

# Psychosocial care in dementia in European higher education

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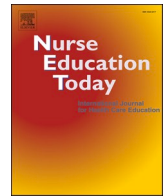
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## Psychosocial care in dementia in European higher education: Evidence from the SiDECar (“Skills in DEmentia Care”) project

G. Ottoboni, PhD<sup>a,\*</sup>, I. Chirico, PhD<sup>a</sup>, P. Povolná, PhD<sup>b,c</sup>, V. Dostálová, PhD<sup>b,c</sup>, I. Holmerová, PhD<sup>b,c</sup>, N. Janssen, PhD<sup>d</sup>, F. Dassen, PhD<sup>d</sup>, M. de Vugt, PhD<sup>d</sup>, Ma.C. Sánchez-Gómez, PhD<sup>e</sup>, F. García-Peñalvo, PhD<sup>e</sup>, M.A. Franco-Martin, PhD<sup>e</sup>, R. Chattat, PhD<sup>a</sup>

<sup>a</sup> Department of Psychology, University of Bologna, Bologna, Italy

<sup>b</sup> Charles University, Faculty of Humanities, Czech Republic

<sup>c</sup> Institute for Postgraduate Medical Education, Prague, Czech Republic

<sup>d</sup> Department of Psychiatry and Neuropsychology, School for Mental Health and Neuroscience, Alzheimer Center Limburg, Maastricht University Medical Center, Maastricht, the Netherlands

<sup>e</sup> University of Salamanca, Salamanca, Spain

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### ABSTRACT

In dementia care, psychosocial interventions can increase people's quality of life with dementia and their caregivers. Despite their effectiveness, their translation into practice lacks the desirable systematicity. Systematic educational programs on psychosocial interventions in dementia will improve this translation, as it prepares professionals to face the complexity of dementia care. This study aimed to systematically map out the extent to which higher education programs in Europe include teaching activities about psychosocial care of dementia.

We collected quantitative and qualitative data about 303 higher education teaching activities on psychosocial care in dementia across Europe. The analysis revealed that the number of teaching activities focusing on psychosocial care in dementia was relative.

Although the results reflected UNESCO indications, the teaching activities on psychosocial care in dementia appeared less systematized than optimal. As world health agencies recommend, international higher education systems should consider more psychosocial care topics because they can prepare professionals to respond timely and effectively to dementia patients and caregivers' needs.

### 1. Introduction

Dementia is a public health priority in many world agency agendas (e. g., Alzheimer Europe Office, 2018; G20 Summit in Osaka, Japan, 28-29/06/2019—Consilium, 2019; OECD; WHO and ADI (A. c. Di), 2012). Annually, about 10 million new cases of dementia are registered (WHO, 2017): by 2050, more than 40 million people in “Organization for Economic Co-operation and Development” countries will develop dementia if no remedies, drugs or curative interventions thrive meanwhile (Health Policy Analyst, Health Division, OECD, 2018).

The legacy of these provisions implores stakeholders to reflect and

act quickly to identify the most beneficial series of actions capable of tackling the problem. Although no effective cure exists yet, several psychosocial interventions aimed at maintaining or preserving personhood, improving wellbeing and interpersonal relationships, everyday functional abilities, and cognitive capabilities exist (Dickinson et al., 2017; McDermott et al., 2019; Olazarán et al., 2010; Moniz-Cook and Manthorpe, 2009; Moniz-Cook et al., 2011). By taking into account the needs, preferences, and abilities featuring both people with dementia, their family, and the social context (Moniz-Cook et al., 2011), such interventions effectively improve the quality of life of all the persons involved in the process of care (Cooke et al., 2001; Herholz et al., 2013;

\* Corresponding author at: Interdepartmental Cancer Research Centre “Giorgio Prodi”, Policlinico S. Orsola-Malpighi, Padiglione 13, V piano, Via Massarenti, 11, 40138 Bologna, Spain.

