (B = -.004, p = .223). For rural NHs, the interaction effect is not significant (B = .001, p = .906). Hence, the results do not provide support for a moderating effect of the location of the NH for the relationship between amount of visits and QoL.

Control variable

The control variable *length of stay* was included as dummy variables in the model to better estimate the coefficients and were significant. For dummy variables *less than six months* (B = 1.178, p = .031), *six months – one year* (B = 1.290, p = .013), *one – two years* (B = 1.392, p = .003) and *two – five years* (B = .994, p = .035), positive significant relationships were found with QoL.

Table 4.

Hierarchical regression model coefficients

Predictor variables	B	*SE* B	z	p	[95% Conf.	Interval]
Constant	12.78555	1.116	11.45	.000	10.598	14.974
ADL independency	-.091	.057	-1.60	.110	-.202	.021
Perceptions on the caregiving role	.099	.113	0.87	.384	-.124	.321
Amount of visits per year	.005	.003	1.50	.133	-.002	.0116
Small scale care	.018	.013	1.41	.158	-.007	.044
Facility size	-.004	.002	-1.27	.203	-.009	.002
Length of stay						
Less than 6 months	1.178	.547	2.16	.031*	.107	2.250
6 months – 1 year	1.290	.519	2.48	.013*	.272	2.308
1 - 2 year	1.392	.466	2.99	.003**	.479	2.304
2 - 5 year	.994	.472	2.11	.035*	.070	1.919

Urbanisation

Strongly urbanised	-.135	.553	-0.24	.807	-1.220	.949
Moderately urbanised	.715	.804	0.89	.374	-.861	2.291
Hardly urbanised	.626	.590	1.06	.289	-.532	1.783
Not urbanised (rural)	.315	.929	0.34	.734	-1.506	2.136

Urbanisation x amount of

visits per year

Strongly urbanised	-.004	.004	-1.19	.235	-.012	.003
Moderately urbanised	-.009	.005	-1.78	.075	-.018	.001
Hardly urbanised	-.004	.004	-1.22	.223	-.012	.003
Not urbanised (rural)	.001	.008	0.12	.906	-.015	.017

*Note. N = 261, * p < .05, ** p < .01*

Discussion

The aim of the current study was to investigate if and which factors of the SEM contribute to the QoL of PwD in NHs in the Netherlands. Using the dataset of the LAD-study conducted by Trimbos Institute (2019-2020), a multilevel mixed model was used to test for contributing factors. Using the SEM, a model was devised in which different predictors were arranged according to the intra-, interpersonal and organizational level. Consequently, several hypotheses were formulated and tested for which each outcome will be presented in the following paragraph.

The first hypothesis related to intrapersonal predictors of QoL. It was hypothesized that higher *ADL dependency* negatively influences QoL. Although the relationship was negative, the effect was not significant; thus H1 is not supported.

Hypothesis 2 and 3 related to the interpersonal predictors of QoL. It was hypothesized that higher *amount of visits by FC* positively influences QoL. Although the relationship is positive, the findings indicate a non-significant relationship; thus H2 is not supported. Moreover, it was

hypothesized that better *perceptions of the caregiving role of FC* positively influence QoL. The relationship appears to be positive, but is nonsignificant, hence H3 is not supported.

Organizational predictors of QoL were tested by hypothesis 4, 5 and 6. H4 is not supported, as results indicated a non-significant positive relationship between *small scale care* and QoL. H5 is also not supported, since, although the relationship is negative, a non-significant result between larger *facility size* and QoL was found. Moreover, a non-significant positive relationship between *NHs with a rural location* and QoL was found; thus H6 is not supported.

Hypothesis 7 tested whether the relationship between *amount of visits by FC* and QoL was moderated by *NHs located in rural environments*. Since no significant interaction effect of NHs located in rural environments on the relationship between amount of visits and QoL was found, there is no evidence to support H7.

Lastly, the control variable *length of stay* appeared to be significant, with almost each category increasing in length of stay, decreasing QoL. This indicates that the longer PwD resides in the NH, the more this negatively influences their QoL.

Summarizing these findings, the multi-level regression analysis indicated that intra-, interpersonal and organizational level factors are, in the current study, not significant predictors of QoL. Hence, this study does not provide evidence to support previous findings and the main research question. The current study found a non-significant effect for the random effects. However, the model fits the data well as each PwD is living in a particular NH, hence why this model has been chosen as PwD are nested on the level of NHs.

