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The personhood in patients with dementia assessed in Italian healthcare professionals: an explorative study

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Aim. The present study aimed to evaluate the differences in the assessment of Personhood in patients with dementia according to professional profiles and years of work experience among Italian healthcare professionals directly involved in the care of patients with dementia. In addition, the correlation between the conferral of personhood and the fundamental determinants of the Montessori method applied to Dementia was also investigated.

Methods. The study was observational, cross-sectional, and multicenter. Data were collected through the online administration of the Personhood in Dementia Questionnaire, between July and September 2020, in residential facilities for the elderly in two Italian regions: Emilia-Romagna and Puglia.

Results. 98 participants were recruited. Of these, 73(74.5%) were social health workers (SHW) and 25(25.5%) were nurses; 40.8% of the participants have worked with people with dementia for less than 5 years, while 59.2% worked for more than 6 years.

No statistically significant differences in the domains between both professions and years of service were registered. Moreover, significance calculations on the domains, found no significant differences between both professionals and the years of experience. However, the Socialization/Montessori method domain showed the highest grading of agreement at 58.8% (n = 346), followed by Self-awareness in the person with dementia at 50.6% (n = 258) and Concept of person and community at < 50%. Finally, the PDQ correlation to the three organizational panel questions were also performed by also considering other three questions.

Conclusions. Patients with dementia might be considered a resource for the healthcare professions. Our results evidence the need for structure training courses in permanent residential facilities, with the goal of increasing the level of knowledge about the subject of personhood, dementia and the benefits of applying Montessori models.

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

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INTRODUCTION

The WHO estimates that approximately 35.6 million people worldwide have dementia, with 7.7 million new cases each year and one new case of dementia diagnosed every 4 seconds. This high incidence has been defined by Alzheimer's Disease International as a global public health priority. In Italy, according to ISTAT, about 1 million people are affected by this disease and about 3 million are directly or indirectly involved in the care of their loved ones.

The number of people with dementia, and mainly Alzheimer's Disease, could triple in the next 40 years with very high social and economic costs [1,2]. Currently, there is no therapy that acts on the causes of the disease that would allow its cure or regression. As a result, there are essentially two pharmacological goals: to slow the progression of cognitive impairment and to keep the most disabling non-cognitive symptoms such as hallucinations, aggression, depression, and behavioral disorders under control through the use of antidepressants, anxiolytics, hypnotics, and antipsychotics [3,4]. However, pharmacological therapy fails in several cases to fully control the symptoms and for this reason it becomes increasingly important to invest in interdisciplinary planning of behavioral assistance with non-pharmacological interventions focused on the remaining strengths of the patient, reducing the use of unnecessary drugs [5]. Such rehabilitative interventions must necessarily be personalized according to the aptitudes and wishes of the subject, so as to achieve total involvement and participation, maximizing the possibility of achieving positive effects [6].

Among the major theorists of the preservation of dignity and personality in the dementia patient there is certainly Tom Kitwood, who in the early '90s – with the publication of his "Dementia Reconsidered" – was able to question the foundations of care relationships between caregivers and patients with cognitive impairment [7]. The conceptual basis on which his model, called Person Centered Care (PCC), is structured is Personhood, which considers the individual as an equal partner from the moment of planning the therapeutic project and in the evaluation of care, to ensure that this is as appropriate to their needs. This is a holistic and personalized view, which considers the subjectivity of patients and how they fit into a given environment, their strengths, their plans, and their rights [8]. One of the main difficulties lies in the conceptualization of personality in dementia, which could be understood as the way the person experiences and perceives the pathology [9]. Personality in dementia is predominantly conceptualized as relational and related to social interactions [10]. This view of personality in dementia seems to have many points of contact with the approach defined as Montessori Programming for Dementia [11], which consists in the adaptation of the Montessori method – born for its pedagogical applications in pediatric settings – to people with dementia. The Montessori method adapted for Alzheimer's offers a variety of activities (such as gardening, cooking, conversation, etc.) in an open, free, cognitively stimulating environment rich in social interactions [12,13].

