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Research Paper

Factors influencing the proxy-rated quality of life of residents with dementia in long-term care units

Luana Vella (luana.vella.16@um.edu.mt)
St. Vincent De Paul Residence (SVP), Malta
Anthony Scerri
Department of Nursing, Faculty of Health Sciences, University of Malta.

Abstract:

Quality of life (QoL) is slowly becoming one of the most important outcomes in older persons with dementia. Up to two-thirds of residents in long-term care facilities have some type of dementia. Understanding the QoL of a person living with dementia in long-term care (LTC) will ensure that the care being provided is person-centered. The study aimed to measure the proxy-rated QoL of older persons with dementia living in dementia-friendly units in a long-term care facility in Malta as perceived by nurses taking care of them. A quantitative cross-sectional survey design was adopted. The proxy-rated QoL of the participants was measured using the QUALID scale. Moreover, the presence of behavioural and psychological symptoms of dementia (BPSD) of residents with dementia was measured using BEHAVE-AD scale. This was done through questionnaires administered as interviews with nurses who work with dementia residents. Additional data was gathered from the patients' personal files such as their age, gender, mini-mental state examination score and Barthel Index score. This is the first local study that sought to measure the QoL of residents with dementia in LTC units. The mean QoL score of the participants was 22.14. Sociodemographic characteristics such as age and gender, were not found to be significantly associated with the QoL. A higher level of functional dependency and higher presence of BPSD were associated with a lower QoL. The participants' cognitive abilities were found to be negatively associated with their QoL when analysed on their own. However, no significant association was found when they were analysed with other factors. The presence of BPSD and the functional dependency of the participants were the most important predictors of their QoL. Therefore, LTC facilities should focus more on improving and maintaining the functional status of persons with dementia as well as reducing the presence of BPSD, in order to maintain their QoL.

Keywords: Quality of life, dementia, long-term care, behavioural and psychological symptoms, activities of daily living

1. Introduction

Dementia is a clinical disorder characterised by a gradual deterioration in cognitive function that causes interference with the person's ability to function Characteristic symptoms of dementia tend to be persistent, gradual and progressive and these include alterations in behavior, cognition and function. The clinical manifestation of theses symptoms usually varies by a great degree among different individuals who suffer from dementia. The cognitive deficits are often manifested as impairments in communication and language, memory loss, difficulty in performing certain tasks which were learned previously throughout the persons' lives, difficulty to recognise objects and

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compromised executive function including judgement, planning and reasoning (Duong, Patel & Chang, 2017).

Several dementia-specific QoL measures have been created, some of which use self-ratings while others use observational data or proxy-ratings as a source of information (Dichter et al., 2011). Some researchers have concluded that QoL should only be self-reported, while others consider proxy-rated QoL as well (Ettema et al., 2005). Since QoL is a subjective concept, self-reported QoL is considered to be a better standard when measuring QoL in persons with dementia. However, due to the fact that the deterioration in cognitive abilities of persons with dementia is characterised by concentration and memory deficits, this can result in a decrease in their communicative and decision-making abilities (Dichter et al., 2013). Consequently, the validity and reliability of self-reported QoL in later stages of dementia has been questioned, making the proxy-rated QoL a preferred way to measure the QoL of persons with advanced dementia (Dichter et al., 2013).

Up to two-thirds of residents living in LTC units have some form of dementia (Matthews & Dening, 2002). Older people who live in a residential care home tend to have a poor Quality of Life (QoL) due to several factors, such as the deterioration in their health condition, having a fixed daily routine, alterations in the environment they live in and changes in their normal patterns of social interaction (Kane et al., 2003). Over the past years, the Quality of life (QoL) of older persons with dementia has become progressively established as one of their important outcomes (Keating & Gaudet, 2011). Although progress has been made with regards to the measurement as well as the definition of QoL, research related with the QoL of persons with dementia living in long-term care (LTC) settings, especially in long-term care units, has not been studied in depth (Crespo, Hornillos & de Quirós, 2012). Therefore, the aim of this study is to measure the proxy-rated QoL of residents with dementia who reside in Maltese dementia-friendly long-term care units and to identify the associated factors.