E-mail addresses: [giovanni.ottoboni@unibo.it](mailto:giovanni.ottoboni@unibo.it) (G. Ottoboni), [ilaria.chirico2@unibo.it](mailto:ilaria.chirico2@unibo.it) (I. Chirico), [povolna@ipvz.cz](mailto:povolna@ipvz.cz) (P. Povolná), [vladka.dostalova@seznam.cz](mailto:vladka.dostalova@seznam.cz) (V. Dostálová), [iva.holmerova@gerontocentrum.cz](mailto:iva.holmerova@gerontocentrum.cz) (I. Holmerová), [niels.janssen@maastrichtuniversity.nl](mailto:niels.janssen@maastrichtuniversity.nl) (N. Janssen), [f.dassen@maastrichtuniversity.nl](mailto:f.dassen@maastrichtuniversity.nl) (F. Dassen), [m.devugt@maastrichtuniversity.nl](mailto:m.devugt@maastrichtuniversity.nl) (M. de Vugt), [mcsago@usal.es](mailto:mcsago@usal.es) (Ma.C. Sánchez-Gómez), [fgarcia@usal.es](mailto:fgarcia@usal.es) (F. García-Peñalvo), [mfm@intras.es](mailto:mfm@intras.es) (M.A. Franco-Martin), [rabih.chattat@unibo.it](mailto:rabih.chattat@unibo.it) (R. Chattat).

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Eggermont and Scherder, 2006; O'Connor et al., 2009a, 2009b; Olazarán et al., 2010; Moniz-Cook et al., 2011; McDermott et al., 2019; Pusey and Richards, 2001).

Unfortunately, despite the reported efficacy, psychosocial cares are often offered to people with dementia (PWD) in a sub-optimal way. Some authors discussed the problem as originating from services' organizational structures (Cheston, 2000; Gevers, 2006; Hinton et al., 2007; Cadieux et al., 2013); other authors, instead, argue that the education patch needs to be improved (Downs et al., 2009; Draper et al., 2009) as it impacts on workers' skills and attitudes (Gonczi, 2013; Van Der Roest et al., 2007; Cadieux et al., 2013; Krolak-Salmon et al., 2017). On the other hand, even the guidelines defining care standards, education programs, and competency frameworks lack critical features that a proper education may transfer (Traynor et al., 2011). Moreover, at the content level, the competencies appeared heterogeneous and not eligible to prepare professionals to face the complexity of dementia care (Traynor et al., 2011). Similar scenarios emerge in other reports (Downs et al., 2009; Murphy, 2017; Pulsford et al., 2007). In the UK, Pulsford et al. (2007) found that the topics concerning dementia were usually taught indirectly, incorporated within broader teaching content, encapsulated in short modules, or delivered through seminars. Moreover, care contents emerged to be delivered flexibly through work-based learning programs or left elective. Pulsford et al. (2007) concluded by reporting that most of the trainings UK professionals received were CPD courses (Continuous Professional Development). At that time, the number of diplomas and the degree level courses addressing dementia care were scarce. Ten years later, the number of teaching courses increases, but it was still sub-optimal (Murphy, 2017).

## 2. Aim

As no study had yet ascertained the ways teaching activities on psychosocial care in dementia are systematized and widespread across Europe, in this work, we investigated how the education on psychosocial care in dementia populated European HE systems.

The work represents one of the actions composing the Erasmus+ project entitled *Skills in Dementia Care: Building psychosocial knowledge and best practice in dementia care* (SiDeCar; <https://sidecar-project.eu/>). By capitalising on the indications from both the existing European Higher Education system and the European National Dementia Plans (Chirico et al., 2021), the SiDeCar project is developing a well-systematized and evidence-based study program on psychosocial care in dementia capable of training the next European workforce.

## 3. Methods

To understand how teaching activities on psychosocial care in dementia populated EU study programs, we collected and ascertained quantitative and qualitative data. The data derived both from experts in dementia and manual searches authors performed on the Internet. Once we collected the data, we implemented internal comparisons to overview the European state of teaching psychosocial care activities in dementia.

