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Psychosocial care in dementia in European Higher Education: evidence from the SiDeCar (“Skills in DEmentia Care”) project

Ottoboni G.¹, Chirico I.¹, Povolná P.^{2,3}, Dostálová V.^{2,3}, Holmerová I.,^{3,2} Janssen N.⁴, Dassen F.⁴, de Vugt M.⁴, Sánchez-Gómez, M^a.C.⁵, García-Peñalvo F.⁵, Franco-Martin, M. A.⁵, Chattat. R.¹

¹Department of Psychology, University of Bologna, Bologna Italy;

²Charles University, Faculty of Humanities;

³Institute for Postgraduate Medical Education;

⁴Department of Psychiatry and Neuropsychology, School for Mental Health and Neuroscience, Alzheimer Center Limburg, Maastricht University Medical Center, Maastricht, The Netherlands;

⁵University of Salamanca, Salamanca, Spain

Orcid numbers and emails

Ottoboni G.	0000-0002-7649-6642	giovanni.ottoboni@gmail.com
Chirico I.	0000-0001-9799-0204	ilaria.chirico2@unibo.it
Povolná P.	0000-0002-2786-0911	povolna@ipvz.cz
Dostálová V.	0000-0002-6158-1334	vladka.dostalova@seznam.cz
Holmerová I.	0000-0003-2375-4174	iva.holmerova@gerontocentrum.cz
Janssen N.		niels.janssen@maastrichtuniversity.nl
Dassen F.	0000-0002-9590-252X	f.dassen@maastrichtuniversity.nl
de Vugt M.	0000-0002-2113-4134	m.devugt@maastrichtuniversity.nl
Sánchez-Gómez, M ^a .C.	0000-0003-4726-7143	mcsago@usal.es
García-Peñalvo F. J.	0000-0001-9987-5584	fgarcia@usal.es
Franco-Martin, M. A.	0000-0002-3639-2523	mfm@intras.es
Chattat. R.	0000-0002-3889-2839	rabih.chattat@unibo.it

Corresponding author:

Please address any communication to

Giovanni Ottoboni, PhD,

Interdepartmental Cancer Research Centre "Giorgio Prodi",

Policlinico S.Orsola-Malpighi, Padiglione 13, V piano,

Via Massarenti, 11

40138 - Bologna

giovanni.ottoboni@gmail.com

Description of authors' roles:

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.

Conflict of interest declaration

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

Compliance with ethical standards

Informed consent

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

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Short-Bio

Giovanni Ottoboni (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 (SIDECAR) 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, M.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. J. (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 of Medicine of 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 (SIDECAR) to develop Higher Education curricula on psychosocial care in dementia and is collaborator on a JPND project on social health.

Psychosocial care in dementia in European Higher Education: evidence from the SiDECAR ("Skills in DEmentia Care") project

Abstract

In dementia care, psychosocial interventions can increase people's quality of life with dementia and their caregivers. Despite their effectiveness, however, 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's 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.

Keywords: Caregivers, Universities, Global Health, UNESCO, Translations, Surveys and Questionnaires, Health Services, Dementia

Running title: Higher Education on psychosocial care in dementia

1 Introduction

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

9 The legacy of these provisions implores stakeholders to reflect and act quickly to
10 identify the most beneficial series of actions capable of tackling the problem.
11 Although no effective cure exists yet, several psychosocial interventions aimed at
12 maintaining or preserving personhood, improving wellbeing and interpersonal
13 relationships, everyday functional abilities, and cognitive capabilities exist
14 (Dickinson et al., 2017; McDermott et al., 2019; Olazarán et al., 2010; Moniz-Cook
15 & Manthorpe, 2009; Moniz-Cook et al., 2011). By taking into account the needs,
16 preferences, and abilities featuring both people with dementia, their family, and the
17 social context (Moniz-Cook et al., 2011), such interventions effectively improve the
18 quality of life of all the persons involved in the process of care (Cooke *et al.*, 2001;
19 Herholz, Herholz and Herholz, 2013; Eggermont and Scherder, 2006; O'Connor *et*
20 *al.*, 2009b, 2009a; Olazarán *et al.*, 2010; Moniz-Cook *et al.*, 2011; McDermott *et al.*,
21 2019; Pusey and Richards, 2001).