2. Methodology

2.1. Design

The study used a cross-sectional design by collecting data only once, to obtain the current state of the participants at a point in time (Lau & Kuziemsky, 2017). Furthermore, a descriptive approach was used, since the study described the distribution of the variables of interest without any concern for a causal relation (Aggarwal & Ranganathan, 2019).

2.2. Participants

Whilst the older persons were not directly involved in the study, the data collected from the nurses and from their personal files was directly related to them. As a result, the older persons with dementia will be referred to as participants, even though the interviews were held with nurses who assisted them in the dementia-friendly long-term care units. The population was made up of 77 individuals including both males and females, living with dementia who were residing in four of the dementia-friendly units in a large long-term care facility in Malta.

Inclusion criteria	• All residents with dementia at any stage of the condition residing in the four selected dementia-friendly units • The nurses interviewed about the participants had to be working in chosen wards for at least six months
Exclusion criteria	• Nurses working in the relieving pool were not interviewed • Any residents residing in the dementia-friendly wards who did not have a diagnosis of dementia • Residents with a MMSE<=15, who were not able to provide consent and did not have a next of kin from whom a proxy consent could be obtained.

Table 1. The inclusion and exclusion criteria used to select the participants and the nurses' interviewed in this study

Older persons with dementia who have BPSD such as agitation, aggression, mood disorders and wandering are located in specialised dementia units at the long-term care facility. One can find several residents with dementia residing in other geriatric units, however, the ones who are residing in the selected dementia friendly units are those who exhibit the most challenging behaviors, usually requiring more individual and collective supervision and a closed ward; a ward where the main exits together with other exits, such as those that lead to gardens and other outdoor areas, are always closed. Dementia is greatly associated with BPSD which occur in nearly all persons living with dementia (Savva,

2009). The patients residing in these units are the ones that present with the most severe cases of BPSD. Table 1 summarises the and exclusion criteria used to select the participants and the nurses' interviewed in this study.

2.3. Instruments used

Apart from the demographic variables, such as the particiants' age and gender, two validated psychometric tools were used in the data collection process. These include the Quality of Life in Late-stage Dementia (QUALID) Scale (Weiner, 2000) and the Behavioural Pathology in Alzheimer's Disease (BEHAVE-AD) rating scale (Reisberg, 1987).

The QUALID scale is a questionnaire specifically developed to measure the QoL in persons with advanced dementia via observation in the timespan of a whole week (Benhabib et al., 2013). It is based on the professional input of experts in the field of care of older people living with dementia. This scale provides information regarding the QoL of the resident through assessments done by their proxies who, in this case, were nursing staff. The scale involves eleven different observable behaviours which contain both negative and positive aspects of particular and evident behavior and mood of the residents, which is understood to be suggestive of the QoL in late-stage dementia. These 11 items were evaluated by frequency of occurrence on a five-point Likert scale, which were then added up to range from 11 (which indicates the best QoL); to 55 (which indicates the worst QoL) (Benhabib et al., 2013). The completion time of the scale is approximately 5 minutes. The QUALID scale (Weiner, 2000) was chosen since it assesses the QoL according to the participants' proxies and does not require direct contact with the persons with severe dementia who may problems responding to the questions.

The BEHAVE-AD rating scale was also used to measure the behavioural disturbances present in the persons with dementia (Reisberg et al., 2014). This instrument is also based upon information provided by the carer of the participants. It is a scale that contains 25 behavioural disturbances which are evaluated by frequency of occurrence on a 4-point Likert scale.

Moreover, the MMSE score and Barthel Index score were also collected from the personal files. The MMSE is a test commonly used in clinical settings to measure cognitive impairment and for screening of dementia during which a clinician asks a number of questions to the participant regarding language, orientation, recall and attention (Folstein et al., 1975). The Barthel Index is an instrument based an informant's observations, used for the evaluation of physical function of geriatric patients (Bouwstra et al., 2019). It is a scale that measures the performance of ten activities of daily living, some of which are mobility, dressing and grooming. The Barthel Index can be utilised for various clinical outcomes such as assessing the effects of treatment, establishing the degree of disability and discharge planning (Bouwstra et al., 2019).

