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The "Personhood in Dementia Questionnaire": Italian translation and validation for the assessment of the level of personality attributed to people with senile dementia by health care personnel

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Objective. To validate a survey tool in Italian, useful for assessing the perceptions and beliefs of healthcare professionals with respect to the person with dementia, with particular attention to the levels of dignity and personality (Personhood) that operators address to residents of facilities for the elderly.
Methods. Data collection took place in two distinct periods, the first (T1) from May 2021 to July 2021; the second starting from December 2021 to February 2022 (T2).
Results. The test-retest stability in the two measurements performed was confirmed by the value of the correlation coefficient Rho, very high and statistically significant ($p < .05$) in the comparison of each item at T1 and T2, respectively.
Conclusions. The validity of the construct of the tool could be studied by future research through a more widespread use able to provide data and food for thought to enrich the debate currently underway.

Key words: dementia, healthcare worker, nurse, patient, personhood, translation, validation

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INTRODUCTION

Nearly 50 million people worldwide suffer from dementia and, at least according to current forecasts, this condition will triple in the next 2050 [1]. Dementia represents one of the most difficult challenges both in medicine and nursing, since for the care burden entailing and also for the consequent economic costs. Additionally, it requires a challenge from the ethical aspect in respecting the person and recognizing their values, even in a compromised health condition. Dementia is a set of clinical manifestations caused by multiple factors that is characterized by progressive brain dysfunction. A vision of dementia is often shared as a pathology that cancels the perception of one's own experience and leads to living in an eternal

present, without a past and without a future. Dementia is a syndrome that can be caused by a combination of cognitive changes and loss of skills which are in turn caused by various factors [2]. All neurocognitive disorders share similar symptoms, such as: memory impairment, reduced attention, reduced processing speed and judgment which combined can prevent a person from making safe decisions. Making an early diagnosis of dementia becomes of fundamental importance, which is why several studies have focused attention on risk factors [3]. Review literatures suggested how some dementia risk factors are attributable to exposure to air pollution, aluminum, silicon, selenium, pesticides, vitamin D deficiency and exposure to electric and magnetic fields [4,5]. Another review [6], which included studies conducted in the United States, Canada, Taiwan, Sweden and the United Kingdom, found that exposure to air pollution increases the risk of hypertension, lipids, atherosclerosis, oxidative stress, insulin resistance, endothelial dysfunction, creating a greater propensity for clotting, inflammation and stroke. All of this leads to an increased risk of cognitive impairment and dementia. Cognitive impairment has been shown to be less likely in those taking drugs to control vascular-type risk factors. A meta-analysis of eight studies, conducted on the European population, showed a prevalence of the disease of 5.1% in women and 3.3% in men with an exponential increasing according to age. In fact, it highlighted 0.9% in the age group between 65 and 74 years, 7.7% in the age group between 75 and 84 and 22.5% for those over 85 [7]. In this scenario, it was needed to respect the functionality of the body transformations, according day by day, more similar to those of a child. In this regard, Avoncelli (2018), highlighted how important an intervention approach was that did not replace the individual affected by dementia, but support them in all their difficulties, such as a strategy to make them feel still active and able to relate with their environments [8]. What in recent years is having an important diffusion in the process of treating patients suffering from dementia is the use of the Montessori method, with the aim of making the autonomy of these patients stable and constant (in children instead the goal is the conquest of autonomy). Independence and autonomy are two of the principles underlying the Montessori method. Maria Montessori's pedagogical philosophy is increasingly applied in the elderly and is recognized as a valid method that supports the independence of older people. A study carried out in Australia in 44 residential facilities showed that personalized individual interaction activities based on the Montessori method improve the patient's agitation by making him actively participate in control sessions. In the process of assisting the person with dementia, treatment based mainly on biomedical needs is still widespread, although in the last period a new approach called "People centered" or a person-centered care is spreading. During the pandemic, the loneliness of many elderly people, without meeting their families, due to restrictions, has certainly highlighted the need to investigate these aspects [7]. The study was conducted by administering anonymous questionnaires to residential facilities for the elderly in the Puglia region, mainly in the provinces of Lecce and Bari. The study, one of the few conducted in Italy, aims to investigate through an observational survey, the perceptions and beliefs of health workers with respect to the patient with dementia, with particular attention to the levels of dignity and personality [Personhood] that workers address to residents of facilities for the elderly. Secondary objective, to evaluate the possible application of Montessori dynamics within structures for the elderly (stimulating environment, engaging activities, social interactions) [9].