22 Unfortunately, despite the reported efficacy, psychosocial cares are often offered
23 to people with dementia (PWD) in a sub-optimal way. Some authors discussed the
24 problem as originating from services' organizational structures (Cheston, 2000;
25 Gevers, 2006; Hinton *et al.*, 2007; Cadieux, Garcia and Patrick, 2013); other
26 authors, instead, argue that the education patch needs to be improved (Downs *et*
27 *al.*, 2009; Draper *et al.*, 2009) as it impacts on workers' skills and attitudes (Gonczi,
28 2013; Van Der Roest *et al.*, 2007; Cadieux, Garcia and Patrick, 2013; Krolak-
29 Salmon *et al.*, 2017). On the other hand, even the guidelines defining care
30 standards, education programs, and competency frameworks lack critical features
31 that a proper education may transfer (Traynor, Inoue, & Crookes, 2011). Moreover,

32 at the content level, the competencies appeared heterogeneous and not eligible to
33 prepare professionals to face the complexity of dementia care (Traynor, Inoue, &
34 Crookes, 2011). Similar scenarios emerge in other reports (Downs et al., 2009;
35 Murphy, 2017; Pulsford, Hope, & Thompson, 2007). In the UK, Pulsford and
36 colleagues (2007) found that the topics concerning dementia were usually taught
37 indirectly, incorporated within broader teaching content, encapsulated in short
38 modules, or delivered through seminars. Moreover, care contents emerged to be
39 delivered flexibly through work-based learning programs or left elective. Pulsford
40 and colleagues (2007) concluded by reporting that most of the trainings UK
41 professionals received were CPD courses (Continuous Professional Development).
42 At that time, the number of diplomas and the degree level courses addressing
43 dementia care were scarce. Ten years later, the number of teaching courses
44 increases, but it was still sub-optimal (Murphy, 2017).

45 Aim

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

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

57 Methods

58 To understand how teaching activities on psychosocial care in dementia populated
59 EU study programs, we collected and ascertained quantitative and qualitative data.
60 The data derived both from experts in dementia and manual searches authors
61 performed on the Internet. Once we collected the data, we implemented internal

62 comparisons to overview the European state of teaching psychosocial care
63 activities in dementia.

64 Ethical aspects

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

68 Design

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

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

79 Furthermore, the survey structure assisted the authors' manual searches on the
80 universities' websites hosted in each SiDeCar project partners' countries (i.e., Italy,
81 Czech Republic, The Netherlands, and Spain), plus Ireland and the United
82 Kingdom¹. The webpages we read by the project partners in each country by
83 seeking clues about psychosocial care in dementia, concerning study programs on
84 medicine, nursing, physiotherapy, occupational therapy, psychology, motor
85 sciences, and social sciences (sociology included). The search involved analysing
86 each teaching activity title; synopsis and the syllabus, in case provided, were used
87 to check for consistency. The information gathered during this part of the
88 investigation aimed at increasing the number of data provided by the experts. The
89 data collection process lasted between November 2018 and July 2019.

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

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

111 Moreover, participants had to indicate whether the activity was mandatory or
112 elective and delivered traditionally or blended (i.e., mix between online and in-
113 person teachings). Besides, they should tell the number of hours and credits
114 characterizing the teaching activity and the number of attending students. Finally,
115 participants could report the person in charge to be publically contacted and the
116 related website.

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

121 Data analysis

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

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

135 For what concerned the qualitative analysis, a summative content analysis was
136 conducted, in which teaching activities' titles were analysed to extract the
137 underlying context (Hsieh and Shannon, 2005). The teaching activities were

138 processed if their title included at least one of the following terms: psychosocial
139 care, dementia. The analysis involved the title primarily; synopsis and syllabus
140 supported consistency check, in case provided. For the qualitative research, we did
141 not sort the data according to either data entries or features.

142 Results

143 Quantitative data

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

146 Most teaching activities were framed within the Second cycle of post-graduate
147 programs (62%), while less derived from First cycle teaching activities (16.5%). In
148 the remaining 21.5% entries, there was no cycle indication. Once we sorted the
149 data according to the entry, the data appeared to spread more among the cycles
150 when they were collected manually (See Table 2; manual entries, $p < .001$; experts,
151 $p > .5$).