## 4. Ethical aspects

Although participants could indicate the university where they worked and the hosting country, for this study, we did not request them to sign-up, or trace any personal information, IP addresses included.

### 4.1. Design

Data populated an online survey composed of ad-hoc made items. The survey accomplished a twofold task. It ordered the experts' teaching activities, and it served to pile the outcomes resulting from manual searches on the Internet.

Experts provided their contribution by following a link published on both the SiDeCar project website or recruited by emails sent to the INTERDEM Network and INTERDEM Academy (<http://interdem.org/>). The INTERDEM Network represents a European network of researchers and academics devoted to study, discuss and tackle psychosocial issues in dementia; INTERDEM Academy is the cognate training network for researchers in their early career stage. The link was also distributed to authors' contacts.

Furthermore, the survey structure assisted the authors' manual searches on the universities' websites hosted in each SiDeCar project partners' countries (i.e., Italy, Czech Republic, The Netherlands, and Spain), plus Ireland and the United Kingdom.<sup>1</sup> The webpages we read by the project partners in each country by seeking clues about psychosocial care in dementia, concerning study programs on medicine, nursing, physiotherapy, occupational therapy, psychology, motor sciences, and social sciences (sociology included). The search involved analysing each teaching activity title; synopsis and the syllabus, in case provided, were used to check for consistency. The information gathered during this part of the investigation aimed at increasing the number of data provided by the experts. The data collection process lasted between November 2018 and July 2019.

### 4.2. Instrument

Once participants accessed the survey, a few lines of introduction set both its aim (i.e., "At this purpose we want to ask you a few questions to identify the EU courses providing students with knowledge about psychosocial care in dementia.") and the aims of the project (i. e., to develop and disseminate an up-to-date and innovative, evidence-based curriculum of studies concerning psychosocial care for people with dementia, formal and informal caregivers). After that, participants started responding the questions. These were all in English.

The first was a filter question: participants could only proceed if they indicated the presence of teaching content on psychosocial care in dementia in their universities. They could also specify the name of the university and the hosting country.

The remaining questions asked participants to indicate any courses, modules, or topics on psychosocial care in dementia they were aware of running in their universities or in universities they know. Afterwards, participants must specify the type of content hosting the teaching activity, i.e., in a First, Second or Third level study content. To respond to the question, participants were acknowledged about how the Bologna process structures its cycles (See Table 1).

After filling out these questions, we ascertained if the teaching activity regarded an entire course, if delivered during a module hosted within a course, or as a spare topic discussed occasionally.

Moreover, participants had to indicate whether the activity was mandatory or elective and delivered traditionally or blended (i.e., mix between online and in-person teachings). Besides, they should tell the

**Table 1**

The table summarizes the three cycles of study programs as they are clustered in the Bologna process.

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- The First cycle study programmes includes undergraduate study programmes ISCED 6 level: from 3 to 4 years when following an ISCED level 3 (i.e., secondary school) from 1 to 2 years when following another ISCED level 6
  - The Second cycle includes post-graduate programmes ISCED 7 level from 1 to 4 years when following an ISCED level 6 from 5 to 7 years when following directly ISCED level 3 (e.g., medicine)
  - The Third cycle includes doctoral study programmes ISCED 8 level, three years minimum.
- 

<sup>1</sup> Please note that UK was still part of the EU in times of study design.

number of hours and credits characterizing the teaching activity and the number of attending students. Finally, participants could report the person in charge to be publically contacted and the related website.

As already reported, no response after the first one was mandatory; participants could skip any question in case of missing information. Once they reached the last question, participants had the chance to amend what they indicated and to submit the inputs.

#### 4.3. Data analysis

If the experts' data showed inconsistencies or irregularities, as truncated indications or misspelt, the authors performed additional searches on the Internet to reconcile the information. Once the database was consistent, the data were analysed both quantitatively and qualitatively.