Objectives

The aim of the present study was to validate an Italian survey tool that evaluates the perceptions and beliefs of healthcare professionals with respect to the patient with dementia, with particular attention to the levels of dignity and personality [Personhood] that healthcare workers address to residents of facilities for the elderly.

METHODS

From May 2021 to February 2022, an observational, cross-sectional and multicentre online study was conducted among healthcare workers, specifically, nurses and socio-health workers, employed in assisted health residences located throughout the country. Data collection took place in two distinct periods, the first (T1) from May 2021 to July 2021; the second starting from December 2021 to February 2022 (T2).

Inclusion criteria

The sample was of convenience and consisted of all nurses and social health workers who agreed to participate in the survey by signing the informed consent. All participants recruited were employed in the field of care for patients suffering from dementia. Those who did not sign informed consent were excluded.

The questionnaire

The questionnaire was administered in twice by also considering always different healthcare workers in order to compare the answers obtained. The main tool of the survey was the Personhood in Dementia Questionnaire (PDQ) translated and adapted to the Italian language, in agreement with the author using a forward-backward

translation system [10]. The personhood in patients with dementia tool consisted of 20 items to which the participant was required to respond by expressing their levels of agreement on a 7-level Likert Scale, from completely disagree (1) to completely agree (7). Values between 1 and 3 outlined a variable level of disagreement (fully, fairly, slightly), value 4 was identified as neither disagree nor agree, while values between 5 and 7 allowed participants to express a variable level of agreement (slightly, fairly, fully). Higher scores reflected higher levels of Personhood. The original tool, designed for permanent residential facilities for patients with dementia, aimed to combine different aspects of the caregiver-patient approach, ranging from the degree of awareness of the person with dementia to their active participations in the social life of the facility. Three questions were added to the PDQ that sought to probe the application of key determinants of the Montessori Method as applied to dementia (stimulating environment, engaging activities, social interactions). The questionnaire was supplemented with social-demographic questions, as: years of working life, years of experience in people with dementia, region of residence. The questionnaire was supplemented with social-demographic questions, as:

- years of experience in people with dementia, as until 5 years or over 6 years;
- healthcare worker role, as dealing with nurse or social health worker.

Data analysis

All data were collected in an Excel data sheet and per formed thanks to the Statistical Package for the Social Sciences (SPSS) version 20. Sampling characteristics were performed as frequencies and percentages, specifically as regards healthcare worker role and years of work experience. Cronbach's Alpha coefficient (α) was assessed to evaluate the internal consistency of the scale. It was calculated on the first data collection (T1), which took place from May 2021 to July 2021 and on the second data collection (T2), which took place from December 2021 to February 2022, without considering in any case the Region of Italy to which the participant belonged. All the answers received were assessed as distribution curves performing the Shapiro-Wilk and Kolmogorov-Smirnov tests. As the distributions of the variables analyzed did not conform to Gaussian distribution ($p < .001$), test-retests stability were assessed using Spearman's rho correlation coefficients. The t-test with independent samples allowed to calculate the significance between T1-T2, between profiles and years of experience. All p-values < .05 were considered as statistical significant.

Table I. Sampling characteristics (n = 160).

Characteristics/enrollement	T1 n(%)	T2 n(%)
Role:		
Nurse	35(43.80%)	71(88.80%)
Social health worker	45(56.20%)	9(11.20%)
Years of work experience:		
≥ 5 years	41(51.30%)	36(45.00%)
< 6 years	39(48.80%)	44(55.00%)

RESULTS

The Italian version of the "Personhood in Dementia Questionnaire" was reported in Appendix I. A total of 160 healthcare workers including nurses and social health workers were recruited whose socio-demographic characteristics, divided into the two distinct moments of survey, were reported in Table I.