In previous studies, PwD were defined as a vulnerable group with more risk of a low QoL (Willemse et al., 2019), where factors from different levels of influence, such as the intra-, interpersonal and organizational, influence PwD's QoL (Beerens et al., 2013, Martyr et al. 2017, Harrington et al., 2000, Xu et al. 2013). As results of the current study do not support previous findings, discrepancy between these findings can be explained by the type of regression model that was used. While previous studies identified intra-, interpersonal and organizational factors individually, the current study aimed to identify factors from these levels simultaneously according to the SEM (McLeroy et al., 1988). The SEM (McLeroy et al., 1988) describes how factors from different levels influence QoL, while providing clarity on how these factors operate and interact together. The current research showed that the hierarchical regression model was significant,

indicating the model did provide some of the variance of QoL. However, the predictors examined for the current study did not provide any clarity regarding the variance of QoL.

A possible explanation for the current study's unexpected outcomes, is the use of a QoL outcome based on a sum calculation of the nine subscales (described in appendix C). QoL is a multidimensional concept and as such difficult to measure, hence why the QUALIDEM exists of nine subscales that differ in content. Calculating a sum score for QUALIDEM could result in loss of information (Dichter et al., 2016), hence possible explaining the found non-significant effects. As such, hypothesizing for each QUALIDEM subscale could have resulted in different outcomes. For example, interpersonal factors might affect one or some subscales, but not a sum of all subscales. More specifically, amount of visits of FC could affect the subscale social relations, which measures PwD's social behaviour, or the subscale positive affect, which measures PwD's mood. Although each factor could have affected the subscales differently on an independent level, using a sum score of QoL was necessary for the scope of the current research. Moreover, Dichter et al. (2016) describe that an overall QUALIDEM score is recommended as overall scores can be necessary.

Secondly, ADL independency of PwD was included as a predictor. Most previous research indicated that a higher ADL independency positively influences QoL (Henskens, 2019, Sloane et al., 2005). However, Sloane et al. (2005) indicate that ADL dependency did not explain more than a quarter of the variance in the QoL, while another study showed that total ADL performance was only impacting on QoL in mild dementia (Giebel, Sutcliffe & Challis, 2015). For the current study, the sample consisted of PwD of which the diagnosis of dementia was either moderate or severe. Hence, this could explain a non-significant effect for ADL and QoL in the current study. Moreover, ADL is measured through six different functions (bathing, dressing, toileting etc.) and as such, some functions could affect QoL differently

Thirdly, although the relationships were positive on the interpersonal level, non-significant effects could possibly be due to the absence of including variables of objective measures of PwD's social relationship, as the FPCR measures solely FC's perspective on the caregiving role. Thus, the FPCR does not provide any information on the quality of the social relationship with the PwD. However, it indirectly describes the quality of care of the NH. Moreover, amount of visits by FC does not provide any important information such as the duration of the visit. Nonetheless, although results do not support previous findings (Quinn et al., 2012, Thorgrimsen et al. 2003), QoL of PwD

could be dependent of their social relationship with other residents or CS of the NH (Forsund et al., 2018), which the current research did not include.

Moreover, location of the NH did not influence QoL. Previous research presented mixed results when examining the influence of location of the NH on QoL (Barr and Russell 2007; Hospers, 2019; Philips et al., 2004). Therefore, the current results are neither contradictive nor complementary. Nonetheless, some authors concluded that PwD in rural NHs have higher QoL due to, for example, better quality of care (de Souto Barreto et al., 2014; Ploegman et al., 2017). However, as depicted previously in table 2, mean scores on QoL of PwD divided by the NH's location did not differ greatly. Thus, an explanation for the current study's findings could be that there was not enough variation in QoL by NH's location to pick up any effects.