In the setting where the study was conducted, the Barthel Index scale are carried out by the occupational therapists taking care of the residents, whereas the MMSE is usually carried out by the doctors taking care of the residents. For this study, the most recent scores of both the MMSE and the Barthel Index were used in order to make sure that these reflect the current cognitive and physical function of the participants. At the long-term facility where the study was conducted. the original version of the Barthel Index is used which includes a scale that ranges from a score of 0-20.

2.4. Data collection and data entry

Following the process of recruiting the participants for the study, and getting consent, the process of data collection was carried out. The QUALID scale and the BEHAVE-AD rating scale questionnaires were administered by interviewing the nurse who, at the time of the interview, was taking care of the participant. This approximately took 20 minutes. All other information such as the MMSE and Barthel Index scores, age and gender of the participants were collected from their personal files. All data collected was assigned codes and any personal information was replaced by pseudonyms to protect the privacy of the residents. IBM SPSS Version 27 was used for the data entry process.

2.5. Reliability and Validity

Before starting this study, the reliability and validity of the QUALID scale and the BEHAVE-AD rating scales was ascertained. With regards to the QUALID scale, various studies have been carried out that assessed its validity and reliability (Weiner, 2000; Falk, Persson & Wijk, 2007; Garre-Olmo et al., 2010; Røen et al., 2015). In the study carried out by Weiner (2000), a Cronbach's α of 0.769 was obtained suggesting a very good internal consistency in all items. Test-retest reliability of the QUALID scale was also assessed. Test-retest reliability was excellent with

an intraclass correlation of 0.807 indicating that there was only a slight difference in the scores when the two assessments were compared.

The BEHAVE-AD was also found to be reliable by various studies (Levy et al., 1994; Monteiro et al.; 1998; Sclan et al., 1996). In the study carried out by Sclan et al. (1996), the reliability of the BEHAVE-AD was demonstrated by calculating interrater agreement. For the categories of the BEHAVE-AD both rater agreement and rater consistency coefficients varied between 0.65 to 0.91. For the overall score of the BEHAVE-AD both rater agreement and rater consistency coefficients were 0.96, suggesting very good reliability (Sclan et al., 1996).

2.6. Data analysis

Statistical tests were used to investigate the relationship between the QUALID and other variables such as the age and the scores of the BEHAVE-AD, MMSE and BARTHEL Index. In addition, the association between the BEHAVE-AD and the other variables was also analysed. Since almost all of these variables are continuous, except for gender, the normality assumption was tested first. The normality assumption was done using the Shapiro-Wilk test which is a test that depends on the association between the data and the scores. When the distribution was fairly normal, the Pearson correlation test was used. An analysis of covariance (ANCOVA) regression model was also created to identify the most significant predictors of the participants' proxy-rated QoL.

2.7. Ethical considerations

Approval from the Social Wellbeing Faculty Ethics committee was obtained (ID: 7298 05.12.2020). Moreover, approval from the CEO and Medical Superintendent of long-term care facility was also obtained. Consent was also obtained from all four gatekeepers of the dementia-friendly units included in the study. The role of the gatekeepers was to contact the next of kin of every participant and ask them for their permission for their contact number. Moreover, permission from the authors of both the QUALID scale and the BEHAVE-AD rating scale was obtained.

Consent was obtained from every participant prior to collecting data. Whenever possible consent was obtained from the participants themselves, however, in those cases when the patients had a MMSE score lower or equal to 15 and did not have the ability to understand what the study entails or were not able to write, consent from the participants' next of kin was sought. Every next of kin was contacted by phone, explained what the study entailed, and then consent was either sent via email or, whenever this was not possible, it was obtained verbally over the phone by recording the phone call after asking for permission to do so from the next of kin. Moreover, those who were not able to provide informed consent themselves and who also did not have a next of kin who could provide informed consent on their behalf, were excluded. This was done in order to respect the participants' privacy.

In order to ensure that these principles were always respected throughout the study, the selection of the desired participants for the study was guided by the research questions in order to avoid excluding any individual eligible to participate. Those who declined to participate in the study were treated fairly without any negative repercussions. Furthermore, the participants' privacy was always maintained by the use of procedures for confidentiality and anonymity. Throughout the process of data collection, pseudonymisation was used and it was stored securely and separately from any codes and personal data in an encrypted file on a password-protected computer.