The sample size measurement gave a satisfactory result (KMO = .719), with Bartlett's sphericity test < .0001. The homogeneity of the scale was evaluated thanks to the Cronbach coefficient α, which gave results equal to α = .652 for the measurements made at T1 and to α = .709 for the measurements at T2. The test-retest stability in the two measurements performed was confirmed by the value of the correlation coefficient Rho, very high and statistically significant ($p < .05$) in the comparison of each item at T1 and T2, respectively (Tab. II).

Table III shows a certain homogeneity in the answers both in the two profiles and in the years of experience. The only significant differences can be seen for the profile in item no.8 ($p = .006$) and in question 11 ($p = 0.37$), while as regards the years of experience the differences are proved in item no. 1 ($p = .06$), item no. 13 ($p = .019$) and in item no. 16 ($p = .013$).

DISCUSSION

The aim of the present study was to validate an Italian survey tool, useful to assess the perceptions and beliefs of healthcare professionals with respect to the person with dementia, with particular attention to the levels of dignity and personality (Personhood) that healthcare workers addressed to residents of facilities for the elderly. The increase in public health of dementia syndromes has led over the years to the use of person-centered practices to ensure optimal and independent functioning of the individual and his family. In Italy, in fact, according to demographic projections, in 2051 there will be 280 elderly people for every 100 young people, with an increase in all chronic diseases related to age, and among

Table II. T-test, α-Cronbach and Spearman correlations for each item of the "Personhood Dementia Questionnaire" at T1 and T2.

	T1	T2					
	n = 80	n = 80					
	M ± SD		t	p	α	rS	p
Self-awareness in the person with dementia							
Item no. 1: residents with dementia have a sense of purpose	4.65 ± 1.23	4.63 ± 1.32	.124	.902	.807	.715	< .0001**
Item no. 2: most residents with dementia are still capable of making some informed choices about their lives	4.33 ± 1.39	4.53 ± 1.63	-.832	.407	.862	.766	< .0001**
Item no. 3: residents with dementia have a basic right to make any choices they can about their care	4.04 ± 1.56	3.85 ± 1.64	.739	.461	.699	.540	< .0001**
Item no. 15: residents with end-stage dementia have some awareness of what is happening around them	3.79 ± 1.84	4.29 ± 1.91	-1.683	.094	.949	.890	< .0001**
Item no. 20: most residents with dementia feel the same range of emotions as I do	5.68 ± 1.01	5.64 ± 1.20	.213	.832	.663	.468	< .0001**
Concept of person and community							
Item no. 4: residents with very advanced dementia are so low-functioning that they are no longer persons	3.20 ± 2.00	3.50 ± 2.28	-883	.378	.919	.834	< .0001**
Item no. 5: residents with end-stage dementia can no longer contribute to the world in any meaningful way	3.95 ± 1.77	4.20 ± 2.08	-.816	.415	.936	.894	< .0001**
Item no. 6: residents with dementia contribute to a sense of community within our long-term care facility	5.21 ± 1.18	5.86 ± 1.31	-3.289	.001**	.902	.711	< .0001**
Item no. 7: all residents with dementia should be treated with respect	6.38 ± .487	6.78 ± .420	-5.561	< .0001**	.450	.294	.008**
Item no. 8: residents with advanced dementia are no longer true participants in life; instead, they watch from the sidelines	2.85 ± 1.84	4.08 ± 1.88	-4.153	< .0001**	.459	.244	.029*
Item no. 11: residents with dementia can continue to play an important role in their families	5.85 ± 1.19	5.61 ± 1.43	1.138	.257	.651	.345	.002**
Item no. 14: as dementia advances, residents with dementia no longer experience basic feelings such as pleasure	3.88 ± 1.87	4.16 ± 2.14	-.902	.368	.942	.883	< .0001**
Item no. 18: residents with advanced dementia are no longer persons like you and me, because they do not think and reason logically	4.00 ± 1.75	3.65 ± 2.51	1.021	.309	.344	.229	.041*