Furthermore, most previous studies that examined QoL in relation to the urban-rural environment, were conducted in the USA (Bitzan & Kruzich, 1990) or Australia (Parmenter et al., 2012). The differences between urban and rural environments in these countries might not be applicable to the Netherlands. For example, geographical distances are greater in the USA, Canada and Australia and PwD in rural NHs in those countries could be more socially isolated than in the Netherlands. Especially since the lack of good public transport (Nutley, 2003) decreases the likelihood to frequent visiting. This could also explain the non-significant effects found for the tested interaction effect. The current study was based on previous research indicating that children and higher educated people of PwD leave to more urban areas, while the aging population in the more rural areas is increasing (Hospers, 2019). Although the interaction was negative for rural NHs on amount of visits and QoL, it was non-significant. As previously stated, this is possibly explained by smaller geographical distances as well as better public transport in the Netherlands. As such, FC might not experience a barrier to frequent visiting.

Lastly, it is important to note that the current study included five categories of urbanisation, whereas previous research on this topic focused on two distinctions (urban versus rural). Including five categories instead of two, could possibly have affected the study's statistical power and as such the significance of effects.

Strengths and Limitations

The current study presented itself with several strengths and limitations. Firstly, the use of the hierarchical linear model lends itself well to examine multiple predictors, while ensuring that

each PwD is nested under the level of NHs. The model chosen for the current study is therefore a well-considered fit for the data. While previous research has focused on examining predictors of QoL from different levels individually, this study aimed to identify how these predictors influence QoL simultaneously according to the SEM. This is, in relation to the topic, relatively new for research. Moreover, including the rural and urban division of the NHs and its influence on QoL is particularly new for research in Europe and specifically the Netherlands.

Furthermore, a strength of this study is that it used a nationwide population-based dataset conducted by Trimbos Institute. Due to the fact that the current research used observations from NHs from different degrees of urbanisation, the current study gained more information by having five categories of urbanisation, rather than dividing urbanisation into two categories (urban – rural). This is both a strength as a limitation, as a distinction of two categories could possibly increase the statistical power of the current study or could create different (significant) effects.

As previously stated, a sum score of the QUALIDEM is calculated for QoL, though the QUALIDEM user report advices against calculating an overall score (Dichter et al., 2016). Hence, using a sum score of QoL is a limitation of the current study, especially since QoL is a multidimensional concept (Lawton, 1983). Furthermore, QUALIDEM is quite a new instrument to measure resident's QoL. Despite its proven reliability and validity, responsiveness to change over time has not been studied yet (Ettema et al., 2007). Additionally, the current study does not look at the different subscales of the QUALIDEM and using a sum score limits the scope of the current research.

Another limitation is the use of cross-sectional data, which decreased the chances of establishing causal inferences. Additionally, the sample size of the current study could not provide statistical power to generalize the findings to the population. Therefore, these study's findings should be interpreted with caution.

Lastly, the study did not control for demographic factors such as sex, ethnicity, gender, age or educational level. However, the study partly controlled for cognitive impairments, that might cause lower QoL for PwD (Stites et al., 2018), since ADL considers the severity of dementia of PwD based on the CPS (Morris et al., 1994). Moreover, factors from the community and policy level were not included. Hence, possible influential factors such as neighbourhood characteristics (nature, noise or air pollution), national health care policies and NHs regulations, were overlooked.

Directions for future research

Based on the limitations, several directions are advised for future research. Primarily, future researchers are advised to use a larger sample and to distinguish the degrees of urbanisation in two categories (urban versus rural) to increase statistical power. Next, the current study examined predictors from three levels of the SEM. We advise to include factors from the community and policy level, such as neighbourhood characteristics and health care policies. Moreover, other variables from the SEM levels examined in previous research could be included. For example, quality of care, which previous research identified to be dependent of the rural or urban environment could be considered.

Lastly, no ''gold standard''exists for measuring QoL, but future researchers could elaborate on the different aspects of the multidisciplinary concept of QoL of PwD, and how these could be affected differently by variables from the SEM levels.. These suggestions contribute to the current study's goal to research how social-ecological factors from different levels could affect QoL of PwD.

Implications

The present study was the first study to examine QoL of PwD from a holistic perspective using the SEM (Mcleroy et al., 1988), while simultaneously looking at the influence of the NH's location on QoL of PwD. Since the burden for caring of PwD increases, policies helping NHs structure their health care to increase QoL of PwD should be prioritized. Additionally, to increase QoL, it is important to spend attention to how the rural or urban environment could affect this. Previous studies showed differences in quality of care and QoL of PwD dependent on the NHs' location in the USA, Canada and Australia. Although care as well as NH characteristics in these countries could differ from the Netherlands, it is advised for policy makers and health care professionals to contemplate carefully how the environment could affect QoL of PwD. Moreover, policy makers and health care professionals should not blindly focus on factors that influence QoL individually. Instead, as QoL is a multidisciplinary construct, it is recommended to shape health care using a holistic approach.