152

153 ----- Insert Table 2 about here -----

154 ----- Insert Table 3 about here -----

155

156 Many of the teaching activities were courses (58.1%; modules = 31.4%; topics =
157 9.6%). As before, even in this analysis, the data distribution appeared to
158 differentiate more within the manual entries than within the experts' ones (Table 2;
159 manual entries, $p < .001$; experts, $p > .1$). When the data were sorted according to
160 the study cycle (Table 3), courses and modules belonging to First cycle study
161 programs were similar ($p > .1$), and both much higher than topics ($p < .001$). In the
162 Second cycle, the number of courses was the highest ($p < .001$).

163 Besides, the activities were mostly required (58.4%, elective = 16.5%, NA =
164 25.1%), and the variability was driven by the data manually entered (Table 2.
165 Manual entries, $p < .001$; experts, $p > .1$). Once we sorted the data according to the

166 cycle of studies, the required activities overcome the elective ones in both of them
167 ($P_s < .005$).

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

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

178 Finally, the geographical data distribution was very different (Table 4; $K = -.14$, p
179 $= .03$), and this emerged even when the distribution was analysed per data entry
180 (Manual entries, $p < .001$; experts, $p < .001$).

181 ----- Insert Table 4 about here -----

182 Qualitative data

183 The data showed that only one teaching activity explicitly mentioned
184 psychosocial care in dementia in its title. This activity was the UK Second cycle
185 course entitled "Psychosocial approaches to care and treatment of people with
186 dementia". Moreover, another UK Second cycle course referred to psychosocial
187 care in dementia, and its title was "Dementia in health and social care". Besides
188 these two instances, other thirty-six teaching activities embedded the terms
189 "dementia care" in their titles: 86.4% represented Second cycle activities (5.4%
190 First cycle courses, $NA = 8.2$); 29 were courses, 7 modules, but no spare topics.
191 Further analysis indicated that 27.7% of the teaching activities focused on practical
192 perspectives: in particular, three titles included the term "planning", thirty-seven of
193 them embedded the term "interventions", twenty-four titles displayed the word
194 "therapy", nine of them had "approach" in the title, while seventeen titles reported
195 the term "rehabilitation", and three titles, the word "practicum". On the contrary,

196 3.0% of the data suggested that teaching activities focused on theoretical
197 perspectives: one teaching title reported the term "theories", three titles embedded
198 the word "perspective", three others displayed the word "ethic", and two of them the
199 word "society".

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

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

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

215 Discussion

216 Aimed at understanding the extent to which teaching activities on psychosocial
217 care in dementia resides within the European HE systems, we ascertain European
218 experts in dementia and searched European universities websites. Results from
219 both approaches were aggregated because of the low response rate of experts.
220 Results showed that teaching activities on psychosocial care in dementia mainly
221 were delivered in courses situated within study programs; a smaller amount
222 appertained to modules, and very few were spare topics provided within courses or
223 modules. This pattern emerged more in teaching activities that belonged to the
224 Second cycle of study programs than in the ones included in the First cycle. The

225 same difference emerged when we sorted the activities per the required/elective
226 feature and the traditional/blended one.

227 Most of the activities within the courses belonging to the Second cycle of study
228 programs entails further that psychosocial care in dementia represents a complex
229 topic that necessitates the students to achieve propaedeutic knowledge. Indeed,
230 psychosocial interventions are those physical, cognitive, or social activities aimed at
231 minimizing the risk of future disability while maintaining- or improving interpersonal
232 relationships, functioning, and wellbeing in both people with dementia and their
233 carers (McDermott et al., 2019; Moniz- Cook, Vernooij-Dassen, Woods, Orrell, &
234 INTERDEM Network, 2011). By focusing on people's experience and history,
235 personal needs, preferences and abilities, as well as on the social context, they
236 work to reduce the *malignant social psychology* (Kitwood & Kitwood, 1997; Moniz-
237 Cook & Manthorpe, 2009; Moniz- Cook, Vernooij-Dassen, Woods, Orrell, &
238 INTERDEM Network, 2011). Such a perspective interests all the people involved in
239 the disease since the delivery of the diagnosis, i.e., patients, formal and informal
240 caregivers, the propaedeutic teachings psychosocial knowledge necessitates in the
241 EU HE systems indicate the students how complex is the context where dementia
242 insists. Simultaneously, the fact that the contents of psychosocial care in dementia
243 are delivered in required activities more frequently than in elective one endorses
244 that the teaching contents are critical in the study program. Moreover, the traditional
245 teaching method, i.e., the frontal/ in presence one, apart from being the most
246 frequent academic method, provides the opportunity to stress the importance of the
247 relationship in psychosocial care. During such teachings, students and lecturers
248 interact and may ascertain the social experiences at the basis of this form of care.
249 The data's geographical distribution shows a situation very similar to the one
250 featuring the national dementia plans (Chirico et al., 2021). In both cases, only
251 some countries have consistent dementia-related policies (Hvalič-Touzery *et al.*,
252 2018). Finally, concerning the study effort, the data we yielded appear to reflect EU
253 indications. Typically, the study effort is quantified using a Bologna processes tool:
254 the ECTS. The system originated to make any study programs very transparent
255 and transferrable across Europe. Usually, 60 ECTS relate to teaching activities that