The Montessori Method applied to dementia has been shown to be particularly effective in managing eating behaviors [14], as well as increasing social interactions and affectivity [15].

These unconventional approaches, such as PCC and the Montessori Model applied to Dementia, tend to address the need for the caregiver to not lose sight of the person, with their lived experience and abilities, beyond the limitations of cognitive impairment.

AIM

The present study aimed to evaluate possible differences in the assessment of Personhood in patients with dementia according to professional profiles and years of work experience among healthcare professionals directly involved in the care of these patients. In addition, the correlation between the conferral of personhood and the fundamental determinants of the Montessori method applied to Dementia was investigated.

METHODS

Research strategy

This study was observational, cross-sectional, and multicenter. Data were collected through the administration of an online questionnaire, between July 2020 and September 2020, in residential facilities for the elderly in two Italian regions: Emilia-Romagna and Puglia. All nurses and social-health workers (SHW) who spontaneously agreed to participate in this survey were enrolled. Regarding the Emilia Romagna Region, collaboration was requested from the permanent residential structures managed by Public Company to the Person (ASP) Romagna Faentina and ASP Bassa Romagna, while regarding the Puglia Region, the request was directly sent to individual healthcare facilities for patients with dementia in the Province of Lecce.

The questionnaire

The main tool of the survey was the Personhood in Dementia Questionnaire (PDQ) [16] translated and adapted to the Italian language, in agreement with the author, using a forward-backward translation system. This

tool consisted of 20 items to which the participant was required to respond by expressing their levels of agreement on a7-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 [17]. 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.

Data analyses

All data were collected in an Excel data sheet and performed thanks to the Statistical Package for the Social Sciences (SPSS) version 20.

Descriptive statistics calculations were performed by determining the mode, median, mean, standard deviations with 95% CI, frequencies, and percentages. Differences were determined through t-test for cardinal variables and chi-square for categorical variables. Correlations were performed through Pearson's coefficient.

RESULTS

The total sample consisted of 100 participants, two of whom were excluded for not signing the informed consent. Of the 98 participants considered, 73 were social health workers (74.5%) and 25 are nurses (25.5%). The regions of residence and work in which participants practice were: Emilia Romagna (69.4%), Puglia (28.6%) and others (2%). Results show that 40.8% of the participants have worked with people with dementia for less than 5 years, while 59.2% worked for more than 6 years (Tab. I). If we consider the analysis of the questionnaire it could be divided into three main sections (Tab. II), identified by three characteristics of the relationship with the demented patient: self-awareness in the person with dementia (items no. 1, 2, 3, 15, 20), the concept of person and community (items no. 4, 5, 6, 7, 8, 11, 14, 18, 19) and socialization/Montessori method (items no. 9, 10, 12, 13, 16, 17).

Table I. Sampling characteristics (n = 98).

Social-demographic characteristics	n; %
Professional profile	
Registered Nurse	73 (74.5%)
Social-health workers (SHW)	25 (25.5%)
Region of Italy	
Emilia Romagna	70 (71.4%)
Puglia	28 (28.6%)
Years of work experience	
0-5 years	40 (40.8%)
≥ 6 years	58 (59.2%)

Table II divided the instrument into areas and determined the moda, median, and mean for each area. The mean rating was obtained from the sum of the likert scores given by SHW and nursing staff for each PDQ question. The parametric calculation through the t-test, shows no statistically significant differences in the domains between both professions and years of service.