Conclusion

In conclusion, this study has brought a better understanding of QoL of PwD by testing a holistic model using the SEM as a theoretical framework. However, there are opportunities that could improve determining factors predicting QoL of PwD in rural or urban environments. Finally, it was advised to conduct more research and revise certain research design methods, which is required to disentangle the challenge of increasing PwD's QoL.

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Appendices

Appendix A.

Visualisations of the regression model and interaction relationship

Figure A2.
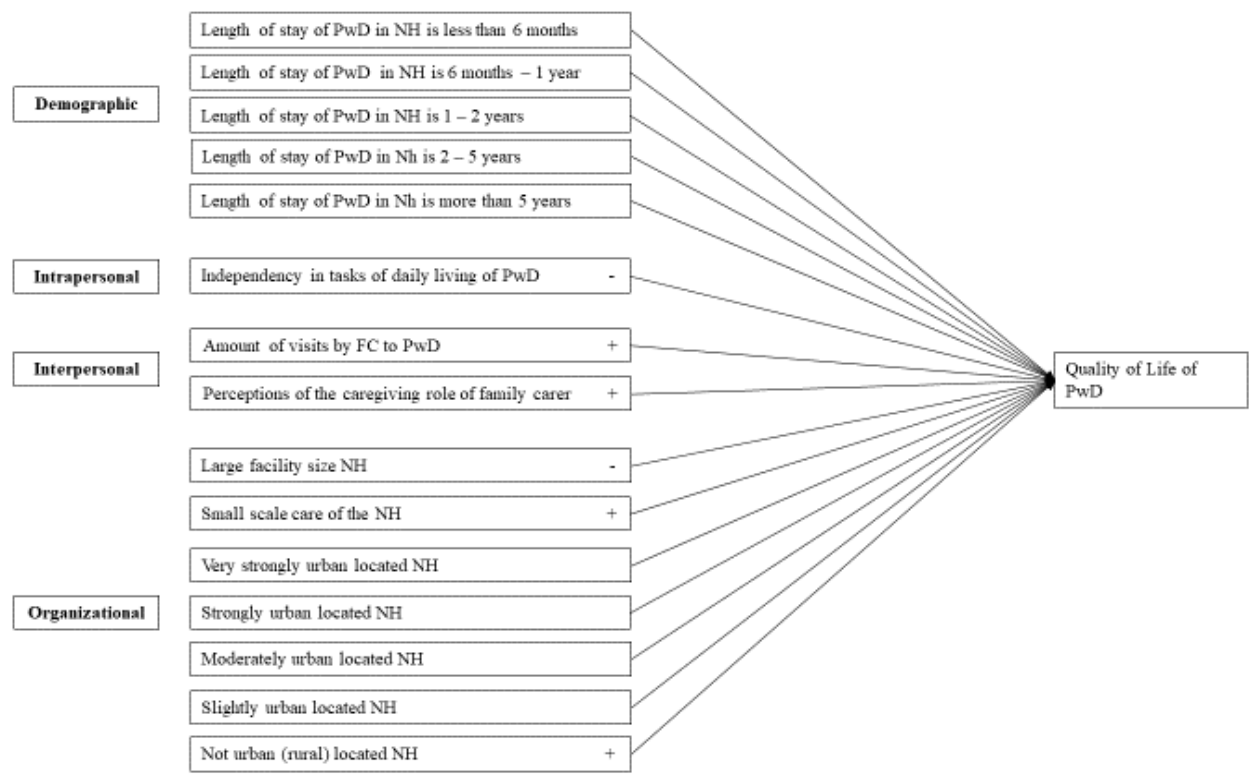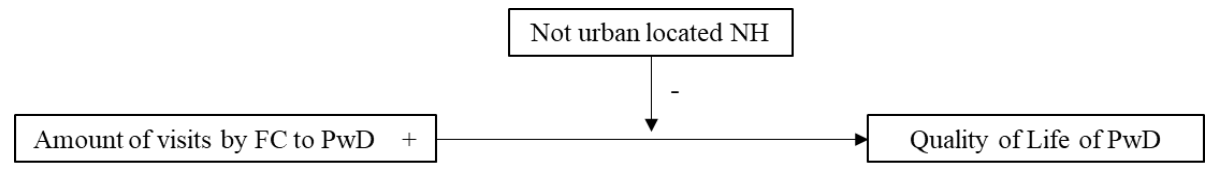
Visualisation of the regression model

Figure A3.
Visualisation of the moderation relationship

Appendix B.