The first analysis consisted of calculating the percentage of teaching activities according to the Bologna three-cycle structure (i.e., bachelor, master, and Ph.D. study programs). We figured how activities were provided as courses, modules or spare teaching, how many were either required or elected activities, and how many were traditional or blended activities. These data were then matched and sorted according to the cycle. Finally, we averaged both the number of credits and the number of teaching hours. These analyses were made separately on the two data entries to check for entry bias. According to the data's nature, the analyses adopted parametric or non-parametric tests (i.e., *t*-test,  $X_2$  and Cohen's *K*).

For what concerned the qualitative analysis, a summative content analysis was conducted, in which teaching activities' titles were analysed to extract the underlying context (Hsieh and Shannon, 2005). The teaching activities were processed if their title included at least one of the following terms: psychosocial care, dementia. The analysis involved the title primarily; synopsis and syllabus supported consistency check, in case provided. For the qualitative research, we did not sort the data according to either data entries or features.

## 5. Results

### 5.1. Quantitative data

We gathered 303 teaching activities, of which 74.6% originated from the manual online searches.

Most teaching activities were framed within the Second cycle of post-graduate programs (62%), while less derived from First cycle teaching activities (16.5%). In the remaining 21.5% entries, there was no cycle indication. Once we sorted the data according to the entry, the data appeared to spread more among the cycles when they were collected manually (See Table 2; manual entries,  $p < .001$ ; experts,  $p > .5$ ).

Many of the teaching activities were courses (58.1%; modules = 31.4%; topics = 9.6%). As before, even in this analysis, the data distribution appeared to differentiate more within the manual entries than within the experts' ones (Table 2; manual entries,  $p < .001$ ; experts,  $p > .1$ ). When the data were sorted according to the study cycle (Table 3),

**Table 2**

The table represents the data sorted by entry (*act. stays for activities*).

	Manual search	Experts
Data ( $n = 303$ )	74.6%	25.4%
First cycle act.	13.5%	3.0%
Second cycle act.	57.7%	4.3%
Courses	49.8%	8.3%
Modules	23.4%	7.9%
Topics	0.3%	9.3%
Required act.	57.1%	1.3%
Elective act.	11.2%	5.3%
Traditionally delivered act.	34.0%	4.0%
Blended act.	18.8%	2.0%
ECTS	12 ± 10 ( $n = 174$ )	9.4 ± 9.8 ( $n = 18$ )
Hours	39 ± 21 ( $n = 19$ )	29 ± 22 ( $n = 25$ )

**Table 3**

The table represents the data sorted by cycle (*act. stays for activities*).

	First cycle act.	Second cycle act.
Courses	7.3%	43.9%
Modules	7.9%	15.8%
Topics	1.3%	1.3%
Required act.	12.9%	47.9%
Elective act.	2.6%	9.9%
Traditionally delivered act.	9.6%	27.1%
Blended act.	5.3%	15.5%
ECTS	11 ± 14 ( $n = 32$ )	11 ± 9 ( $n = 157$ )
Hours	34 ± 24 ( $n = 10$ )	37 ± 21 ( $n = 20$ )

courses and modules belonging to First cycle study programs were similar ( $p > .1$ ), and both much higher than topics ( $p < .001$ ). In the Second cycle, the number of courses was the highest ( $p < .001$ ).

Besides, the activities were mostly required (58.4%, elective = 16.5%, NA = 25.1%), and the variability was driven by the data manually entered (Table 2. Manual entries,  $p < .001$ ; experts,  $p > .1$ ). Once we sorted the data according to the cycle of studies, the required activities overcome the elective ones in both of them ( $P_s < .005$ ).

The activities were also delivered more traditionally (38.0%, blended = 20.8%, NA = 41.2%): even in this case, the variability emerged higher between the data manually entered (Table 2. Manual entries,  $p < .05$ ; expert,  $p > .2$ ). After we matched the data per cycle of studies. In both the cycles, the traditional activities were higher than the blended ones ( $P_s < .001$ ).