The likert scores of the responses were channeled into three nominal variables: diasagree, neutral, and agree. In the contingency table (Tab. III), agreement percentages determined by counting likert scores 5, 6, and 7 were calculated. Significance calculations on the domains, found no significant differences between both professionals and the years of experience. However, the Socialization/Montessori method domain showed the highest grading of agreement at 58.8% (n = 346), followed by Self-awareness in the person with dementia at 50.6% (n = 258) and Concept of person and community at < 50%. In the single items some of them prove to be significant, specifically item 4 finds an agreement for 20% (n = 5) among nurses *vs* 17.8% (n = 13) of SHW (p = .036). Concerning the differences with respect to years of work, item 10 resulted in significantly higher agreement among those with 0-5 years of experience (n = 32, 80%) *vs* those with more years of experience (n = 45, 77.6%) (p = .020). In item 16, on the other hand, it was operators with ≥ 6 years who agreed by 25.9% (n = 15) vs the remaining colleagues who were shy (n = 3, 7.5%) (p = .037). In the overall context, 50% (n = 10) of the items showed a percentage of practitioners agreeing with a range between 56.1% (item 15) and 91.8% (item 7). The domain with the highest number of positive items was Socialization/Montessori method with 4 out of 6 items with a percentage > 65%.

Table IV shows the PDQ correlation to the three organizational panel questions developed on expert judgment. Cognitively stimulating communal environments correlate positively with Self-awareness in the person with dementia (r = .310) and Socialization/Montessori method

Table II. PDQ evaluation in sub scale.

		SHW N = 73			Nurses N = 25					0-5 years N = 40			≥ years N = 58				
Sub scales	**R**	**Mo**	**Me**	**μ ± sd**	**Mo**	**Me**	**μ ± sd**	**t**	**P**	**Mo**	**Me**	**μ ± sd**	**Mo**	**Me**	**μ ± sd**	**t**	**P**
Self-awareness in the person with dementia	5-35	16	22	21.88 ± 5.45	16	23	22.80 ± 5.43	-.731	.466	16	23	22.65 ± 5.75	22	22	21.75 ± 5.23	.811	.419
Concept of person and community	9-63	33	34	35.64 ± 5.36	31	36	37.68 ± 7.38	-1.492	.139	33	33	35.33 ± 5.63	34	36	36.71 ± 6.16	-1.138	.258
Socialization/ Montessori method	6-42	30	30	28.20 ±4.75	31	28	27.48 ± 4.37	.671	.504	30	28	27.45 ± 4.01	30	30	28.41 ± 5.03	-1.006	.317
Total PDQ	20-140	96	86	85.72 ± 10.23	87	87	87.96 ± 11.48	-.919	.360	87	87	85.43 ± 10.28	96	87	86.86 ± 10.76	-.665	.508

* $p = < .05$

(r = .282). Caregivers believe that stimulating environments affect residents' purpose (r = .295), patients' choices (r = .243) sense of community (r = .463), respect (r = .406), role in family (r = .373), feelings related to experiences (r = .608), connections among guests (r = .322), socialization (r = .370), relationships with caregiver (r = .315), in association with music (r = .410). The environment stimuli correlated negatively with item "Residents with very advanced dementia are so low-functioning that they are no longer persons" (r = -.243), item "As dementia advances, residents with dementia no longer experience basic feelings such as pleasure" (r = -.243), and item "The needs of residents who still have awareness of their environment should take priority over the needs of those who have less awareness" (r = -.283). When asking respondents whether patients with dementia can take an active part in daily actions of facility management, direct correlations relate to the perception that most residents are able to make some informed choices about their lives (r = .242), to the degree that patients are able to contribute to the sense of community within our long-term care facility (r = .237), to the feelings that patients manifest based on their own experiences (r = .351), on the trace that some patients leave in the lives of caregivers (r = .241) and with the association of other stimuli such as music (r = .252). This question correlates negatively with item "Residents with very advanced dementia are so low-functioning that they are no longer persons" (r = -.261), item "Residents with end-stage dementia can no longer contribute to the world in any meaningful way" (r = -.230), and item "Residents with advanced dementia are no longer true participants in life; instead, they watch from the sidelines" (r = -.272). The last question in which we ask if residents with dementia can move freely within the facility, we find a positive correlation with the perception that caregivers have with respect to which a large proportion of residents with dementia feel the same range of emotions as nurses and SHW (r = .391). The only negative relationship is for item "Residents with very advanced dementia are so low-functioning that they are no longer persons" (r = -.203).