3. Results

A total of 77 older persons residing in the four units included in the study met the criteria and were eligible to participate in the study. From these 77 eligible participants, 50 older persons participated in the study, which resulted in a response rate of 64.93%. 22% (n=11) of the participants were males while 78% (n=39) were females. The average age of the participants was 82.4 years with a standard deviation (SD) of 6.89. The age of the participants was divided into four different categories in order to make the process of comparison easier. The age group between 81 and 90 years old was the most common group accounting for 54% (n=27) of the participants, whereas the least common age group was that between 61 and 70 years old, accounting for only 8% (n=4) of the participants.

From the 50 completed QUALID rating scales, the mean proxy-rated QoL score was 22.14 (SD 6.56). The lowest score obtained was 11 whereas the maximum score obtained was 35. The median score was 21.50 and the modal score was 18, which was obtained by 10% (n=5) of the participants. The scores indicate that the participants

were skewed towards higher QOL (low scores). Table 2 provides further details of the domains in the QUALID scale. It also provides the mean and standard deviation of every domain.

From the 50 completed BEHAVE-AD rating scales, the mean score was 3.18 (SD 6.56), indicating that the participants had a low presence of BPSD. The lowest score obtained was zero whereas the highest score was 12. The median score was three and the modal score was 0 which was obtained from 22% of the participants (n=11). Table 3 displays the percentage mean, and standard deviations of all the behaviours fou nd in the BEHAVE-AD scale. The table indicates that the least common BPSD were those related with paranoid and delusional ideations. Conversely, the most common BPSD was wandering.

The Shapiro-Wilk test was used to test normality for the two measured scales. The QUALID scores was found to be normally distributed (Shapiro Wilk score 0.962; p=0.103) whilst the BEHAVE-AD scores were not (Shapiro Wilk=0.889; p=<0.001). There was a significant positive relationship between the QUALID and BEHAVE-AD scores (Spearman correlation coefficient=0.523l; p=<0.001), indicating that the lower the proxy-rated QoL the higher were the frequency of BPSDs exhibited by the participants. However, there was no association between the QUALID scores and age (Spearman correlation coefficient=-0.044; p=0.380) or gender (mean QUALID male score=20.45 (SD=5.18) vs female score=22.62 (SD=6.88); Independent sample t-test=-0.964; p=0.340). Contrary, when comparing the QUALID scores with the Barthel Index scores of the participants, a negative relationship was found (Spearman correlation coefficient=-0.333; p=0.009), indicating that the higher the functional dependency (i.e., lower the Barthel score) the lower the proxy-rated QoL (i.e. the higher the QUALID score). With regards to the participants mental test scores, the QUALID scores were also found to be negatively related; that is the higher the MMSE scores (the better cognitive status), the lower were the total QUALID scores (the better was the QoL) of the participants (Spearman correlation coefficient=-0.345; p=0.021).

With regards to the association between the BEHAVE-AD scores and the demographic variables, there was no association in the frequency of BPSD and gender (Chi-square test=1.586; p=0.226) and age (Spearman correlation coefficient=0.033; p=0.410).

An Analysis of covariance (ANCOAVA) regression model was built to identify the most significant predictors that influence the proxy-rated QoL. Initially, all the predictors and factors were included in regression analysis. These included gender, age, BEHAVE-AD score, Barthel Index score and MMSE score and the pairwise interactions gender*age, gender*MMSE score, gender* Barthel Index score and gender*total BEHAVE-AD score. Following this, predictors that were not significant were removed one by one until the parsimonious model was obtained. The parsimonious model included two predictors which are contributing significantly to the model fit which were the Barthel Index score, and the Total BEHAVE-AD score (Table 4). According to the regression coefficients found in Table 4, for every 1 score increase in the Barthel Index, the QUALID score decreases by 0.416, whereas for every 1 score increase in the BEHAVE-AD rating scale, the QUALID score increases by 1.131. This means that the more the resident with dementia is functionally independent, the better is the proxy-rated QoL. However, when the presence of BPSD increases, their QoL gets worse.