The number of European Credit Transfer System (or ECTS) provided for the activities were 11.8 on average (standard deviation,  $SD = 10$ ,  $n = 192$ ), whereas, the number of hours was 35.1 on average ( $SD = 21.6$ ,  $n = 31$ ). In neither case, the data entries differed (ECTS,  $t(190) = 1.02$ ,  $p = .30$ ; Hours,  $t(29) = 1.27$ ,  $p = .22$ . See Table 2).

Finally, the geographical data distribution was very different (Table 4;  $K = -.14$ ,  $p = .03$ ), and this emerged even when the distribution was analysed per data entry (Manual entries,  $p < .001$ ; experts,  $p < .001$ ).

### 5.2. Qualitative data

The data showed that only one teaching activity explicitly mentioned psychosocial care in dementia in its title. This activity was the UK Second cycle course entitled "Psychosocial approaches to care and treatment of people with dementia". Moreover, another UK Second cycle course referred to psychosocial care in dementia, and its title was "Dementia in health and social care". Besides these two instances, other thirty-six teaching activities embedded the terms "dementia care" in their titles: 86.4% represented Second cycle activities (5.4% First cycle courses, NA = 8.2); 29 were courses, 7 modules, but no spare topics.

Further analysis indicated that 27.7% of the teaching activities focused on practical perspectives: in particular, three titles included the

**Table 4**

The table indicates the distribution of responders per Nation per data entry.

Country	Manual search	Expert
Spain	47	0
Italy	38	1
Czech Republic	22	0
Netherlands	0	8
United Kingdom of Great Britain and Northern Ireland	88	1
Ireland	31	10
Malta	4	0
France	0	33
Germany	0	7
Portugal	0	6
Belgium	0	3
Norway	0	2
Austria	0	1

term “planning”, thirty-seven of them embedded the term “interventions”, twenty-four titles displayed the word “therapy”, nine of them had “approach” in the title, while seventeen titles reported the term “rehabilitation”, and three titles, the word “practicum”. On the contrary, 3.0% of the data suggested that teaching activities focused on theoretical perspectives: one teaching title reported the term “theories”, three titles embedded the word “perspective”, three others displayed the word “ethic”, and two of them the word “society”.

Moreover, data showed that 4.6% of the teaching activities seemed to focus on the health domain: in particular, five titles included the term “medicine”, seven titles displayed the word “assessment”, and two titles, the term “pharma”. Again, 13.2% of the teaching activities had specific references to the ageing domain: 40 teaching titles included words such as older, (OR) elder, (OR) ageing.

Finally, 30 teachings explicitly referred to the people of interest: one teaching title referred to terms concerning people with dementia and caregiving, one title focused on informal caregivers, three titles specifically mentioned the family, and one title referred to formal and informal caregivers.

Teaching activities were part of the following degrees: Applied cognitive psychology; Clinical psychology; Psychology; Psychological science and techniques; Neuropsychology; Neuroscience and neuropsychological rehabilitation; Nursing; midwifery and social work; Nursing - Dementia care; Social and territorial policies; Advanced care in dementia; Dementia care and practice; Health care practice; Health and social care; Dementia Studies; Medicine.

## 6. Discussion

Aimed at understanding the extent to which teaching activities on psychosocial care in dementia resides within the European HE systems, we ascertained European experts in dementia and searched European universities websites. Results from both approaches were aggregated because of the low response rate of experts. Results showed that teaching activities on psychosocial care in dementia mainly were delivered in courses situated within study programs; a smaller amount appertained to modules, and very few were spare topics provided within courses or modules. This pattern emerged more in teaching activities that belonged to the Second cycle of study programs than in the ones included in the First cycle. The same difference emerged when we sorted the activities per the required/elective feature and the traditional/blended one.