256 require a full-time learning year, spanning between 1,500 and 1,800 hours of study.
257 The credits can be allocated to the different activities, all inherent to achieving the
258 defined learning target. The activities range from educational components, i.e., self-
259 contained and formally structured learning experiences, to dissertations, work-
260 learning activities, and reach work placements (European Commission, 2019).

261 Our results show that the knowledge about psychosocial care in dementia is
262 taught by considering both practical and theoretical perspectives. Teaching
263 activities that prepare students to plan interventions, organize sessions of
264 rehabilitation, or tackle practical issues are delivered alongside activities that focus
265 students on thinking about dementia as a status affecting their entire lives.
266 Psychosocial care is characterised by the theoretical shift both putting the person at
267 the centre of the care and leaving the disease on the background (Kitwood, 2007;
268 Beer *et al.*, 2009; Moniz-Cook *et al.*, 2008, 2011; Huber *et al.*, 2011; Vasse *et al.*,
269 2012). In this light, the intense intersubjective interactions featuring the approach
270 requires a solid ability to handle both the practical and the theoretical aspects that
271 feature such a complexity. A relative number of teaching activities appeared to
272 address students' attention towards the person with dementia and her/his
273 caregivers, although not specifying further information. Caregiving is a crucial
274 aspect in dementia contexts. As pointed out elsewhere (Gérain & Zech, 2019;
275 Ottoboni *et al.*, 2019;), the way caregivers experience their tasks is fundamental to
276 modulate PWD's quality of life, as well as it can exert a detrimental effect on
277 caregivers' health itself (Vitaliano, Zhang & Scanlan, 2003).

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

285 Moreover, such heterogeneity, together with the fact that most of the activities
286 are courses belonging to the Second cycle of studies, and required, indicates that

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

298 At the same time, however, HE institutions should start discussing whether
299 psychosocial care in dementia may become a proper, separated discipline or
300 embedded into each academic course, preparing the future health and welfare
301 workforces. Indeed, the state of the art that we analyzed demonstrate that EU
302 countries fully respect the indications of the ISCED. Specifically, the agency
303 indicates neither dementia or psychosocial care can be included within the scientific
304 fields composing the international educational system (ISCED, 2014; UNESCO,
305 2015). Among the enclosed fields, Social Science, Health and Welfare are the ones
306 featured within psychosocial care contents. In particular, ISCED sorts the general
307 care for older people between the medical and the welfare domain. Within the
308 former, ISCED focuses on maintaining and caring for patients' health during illness
309 and rehabilitation; within the latter, ISCED indicates to deliver psychosocial care
310 both to older adults and people with disabilities.

311 However, within the Second cycle of studies, masters of various natures are
312 hosted: ISCE includes masters offered to full-time students alongside masters for
313 working professionals and study programs that do not provide accreditations to
314 spend in the labour market (UNESCO, 2012; 2015). As observed elsewhere
315 (Pulsford, Hope and Thompson, 2007; Downs *et al.*, 2009; Murphy, 2017; Hvalič-
316 Touzery *et al.*, 2018), skills on dementia care are very often provided in courses
317 that organized outside the universities, i.e., CPD learning programs, once people

318 already got a degree (Hvalič-Touzery *et al.*, 2018). Such heterogeneity can
319 confound students, academic officers, professionals and their agencies, the world
320 of work, and the general audience. It is time to reflect on this and update the ISCED
321 taxonomy to match HE and the labour market.

322 **Strength and limitations**

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

327 **Conclusion**

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

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

342

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Table 1: The table summarizes the three cycles of study programs as they are clustered in the Bologna process.

- 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.

	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	.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 2: The table represents the data sorted by entry (*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)

Table 3: The table represents the data sorted by cycle (*act.* stays for activities).

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

Table 4. The table indicates the distribution of responders per Nation per data entry.