these dementias, therefore integrating some Montessori activities into the routine of geriatric patients can prove to be an extremely useful and interesting choice [11]. The Montessori method applied to the elderly is based on fundamental principles such as the environment, the material, the preparation of the operator. Our study was mainly attended by professional Nurses, with more than 5 years of work experience. In 2014 the International Montessori Association created a "Montessori Group for Aging and Dementia Advisory" with the aim of developing guidelines for the application of the Montessori approach to elderly people with dementia [12]. All this ensures that the elderly participate in meaningful activities, in an environment that facilitates their independence. The increased interest in non-pharmacological treatments for people with Alzheimer's has led several researchers to explore new areas, new techniques, new approaches as a correlation has been highlighted between the use of non-pharmacological therapies and an increase in the quality of life of people with dementia (as well as the improvement of the symptoms themselves related to the disease). The activities underlying the method are extrapolated from daily life for which the environment plays a fundamental role as well as the caregiver [13]. A factor that should not be underestimated is the fact that dementias in general cause an emotional, economic and physical burden on the families surrounding the patient. Often this burden becomes unbearable for them. It is important for people with dementia to socialize [14,15]. The participants in our study highlight how important this aspect is (Item

Table III. T-test-related work experience.

	Nurse	Social Health Worker		≥ 5 years	< 6 years	
	n = 106	n = 54		n = 77	n = 83	
	M ± SD		p	M ± SD		p
Self-awareness in the person with dementia						
Item no. 1	4.62 ± 1.23	4.67 ± 1.37	n.s.	4.86 ± 1.28	4.43 ± 1.14	.036*
Item no. 2	4.40 ± 1.57	4.48 ± 1.41	n.s.	4.49 ± 1.65	4.36 ± 1.38	n.s.
Item no. 3	3.94 ± 1.51	3.94 ± 1.78	n.s.	3.77 ± 1.73	4.11 ± 1.45	n.s.
Item no. 15	4.25 ± 1.89	3.63 ± 1.83	n.s.	4.23 ± 1.92	3.86 ± 1.84	n.s.
Item no. 20	5.58 ± 1.17	5.81 ± 0.95	n.s.	5.62 ± 1.02	5.69 ± 1.18	n.s.
Concept of person and community						
Item no. 4	3.52 ± 2.13	3.02 ± 2.15	n.s.	3.01 ± 2.15	3.66 ± 2.10	n.s.
Item no. 5	4.03 ± 1.91	4.17 ± 1.98	n.s.	3.87 ± 1.90	4.27 ± 1.95	n.s.
Item no. 6	5.58 ± 1.27	5.46 ± 1.32	n.s.	5.51 ± 1.25	5.57 ± 1.32	n.s.
Item no. 7	6.62 ± 0.48	6.48 ± 0.50	n.s.	6.53 ± 0.50	6.61 ± 0.49	n.s.
Item no. 8	3.77 ± 1.87	2.85 ± 1.98	.006**	3.19 ± 2.01	3.71 ± 1.88	n.s.
Item no. 11	5.58 ± 1.38	6.02 ± 1.14	.037*	5.77 ± 1.26	5.70 ± 1.37	n.s.
Item no. 14	3.95 ± 2.08	4.15 ± 1.87	n.s.	4.34 ± 2.05	3.72 ± 1.94	n.s.
Item no. 18	3.74 ± 2.23	4.00 ± 2.03	n.s.	3.81 ± 2.17	3.84 ± 2.17	n.s.
Item no. 19	6.17 ± 0.96	6.35 ± 0.82	n.s.	6.26 ± 0.92	6.20 ± 0.92	n.s.
Socialization/Montessori method						
Item no. 9	4.95 ± 1.54	4.83 ± 1.68	n.s.	4.81 ± 1.64	5.01 ± 1.53	n.s.
Item no. 10	5.84 ± 1.07	5.80 ± 0.93	n.s.	5.90 ± 0.96	5.76 ± 1.07	n.s.
Item no. 12	5.71 ± 1.32	5.67 ± 1.19	n.s.	5.56 ± 1.44	5.82 ± 1.09	n.s.
Item no. 13	6.06 ± 1.12	6.11 ± 1.07	n.s.	6.29 ± 1.07	5.88 ± 1.09	.019*
Item no. 16	4.18 ± 1.88	4.37 ± 1.70	n.s.	3.87 ± 1.98	4.59 ± 1.59	.013*
Item no. 17	4.03 ± 1.80	4.46 ± 1.86	n.s.	4.08 ± 1.88	4.27 ± 1.78	n.s.