Most of the activities within the courses belonging to the Second cycle of study programs entails further that psychosocial care in dementia represents a complex topic that necessitates the students to have achieved propaedeutic knowledge. Indeed, psychosocial interventions are those physical, cognitive, or social activities aimed at minimizing the risk of future disability while maintaining- or improving interpersonal relationships, functioning, and wellbeing in both people with dementia and their carers (McDermott et al., 2019; Moniz-Cook, Vernooij-Dassen, Woods, Orrell, and Interdem Network, 2011). By focusing on people's experience and history, personal needs, preferences and abilities, as well as on the social context, they work to reduce the *malignant social psychology* (Kitwood and Kitwood, 1997; Moniz-Cook and Manthorpe, 2009; Moniz-Cook, Vernooij-Dassen, Woods, Orrell, and Interdem Network, 2011). Because such a perspective interests all the people involved in the disease since the delivery of the diagnosis, i.e., patients, formal and informal caregivers, the propaedeutic teachings psychosocial knowledge necessitates in the EU HE systems indicate the students how complex is the context where dementia insists. Simultaneously, the fact that the contents of psychosocial care in dementia are delivered in required activities more frequently than in elective one endorses that the teaching contents are critical in the study program. Moreover, the traditional teaching method, i.e., the frontal/ in presence one, apart from being the most frequent academic method, provides the opportunity to stress the importance of the relationship in psychosocial care.

During such teachings, students and lecturers interact and may ascertain the interactive ethos that is at the basis of this form of care. The data's geographical distribution shows a situation very similar to the one featuring the national dementia plans (Chirico et al., 2021). In both cases, only some countries have consistent dementia-related policies of education (Hvalič-Touzery et al., 2018). Finally, concerning the study effort, the data we yielded appear to reflect EU indications. Typically, the study effort is quantified using a Bologna processes tool: the ECTS. The system originated to make any study programs very transparent and transferrable across Europe. Usually, 60 ECTS relate to teaching activities that require a full-time learning year, spanning between 1500 and 1800 h of study. The credits can be allocated to the different activities, all inherent to achieving the defined learning target. The activities range from educational components, i.e., self-contained and formally structured learning experiences, to dissertations, work-learning activities, and reach work placements (European Commission, 2019).

Our results show that the knowledge about psychosocial care in dementia is taught by considering both practical and theoretical perspectives. Teaching activities that prepare students to plan interventions, organize sessions of rehabilitation, or tackle practical issues are delivered alongside activities that focus students on thinking about dementia as a status affecting their entire lives. Psychosocial care is characterised by the theoretical shift both putting the person at the centre of the care and leaving the disease on the background (Kitwood, 2007; Beer et al., 2009; Moniz-Cook et al., 2008, 2011; Huber et al., 2011; Vasse et al., 2012). In this light, the intense intersubjective interactions featuring the approach require a solid ability to handle both the practical and the theoretical aspects that feature such a complexity. A relative number of teaching activities appeared to address students' attention towards the person with dementia and her/his caregivers, although not specifying further information. Caregiving is a crucial aspect in dementia contexts. As pointed out elsewhere (Gérain and Zech, 2019; Ottoboni et al., 2018), the way caregivers experience their tasks is fundamental to modulate PWD's quality of life, as well as it can exert a detrimental effect on caregivers' health itself (Vitaliano et al., 2003).

Psychosocial care in dementia does not cover just psychological or sociological care. It considers the entire person from a multifaced perspective accounting for the biological perspective alongside the views previously reported (Kitwood and Kitwood, 1997; Huber et al., 2011). In this light, these results show the teaching activities on psychosocial care in dementia are timely host in various degrees, such as health, nursing, psychology, social and medicine, reinforcing the cross-discipline nature of the psychosocial perspective.

Moreover, such heterogeneity, together with the fact that most of the activities are courses belonging to the Second cycle of studies, and required, indicates that the effort deployed to modify the zeitgeist surrounding people with dementia needs more work. In fact, although the teaching activities are mainly required, the fact that they are delivered in the Second cycle of studies minimally secure that the knowledge about psychosocial care is spread across a broad range of professionals. These are essential aspects in the context of dementia-friendly communities, where professionals with different background-also outside the context of direct dementia care- could contribute if they are educated in such a way of caring (Shannon et al., 2019). Moreover, with the steep rise in the dementia population, it is of the utmost importance to interest and inspire new generations of professionals in this field of research and/or care: to achieve all of this, students' greater reach in the First cycle would indeed contribute.