4. Discussion

The aim of this study was to measure the proxy-rated QoL of persons with dementia residing in dementia-friendly units in a LTC facility in Malta as obtained from informants (i.e., nurses caring for the residents), and to assess what factors are related to it. A quantitative cross-sectional survey design was used. The proxy-rated QoL was measured using the QUALID scale, whilst the BEHAVE-AD rating scale was used to assess the presence of BPSD amongst 50 participants who were recruited for the study. The mean total QUALID score was calculated to be 22.14, whereas the mean total BEHAVE-AD score was 3.18 which indicates that the participants had a moderate QoL and low presence of BPSD. No association was found between the QoL and gender. On the contrary, an association was found between the QoL and the presence of BPSD, cognitive abilities, and functional dependency. Moreover, an ANCOVA regression model that was built, indicated that the predictors that mostly affect the QoL of the participants were the presence of BPSD and functional dependency.

The mean proxy-rated QoL score of the participants was 22.14. When looking at similar studies that used the QUALID scale as the tool to measure the QoL of the participants, the mean QoL scores ranged from 21.50 to 25.19 which were quite similar to the mean score of this study (Barca et al., 2011; Castro-Monteiro et al., 2015). The QUALID scores in this study ranged from a score of 11

Behaviour	Answer	Percentage	Mean	Standard eviation
Smiles	**Once or more each day**	**26%**	**3.04**	**1.43**
	Less than once a day	**4%**		
	Once a day	**26%**		
	Less than once a day	**28%**		
	Rarely	**16%**		
Enjoys Interacting Or Being With Others	**Almost always**	**48%**	**2.58**	**1.76**
	More than half the time	**8%**		
	Half the time	**12%**		
	Less than half the time	**2%**		
	Rarely or never	**30%**		
Appears Sad	**Rarely**	**44%**	**2.40**	**1.54**
	In response to external stimuli – less than once a day	**16%**		
	In response to external stimuli – once a day	**12%**		
	For no apparent reason – less than once a day	**12%**		
	For no apparent reason – once or more each day	**16%**		
Enjoys Touching/Being Touched	**Almost always**	**42%**	**2.32**	**1.36**
	More than half the time	**12%**		
	Half the time	**28%**		
	Less than half the time	**8%**		
Makes Statements Or Sounds That Suggest Discontent, Unhappiness Or Discomfort	**Rarely**	**58%**	**2.06**	**1.43**
	In response to external stimuli – less than once a day	**8%**		
	In response to external stimuli – once a day	**14%**		
	Without cause – less than once a day	**10%**		
	Without cause – more than once a day	**10%**		
Has A Facial Expression Of Discomfort	**Rarely**	**62%**	**1.94**	**1.36**

	Less than once a day	8%		
	At least once a day	10%		
	Nearly half the day	14%		
	Most of the day	6%		
Appears Physically Uncomfortable	Rarely	64%	1.78	1.30
	Less than once a day	16%		
	At least once a day	8%		
	Nearly half the day	2%		
	Most of the day	10%		
Is Irritable Or Aggressive	Rarely	58%	1.86	1.25
	Only in response to external stimuli – less than once a day	16%		
	Only in response to external stimuli – at least once a day	16%		
	Without cause – less than once a day	2%		
	Without cause – once or more each day	8%		
Cries	Rarely	74%	1.50	0.98
	In response to external stimuli – less than once a day	10%		
	In response to external stimuli – once a day	10%		
	For no apparent reason – less than once a day	4%		
	For no apparent reason – once or more each day	2%		
Appears Emotionally Calm And Comfortable	Most of the day	76%	1.46	0.91
	More than half the day	8%		
	Half the day	10%		
	Less than half the day	6%		
Enjoys Eating	Most meals and snacks	84%	1.20	0.50
	Twice a day	12%		
	At least once a day	4%		

Table 2. Percentages, mean and standard deviation of each domain in the QUALID scale.