DISCUSSION

The present study aimed to evaluate possible differences in the assessment of Personhood patients in dementia according to the Montessori's approach in relation to professional profiles and years of work experience among healthcare professionals directly involved in the care of patients with dementia.

The term personhood as used by Kitwood, has been widely referenced in the gerontological literature [17-19], which expresses the perceptions of professionals in their care settings. Although there were studies on the personalization of patient [20,21], there were no studies that emphasized the perception of patient personalization by the total caregiver. Kitwood [7] supposed that there was a relationship between personhood-as-status and person-centered care, and a number of real-world phenomena might be related to beliefs about personhood, such as how often a care provider converses with a patient who does not vocalize. Moreover, the literature highlighted the need for more person-centered approaches to dementia care [22].

Table III. Contingecy table (∑ likert 5+6+7).

	SHW N = 73 n (%)	Nurses N = 25 n (%)	P	0-5 years N = 40 n (%)	≥ 6 years N = 58 n (%)	P	Total agree N = 98
Subscales & items							
Self-awareness in the person with dementia	**177 (48.5)**	**71 (56.8)**	**.209**	**105 (52.5)**	**143 (49.3)**	**.668**	**248 (50.6)**
Item no.1	27 (37.0)	10 (40.0)	.601	16 (40.0)	21 (36.2)	.414	37 (37.8)
Item no.2	32 (43.8)	15 (6.0)	.368	18 (45.)	29 (50.0)	.117	47 (48.0)
Item no.3	30 (41.1)	16 (60.0)	.188	18 (45.0)	29 (50.0)	.117	47 (48.0)
Item no.15	39 (53.4)	16 (64.0)	.248	26 (65.0)	29 (50.0)	.133	55 (56.1)
Item no.20	49 (67.1)	15 (6.0)	.753	27 (67.5)	37 (63.8)	.547	64 (65.3)
Concept of person and community	**302 (46.0)**	**109 (48.4)**	**.106**	**167 (46.4)**	**244 (46.7)**	**.119**	**411 (46.6)**
Item no.4	13 (17.8)	5 (20.0)	.036*	7 (17.5)	11 (19.0)	.605	18 (18.4)
Item no.5	15 (20.5)	8 (32.0)	.430	8 (20.0)	15 (25.9)	.234	23 (23.5)
Item no.6	57 (78.1)	17 (68.0)	.491	30 (75.0)	44 (75.9)	.985	74 (75.5)
Item no.7	69 (94.5)	21 (84.0)	.178	40 (100)	50 (86.2)	.050	90 (91.8)
Item no.8	24 (32.9)	9 (36.0)	.877	13 (32.5)	20 (34.5)	.822	33 (33.7)
Item no.11	47 (64.4)	18 (72.0)	.633	27 (67.5)	38 (65.5)	.795	65 (66.3)
Item no.14	4 (5.5)	4 (16.0)	.250	2 (5.0)	6 (10.3)	.098	8 (8.2)
Item no.18	9 (12.3)	6 (24.0)	.372	2 (5.0)	13 (22.4)	.060	15 (15.3)
Item no.19	64 (87.7)	21 (84.0)	.500	38 (95.0)	47 (81.0)	.078	85 (86.7)
Socialization/ Montessori method	**259 (59.1)**	**87 (58.0)**	**.829**	**139 (57.9)**	**207 (59.5)**	**.890**	**346 (58.8)**
Item no.9	50 (68.5)	16 (64.0)	.684	31 (77.5)	35 (60.3)	.205	66 (67.3)
Item no.10	56 (76.7)	21 (84.0)	.661	32 (80.0)	45 (77.6)	.020*	77 (78.6)
Item no.12	59 (80.8)	15 (60.0)	.097	28 (70.0)	46 (79.3)	.526	74 (75.5)
Item no.13	66 (904)	20 (80.0)	.203	38 (95.0)	48 (82.8)	.152	86 (87.8)
Item no.16	12 (16.4)	6 (24.0)	.672	3 (7.5)	15 (25.9)	.037*	18 (18.4)
Item no.17	16 (21.9)	9 (36.0)	.163	7 (17.5)	18 (31.0)	.319	25 (25.5)

*$p = < .05$

Specifically, Edvardsson and Innes [23] assessed person-centeredness and found that this approach was not typically considered as a primary outcome measure in studies of person-centered care.