At the same time, however, HE institutions should start discussing whether psychosocial care in dementia may become a proper, separated discipline or embedded into each academic course, preparing the future health and welfare workforces. Indeed, the state of the art that we analysed demonstrates that EU countries fully respect the indications of the ISCED. Specifically, the agency indicates neither dementia nor psychosocial care can be included within the scientific fields composing the international educational system (ISCED, *Fields of Education and*

*Training. Appendix I, 2014; UNESCO, 2015*). Among the enclosed fields, Social Science, Health and Welfare are the ones featured within psychosocial care contents. In particular, ISCED sorts the general care for older people between the medical and the welfare domain. Within the former, ISCED focuses on maintaining and caring for patients' health during illness and rehabilitation; within the latter, ISCED indicates to deliver psychosocial care both to older adults and people with disabilities.

However, within the Second cycle of studies, masters of various natures are hosted: ISCED includes masters offered to full-time students alongside masters for working professionals and study programs that do not provide accreditations to spend in the labour market (UNESCO, 2012, 2015). As observed elsewhere (Pulsford et al., 2007; Downs et al., 2009; Murphy, 2017; Hvalič-Touzery et al., 2018), skills on dementia care are very often provided in courses that organized outside the universities, i.e., CPD learning programs, once people already got a degree (Hvalič-Touzery et al., 2018). Such heterogeneity can confound students, academic officers, professionals and their agencies, the world of work, and the general audience. It is time to reflect on this and update the ISCED taxonomy to match HE and the labour market.

## 7. Strength and limitations

In this study, the main strength concerns its focus on the psychosocial aspects of dementia contexts; the main limitation regards the data entries. More experts' involvement and automatic search algorithms would be necessary to avoid biases deriving from the manual input and analysis in future research.

## 8. Conclusion

World agencies insist on the need to secure high levels of the quality of care provided to both PWD and their caregivers (WHO and ADI (A c. Di), 2012; WHO, 2017). One way to fulfil such a target entails securing the next generation of professionals with high levels of knowledge and training about dementia since the first level of studies.

The development of new, systematized, and regularly updated study programs would build a new workforce comprehensively prepared to provide psychosocial care for dementia (Beard et al., 2016). Moreover, it would contribute to the development of a new culture in dementia care. Such a workforce would be capable of speaking a common language to implement international and national dementia plans and much more detailed and valuable guidelines. Again, by sharing the same view, the new workforce would foster further the translation of what research indicates as truly useful in both still-to-be-trained and already-trained professionals.

## Informed consent

Due to the anonymous data collection, formal consent was not required for this study.

## CRediT authorship contribution statement

All the authors contributed on the study design, supervised the data collection and participated in paper finalization. GO drafted the manuscript, was responsible for data analysis and for coordinating the part of the SiDeCar Project whose outputs underpinned the present paper.

## Declaration of competing interest

No authors have conflicts of interest that are directly relevant to the content of this article.