** $p < .001$; *$p < .05$ is statistically significant

no. 10: Rho = .705, $p > .001$,); Item no. 11: Rho = .345, $p > .002$), in order to maximize residual capacities and raise the sense of community within the nursing home as provided for in item no. 6 (Rho = .711, $p > .001$). A key role was played by health professionals who worked in various fields and who need to be trained in applying this method. Two studies showed the need for more in-depth training [16,17]. The Montessori method could be applied in various contexts, both in homes for the elderly and at home. A review of the literature highlighted and strengthened that the Montessori method constituted a beneficial intervention in the resolution of behavioral symptoms [18,19]. Thanks to the Montessori method, it could be obtained a significant reduction in antipsychotic and sedative drugs, and a better quality of life, a greater ability to feed independently [20]. The Montessori method could also bring benefits in the sentimental field and in particular on the affection of people with dementia. Some studies were conducted by examining the impact of the Montessori philosophy on affection and all showed a reliability of 92-95% [7,21,22]. The authors found that anxiety levels had decreased in just six months of activity. Similarly, high levels of pleasure were observed during the sessions themselves. This aspect also emerged from our data, since statistically significant associations were reported, respectively (Item no. 19: Rho = .995, $p > .001$; Item no. 20: Rho = .428, $p > .001$). Two cross studies also confirmed the reduction in agitation levels and aggressive behaviors in favor of a positive emotional influence. Our study showed the validity of the instrument used, as it demonstrates a test-retest stability in the two measurements performed, confirmed by the value of the correlation coefficient Rho, very high and statistically significant ($p < .05$) in the comparison of each item at T1 and T2.

STRENGTHS AND LIMITATIONS

One of the strengths of the study was to have administered the questionnaire to healthcare workers from different Italian regions, all employed in the dementia patients care. The limitation of this study, however, consisted in having included a small number of employers.

Therefore, more future investigations on the clinical utility of the Personhood in Dementia Questionnaire will be beneficial.

CONCLUSIONS

The Montessori method finds its basis on strong relational values, which can be traced back to three key concepts: respect, dignity and equality. Respect and equality for the person like individual, with their own histories, beliefs, tastes, values and their common disease, such as: dementia. Finally, the maintenance of human dignity as the foundation of all their daily activities [8].
Since Maria Montessori's idea was to treat children as people, seeing in each of them a special being, this can only be true for people with dementia, in which the risk of incurring phenomena such as depersonalization and labeling is very frequent [23]. It has been observed that the more the operator or the caregiver knows and understands the person with dementia, the better she/he will be able to handle and to provide him/her with an environment and some tasks that are engaging and meaningful. These environments allow to maintain specific identity of the person [8]. The sense is that the support of the person suffered from dementia cannot be considered only a purely form of welfare, but above all a form in which human take care of those who are close to the person and who are at experience the disease, providing personalized assistance.
The aim of the research was to validate a survey tool in Italian, useful for assessing the perceptions and beliefs of healthcare professionals with respect to the person with dementia, with particular attention to the levels of dignity and personality (Personhood) that operators address to residents of facilities for the elderly. The validity of the construct of the tool could be studied by future research through a more widespread use able to provide data for thought to enrich the debate currently underway, at national level, on staff training and on how important it is to apply this method within the Healthcare Residences to restore dignity to people with dementia.
The patient with dementia appears an unexplored and at times unexplored territory, like a closed room for the which it is impossible to establish whether she is actually inhabited or not. These results make it quite evident the need to organize training moments at permanent residential facilities, with the aim of increasing the level of knowledge on the theme of personhood, dementia and the benefits of applying Montessori model.

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Conflict of interest

The Authors declare no conflict of interest.

Author contributions

Authors equally contributed to the present study.

Ethical consideration

The present study received a unanimous favorable opinion from the Bioethics Committee of the University of Bologna (Prot. 71554 of 29/3/2019). The tool was totally anonymous and, before administration, details of the informed consent were reported, which had to be expressly accepted by all participants.

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