Behavioural And Psychological Symptom	Type of BPSD	Percentage	Mean	Standard Deviation
Paranoid and delusional ideation				
"People are stealing things" delusion	Not Present	98%	0.04	0.28
	Delusion that people are coming into home and hiding or stealing things	2%		
"One's house is not one's home" delusion	Not present	100%	0	0
"Spouse (or other caregiver is an imposter" delusion	Not present	100%	0	0
Delusion of infidelity	Not present	100%	0	0
Other suspiciousness/paranoia	Not present	94%	0.10	0.42
	Suspiciousness	2%		
	Paranoid	4%		
Other delusions (non-paranoid)	Not present	92%	0.16	0.55
	Verbal or emotional manifestations as a result of delusions	8%		
Hallucinations				
Visual hallucinations	Not present	86%	0.28	0.76
	Vague, not clearly defined	4%		
	Clearly defined hallucinations of objects and persons	6%		
	Verbal or physical actions or emotional responses to the hallucinations	4%		
Auditory hallucinations	Not present	100%	0	0
Olfactory hallucinations	Not present	100%	0	0
Haptic hallucinations	Not present	100%	0	0
Other hallucinations	Not present	100%	0	0
Activity disturbances				
Wandering	Not present	58%	0.50	0.65
	Somewhat, but not sufficient as to require restraint	34%		
	Sufficient as to require restraint	8%		
Purposeless activity	Not present	80%	0.20	0.40
	Repetitive purposeless activity	20%		
Inappropriate activity	Not present	92%	0.08	0.27
	Inappropriate activities	8%		
Aggressiveness				
Verbal outbursts	Not present	82%	0.32	0.74

	Present	6%		
	Present accompanied by anger	10%		
	Present, accompanied by anger, and clearly directed at other persons	2%		
Physical threats and/or violence	Not present	92%	0.10	0.36
	Threatening behavior	6%		
	Physical violence	2%		
Agitation	Not present	70%	0.48	0.89
	Present	20%		
	Present with emotional component	2%		
	Present with emotional and physical component	8%		
Diurnal rhythm disturbances				
Day/night disturbances	Not present	84%	0.26	0.66
	Repetitive awakening during night	8%		
	50% to 70% of former sleep cycle at night	6%		
	Complete disturbance of diurnal rhythm	2%		
Affective disturbance				
Tearfulness (or whimpering or other "crying sounds"	Not present	84%	0.22	0.55
	Present	10%		
	Present accompanied by a clear affective component	6%		
Depressed mood	Not present	86%	0.14	0.35
	Present	14%		
Anxieties and phobias				
Anxiety regarding upcoming events	Not present	100%	0	0
Other anxieties	Not present	84%	0.16	0.37
	Present	16%		
Fear of being left alone	Not present	90%	0.12	0.39
	Present with vocalized fear of being alone	8%		
	Vocalised and sufficient to require specific action on the part of the caregiver	2%		
Other phobias	Not present	100%	0	0

Table 3. Percentages, mean and standard deviations for every behavior in the BEHAVE-AD scale

Parameter estimates						
	95% Wald Confidence Interval			Hypothesis Test		
Parameter	B	Lower	Upper	Wald Chi-square	Df	P-value
(Intercept)	22.785	18.033	27.537	88.318	1	0.000
Barthel index score	-0.416	-0.744	-0.089	6.200	1	0.013
Total BEHAVE-AD score	1.131	0.492	1.770	12.031	1	0.001
(Scale)	32.371	20.262	51.717			

Table 4. Parameter estimates for the most significant predictors in the ANCOVA regression model.

indicating the best QoL, to a score of 55 indicating the worst QoL. Therefore, the mean QUALID score of this study indicates that the participants have a moderate QoL.

With regards to the presence and frequency of BPSD, the mean BEHAVE-AD score of the participants was 3.18 which was quite a low score showing that the participants had a low presence of BPSD. It was noted that the most common BPSD was 'wandering', which was present in 42% of the participants. The majority of the participants (34%) who exhibited the behavior of wandering did not require a restraint whereas, in some of the participants (8%), their wandering was serious enough to require restraint. On the contrary, the least common BPSD were those associated with paranoid and delusional ideation which was exhibited by only 2% of the participants. It is interesting to note that the mean BEHAVE-AD scores for males (1.64) was lower than that of females (3.62). This shows that females had a higher presence of BPSD than males. In addition, when looking at the prevalence of the most common BPSD exhibited by the participants which was 'wandering', 27.3% of males exhibited this behavior whereas in females, this was as high as 46.2%. Furthermore, no statistically significant association was found between the BEHAVE-AD scores and the age of the participants (p-value=0.226).