In this regard, our questionnaire has an advantage since the patient wanted to be framed from a Montessioran perspective. In particular, the Montessori method found its basis on strong relational values, which can be traced to three key concepts: respect, dignity, and equality. Respect for and equality of the person as an individual, with his or her own history, beliefs, tastes, values and pathology. Finally, the maintenance of human dignity as the foundation of all humanactions [12]. Since Maria Montessori's idea was to treat children as persons, seeing in each of them a special being, this may be true only for people with dementia: if not, there is a risk of incurring phenomena such as depersonalization and labeling [24]. It was observed that the more caregivers knew and understood the person suffered from dementia, the better they would be able to manage them and to provide them with an environment and some tasks that were engaging and meaningful. These environments could make it possible to maintain that person's specific identity, who remains alive and unique even in the disease, and to create self-confidence [12]. The meaning was to support the person not only from a purely welfare point of view, but above all from a human point of view and to also take care of those who were close to the person and who were experiencing the disease, providing personalized assistance. The

Table IV. Pearson's correlation coefficient.

	Self-awareness in person with dementia			Concept of person and community								Socialization/Montessori method				
	Item no.1	Item no.2	Item no.20	Item no.4	Item no.5	Item no.6	Item no.7	Item no.8	Item no.11	Item no.14	Item no.19	Item no.9	Item no.10	Item no.12	Item no.13	Item no.17
Item no.21: Common environments are cognitively stimulating	.295**	.243*	.278**	-.243*	/	.463**	.406**	-.357**	.373**	-.243*	.608**	.322**	.370**	.315**	.410**	-.283**
Item no.22: Patients with dementia can take an active part in the daily management of the facility	/	.242*	/	-.261**	-.230*	.237*	/	-.272*	/	/	.351*	/	/	.241*	.252*	/
Item no.23: Patients with dementia can move freely within the facility and interact freely with other guests	/	/	.391*	-.203*	/	/	/	/	/	/	/	/	/	/	/	/

**p = < .01 (2-tails); *p = < .05 (2-tails)

following study allowed us to focus attention on the perceptions of the caregivers who daily provide assistance to patients with cognitive impairment. On the one hand, the well-rooted conviction that the assisted patient – regardless of the disease – could be the object of respect, attention and consideration precisely as a "person" with a personal experience, emotions and feelings that no disease could affect or, worse, inhibit. On the other hand, the operators' responses reflected a moderate level of uncertainty about the real level of awareness, perception and "presence" of the person affected by dementia. Those who daily cared for such fragile subjects, while recognizing their intrinsic dignity, seemed at the same time to wonder how much the subject felt and, consequently, needed assistance to preserve personality. The patient with dementia appeared to caregivers as an unexplored and sometimes unexplored territory, like a closed room for which it was impossible to determine. Our study highlights how there were no differences in the perception of the patient with dementia both considering the professional role and in relation to the number of years of work experience. In this regard, our data seemed to disagree with what was highlighted in the literature [25-28]. On the other hand, encouraging the conception of the patient with dementia as a resource for the profession would prove to be a starting point for a new conception of a series of patients who have many care needs [29-31].

CONCLUSIONS

The following study focused on the perceptions of professionals who daily provide care to patients with cognitive impairment. We found, on the one hand, a well-established belief that the patient under care – regardless of the pathology – should be the object of respect, attention and consideration because he/she is a "person", and, on the other hand, possible uncertainties about the real level of awareness, perception and "presence" of the person with dementia. In this regard, our results evidenced the need to structure training courses at permanent residential facilities as early as undergraduate courses, with the goal of increasing the level of knowledge about the person, dementia, and the benefits of applying Montessori models in a multidimensional approach [30,31].

Ethical consideration
The 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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Conflict of interest
The Authors declare no conflict of interest, financial or otherwise.

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