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- Ottoboni G.** (Orcid Number 0000-0002-7649-6642) is a PhD, licensed psychologist and psychotherapist working at University of Bologna. Research interests regard dementia, evidence-based treatments of support, psychosocial care in dementia, processes of translational in education. Currently, he is co-coordinating an Erasmus + project (SIDE CAR) to develop Higher Education curricula on psychosocial care in dementia and is a member of the INTERDEM Network.
- Chirico I.** (Orcid Number 0000-0001-9799-0204) is a PhD, licensed psychologist and psychotherapist who works as a Post-Doctoral research fellow at the Department of Psychology, University of Bologna. She is involved in European and national projects dealing with psychosocial care in dementia, role of caregiving, young-onset dementia and the effectiveness of family therapy.
- Povolná P.** (Orcid Number 0000-0002-2786-0911) is the Head of the Paramedical Department Institute for postgraduate Medical Education, Assistant Professor at the Charles University - Faculty of humanities, Department of Management and Supervision in Health and Social Care and nurse in cardiology out-patient department. She lectures topics on health and social care area, organizes seminars and conferences, and submits educational programs to Ministry of health for accreditation.
- Dostálová V.** (Orcid number 0000-0002-6158-1334) is a Ph.D. student of Longevity studies at the Charles University in Prague, Faculty of Humanities. She graduated of the Department of Management and Supervision in Social and Health Care Organizations at the Charles University in Prague, Faculty of Humanities. University teacher at the Institute for postgraduate medical education.
- Holmerová I.** (Orcid number 0000-0003-2375-4174), MD, PhD (in social gerontology) is Associate Professor of Social anthropology Charles University Prague. She is founding director of the Centre of Gerontology, founder of Czech Alzheimer Society, and leads the Centre of Expertise in Longevity and Long-term Care, and the PhD programme Longevity Studies, Faculty of Humanities Charles University. She is also Chair of Alzheimer Europe and is a member of the board of INTERDEM and EUGMS. Her research activity spans among longevity, long-term care and dementia.
- Janssen N.** has a bachelor in Applied Psychology and holds a (research) master in health sciences, with a specialization in Health Technology Assessment. His PhD thesis focused on care needs, care use and access to care in people with dementia and early cognitive disorders. He currently works as a post-doctoral researcher and interim training manager at the Alzheimer Centre Limburg, University of Maastricht, The Netherlands.
- Dassen F.** (Orcid number 0000-0002-9590-252X) currently works as Training Manager for INTERDEM Academy and DISTINCT, two innovative training networks for early career researchers in psychosocial dementia research. She is based at the Alzheimer Centre Limburg, University of Maastricht. Her PhD thesis focused on the role of executive functioning in eating behavior.
- de Vugt M.** (Orcid number 0000-0002-2113-4134) is a professor of Psychosocial Innovations in dementia. Trained as a neuropsychologist, she works as a clinical researcher and as a clinician in the memory clinic of the Maastricht University Medical Center+ (MUMC+). She is co-director of the Alzheimer Center Limburg and board member of the European network on research into early detection and timely intervention in dementia (INTERDEM).
- Sánchez-Gómez Ma. C.** (Orcid number 0000-0003-4726-7143) is the Head of Department Didactics, Organization and Research Methods of the University of Salamanca. Professor of research method. Her research work is grounded in the Social Sciences and Health. She has more than 70 international publications indexed in ISI-JCR and SCOPUS, 10 books and 39 book chapters.
- García-Peñalvo F.** (Orcid number 0000-0001-9987-5584) is currently Full Professor, Coordinator of the Doctoral Program in Education in the Knowledge Society and Head of the Research Group in Interaction and e-Learning at University of Salamanca. His main research interests focus on eLearning, computers and education and digital ecosystems. He is the Editor in Chief of the Education in the Knowledge Society journal and the Journal of Information Technology Research.
- Franco-Martin M. A.** (Orcid number 0000-0002-3639-2523) is Head of Psychiatric Department and Mental Health, University Rio Hortega Hospital (Valladolid) and Zamora Hospital; he coordinates the Strategic Alliance of Mental health in the Health areas of Zamora and Valladolid-West; he is member of the Academia de Medicina de Salamanca (Academic) and Director of the Research Psychosciences group of the IBSALHealth Research Institute certificated by Charles III National Institute. He is also President of the Spanish Psychogeriatrics association and member of the board of European Association of Geriatric Psychiatry and INTERDEM Network.
- Chattat R.** (Orcid N. 0000-0002-3889-2839) (MD; PhD) is Associate Professor of Clinical Psychology at the University of Bologna, Italy. His main research and teaching topics are about psychosocial care in dementia and post-diagnostic support. He was involved in several national and European studies on the implementation of psychosocial interventions for people with dementia and their formal and informal caregivers. He contributed to the development of the regional and national dementia plan and is actively involved with local and national Alzheimer association in promoting inclusion and reducing stigma in dementia. He currently coordinates an Erasmus + project (SIDE CAR) to develop Higher Education curricula on psychosocial care in dementia and is collaborator on a JPND project on social health.