When the relationship between the age and the proxy-rated QoL of the participants was analysed, no association was found (p-value=0.380). This is consistent with the findings of various studies including those carried out by Mjorud et al. (2014), Henskens et al. (2019), Crespo, Hornillos (2017). On the contrary, Lai et al. (2014) found that being of a younger age can have a negative influence on the proxy-rated QoL. In addition, in their study, Mjorud et al. (2014) found that the lowest QoL was noted to be in the participants younger than 79 years of age and the participants older than 90 years of age. However, their findings still did not show any statistically significant association between the two variables. One of the possible reasons why age was not found to be associated with the proxy-rated QoL of the residents in this study, is that the presence of BPSD is usually associated with early-onset dementia rather than late-onset dementia (Arnaoudova, 2011). Furthermore, dementia is considered to be of early onset when it is present in persons younger than 65 years of age. In the present study, the participants were all 65 years and older, with the majority of the participants (54%) being between 81 and 90 years old. Therefore, since most of the participants were of similar age, the severity of BPSD could have been similar across all residents; this being the reason why age was not associated with their proxy-rated QoL.

Another objective in this study was to determine whether there is any association between the presence of BPSD in the participants and their proxy-rated QoL. When this association was analysed, a positive relationship between the two variables was found to be statistically significant (p-value <0.001). This means that as the BEHAVE-AD score was increasing, which signifies a higher presence of BPSD, the QUALID score was increasing as well, which signifies a worse proxy-rated QoL. Mjorud et al. (2014) found that agitation and apathy were significantly associated with the QUALID scores of their participants. In their study, Mjorud et al. (2014) also used the QUALID scale as a measure of proxy-rated QoL and decided to construct three QUALID subscales, which included the tension subscale, the sadness subscale and the well-being subscale. Furthermore, apathy was found to be significantly associated with the sadness and well-being subscales of the QUALID scale, whereas agitation was found to be significantly associated with the tension

subscale. Similarly, Henskens et al. (2019) also found that apathy and agitation were the two most common BPSDs that had a negative effect on the QoL of the participants.

When the relationship between the QUALID scores and the Barthel Index scores of the participants was analysed, a negative relationship between the two variables was found to be statistically significant (p-value = 0.009). This means that as the level of dependency decreases, the QUALID score increases indicating a poor proxy-rated QoL. These findings were consistent with those from several other studies. Beerens et al. (2013), Mjorud et al. (2014), Barca et al. (2011) and Marvento et al. (2014), all found that a higher level of functional dependency is negatively associated with the proxy-rated QoL of older persons with dementia living in LTC.

A negative association between the proxy-rated QoL scores of the participants and their MMSE scores was also found to be statistically significant. This means that participants with better cognitive function, have a better QoL. The cross-sectional studies by Mjorud et al. (2014); Barca et al. (2011) and Marventano et al. (2014) all found a negative association between cognitive function and QoL. Although when analysed alone, there was an association between the MMSE score and the QoL of the participants, when analysed together with other factors, no statistically significant association was found. This ultimately shows that the predictors that have the most significant effect on the QoL of persons with dementia living in LTC are the presence of BPSD and functional dependency. This highlights the need to promote interventions that reduce the BPSD of persons with dementia as well as maintaining and improving their functional abilities. As a result, health care workers and caregivers working in these LTC should try and liaise with the physiotherapists and incorporate more physical activity in the daily routine of the older persons, ultimately improving the functional status of their residents.

One of the main limitations encountered, was the fact that it was carried out during a global pandemic in a LTC facility. This did not allow to include all dementia-friendly units found in the facility, due to some of them being closed down with restricted access for a long time. Furthermore, the findings of the study could not be generalised to all the older persons with dementia living in the dementia-friendly units. However, a good response rate of 64.93% (n=50) was achieved therefore, the sample provides quite a good representation of the rest of the residents in the four units.

5. Conclusion

The aims of this study were to measure the proxy-rated QoL of persons with dementia residing in dementia-friendly units in a LTC facility in Malta and assess the different factors related to it. It transpired that the two most significant predictors of the participants' proxy-rated QoL were the presence of BPSD and functional dependency. This provided better insight on how the participants' QoL can be improved, particularly by reducing BPSD and improving the residents' functional dependency. Further international and local research should be carried out to improve the understanding of what exactly effects the QoL of older persons with dementia residing in LTC, possibly through the use self-rated scales.

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Conflict of interest

The authors report no conflicts of interest.

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