Quality of the data

An initial regression has been conducted to check the assumptions of independence of observations, linearity, homoscedasticity, multicollinearity, outliers and normality were met. Independence of observations was assessed by the Durbin-Watson test (DW = 2.027), meaning that the assumption was met and that error terms are independent of each other. The assumption of homoscedasticity was assessed by a scatter plot of the standardized residuals against the predicted standardized residuals. The variance was evenly spread and the assumption was therefore met. Multicollinearity was assessed by controlling the Variance Inflation Factor (VIF) of all variables entered in the model. These values were all below 5.0 and therefore, the assumption of multicollinearity was met. Linearity was checked by the examination of scatter plots. No non-linearity was observed and the assumption of linearity was therefore met as shown in figure 2. Finally, case wise diagnostics of the regression results showed an indication of possible outliers or leverage scores. No problematic values were found for Cook's distance. Some outliers were found for amount of visitors per year. When looking at the data, these values were not extraordinarily and were therefore not excluded from the dataset. Moreover, the leverage value of 0.034 was within the critical range of 0.010 to 0.084, indicating that the outliers were not extreme or influential for the results.

Appendix C.

QUALIDEM subscales and items

Care relationship

Rejects help from nursing assistants

Is angry

Has conflicts with nursing assistants

Accuses others

Appreciates help that he or she receives

Accepts help

Criticizes the daily routine

Positive affect

Is cheerful

Radiates satisfaction

Is capable of enjoying things in daily life

Is in a good mood

Has a smile around the mouth

Mood can be influenced in positive sense

Negative affect

Makes an anxious impression

Is sad

Cries

Restless tense behaviour

Makes restless movements

Is restless

Has tense body language

Positive self-image

Indicates he or she would like more help

Indicates not being able to do anything

Indicates feeling worthless

Social relations

Has contact with other residents

Responds positively when approached

Takes care of other residents

Cuts himself/herself off from environment

Is on friendly terms with one or more residents

Feels at ease in the company of others

Social Isolation

Is rejected by other residents

Openly rejects contact with others

Calls out

Feeling at home

Indicates that he or she is bored

Indicates feeling locked up

Feels at home on the ward

Wants to get off the ward

Having something to do

26 Finds things to do without help from others

Enjoys helping with chores on the ward

Remaining items to be used in future research

Does not want to eat

Enjoys meals

Likes to lie down (in bed)

Appendix D.

Ethical approval

	Faculty of Social and Behavioural Sciences
P.O. Box 80140, 3508 TC Utrecht The Board of the Faculty of Social and Behavioural Sciences Utrecht University P.O. Box 80.140 3508 TC Utrecht	Faculty Support Office Ethics Committee **Visiting Address** Padualaan 14 3584 CH Utrecht

Our Description	21-0270	
Telephone	030 253 46 33	
E-mail	FETC-fsw@uu.nl	
Date	01 February 2021	
Subject	Ethical approval	

ETHICAL APPROVAL

Study: Quality of Life of residents with dementia in nursing homes for long-term care in

The Netherlands Principal investigator: S.I. Pen

Supervisor:

This student research project does not belong to the regimen of the Dutch Act on Medical Research Involving Human Subjects, and therefore there is no need for approval of a Medical Ethics Committee.

The study is approved by the Ethics Committee of the Faculty of Social and Behavioural Sciences of Utrecht University. The approval is based on the documents send by the researchers as requested in the form of the Ethics committee and filed under number 21-0270. The approval is valid through 30 January 2021. Given the review reference of the Ethics Committee, there are no objections to execution of the proposed research project, as described in the protocol and according to the GPDR It should be noticed that any changes in the research design oblige a renewed review by the Ethics Committee by submitting an amendement

Yours sincerely,

Peter van der Heijden, Ph.D. Chair