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# Needs-appropriate services for people with young onset dementia: the perspectives of healthcare professionals

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## **Abstract:**

Young Onset Dementia (YOD) has become a growing challenge in national healthcare systems. Concerns about the situation have already been expressed, however, they mostly report the views of services end-users. Aimed at finding out useful further improvement, interviews reporting the working experiences of professionals addressing healthcare services to people with YOD were analysed qualitatively.

The interviews resulted in four themes and twelve categories. The themes regarded services' complexity and responsiveness, the levels of education and knowledge on YOD, the impact that serving people with YOD reflects on staff working experience and quality of life, and a series of proposals aimed at improving services by giving people with YOD and families the provision of care they deserve.

Although the some of the themes recapped the ones reported in the previous literature, the mixture of internally and externally driven instances represented in the themes depict the complexity featuring the processes of care delivering in the services. Findings are discussed in the light of a pragmatial framework capable to suggest what changes services should implement to be timely responsive.

**Key words:** Young Onset Dementia; Health services; Responsiveness; Education; Personal support; Psychosocial care

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41 **Introduction**

42 Young Onset Dementia (YOD) accounts for all dementia subtypes with symptom onset before  
43 65 (Draper & Withall, 2016). The differential diagnosis of YOD presents significant challenges  
44 due to the broad variation in aetiology compared to dementia with late-onset. Around 30% of  
45 YOD cases are associated with a rare underlying cause, such as movement disorders and  
46 Huntington's disease. In contrast, common neurodegenerative diseases present a different  
47 pattern, with a lower prevalence of Alzheimer's disease and higher prevalence of other  
48 subtypes, such as frontotemporal dementia, which is the second most typical form in YOD  
49 (Carter, Oyeboode, & Koopmans, 2018; Royal College of Psychiatrist, 2018; Vieira et al., 2013).  
50 Estimates on prevalence rates vary across countries and indicate that YOD may account for  
51 5% of all dementia cases in the UK (Prince et al., 2014), while incidence rates range between  
52 0% and 7% (Vieira et al., 2013) with an observed increase of 200% between 2013 and 2017 in  
53 the US (BlueCross BlueShield, 2020). Nevertheless, these estimates may not provide an  
54 accurate depiction, as considerable delays in receiving a YOD diagnosis have been consistently  
55 reported (Carter et al., 2018; Van Vliet et al., 2013). The lack of consistent epidemiological data  
56 poses significant obstacles in providing clear recommendations on structural and organisational  
57 service design and delivery for health and social care services, which currently do not meet the  
58 needs of people with YOD and their families as they are primarily directed towards older people  
59 (Cations et al., 2017; Millenaar et al., 2016).

60 Many factors hinder both a timely YOD diagnosis and post-diagnostic care access (Beattie,  
61 Daker-White, Gilliard, & Means, 2002). People with YOD might experience symptoms that differ  
62 from typical memory loss observed in Alzheimer's disease, such as changes in behaviour and  
63 mood, speech disorders or decision-making difficulties (Woolley, Khan, Murthy, Miller, &  
64 Rankin, 2011). Furthermore, health care practitioners may not be aware that dementia can  
65 occur at a younger age, which often results in misdirected referrals and misdiagnosis for  
66 depression, stress, menopause or other conditions linked to changes in personal life, such as  
67 loss of employment or relationship breakdown (Bakker et al., 2013; Mendez, 2006). Arguably,  
68 misdiagnoses resulting from insufficient or inadequate investigation of symptoms may be  
69 preventable via the education and specialist training of care physicians, general practitioners  
70 and dementia specialists involved in primary and secondary care. Enabling a timely diagnosis  
71 could not only protect people with YOD from experiencing long periods of confusion without

72 understanding the underlying cause (van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010).  
73 Still, it could further prevent unnecessary service costs and precipitate post-diagnostic care  
74 access (Carter et al., 2018).

75 Several studies have also shown that people with YOD have different needs from older people  
76 with dementia (Beattie et al., 2002; Cox & Keady, 1998, 1998; Millenaar et al., 2016), as the  
77 former need to remain physically active, maintain employment, provide care for young children,  
78 and address outstanding financial obligations (Mayrhofer, Mathie, McKeown, Bunn, &  
79 Goodman, 2018; Chirico, Ottoboni, Valente, & Chattat, In press). In contrast, older people's  
80 services tend to include less physically demanding or psycho-social activities, such as historical  
81 events recall, which may not be relevant for younger people. Recent large-scale studies have  
82 provided evidence that people with YOD value post-diagnostic services which provide age-  
83 appropriate support, including advice and information specific to YOD (Stamou et al. 2020).  
84 They also value services offering interventions that promote an active physical and social  
85 lifestyle, address diagnosis-specific mental health concerns, and provide opportunities to  
86 maintain independence by having a voice and retaining financial security and physical safety  
87 (Stamou et al. 2020). Enabling the provision of age- and needs-appropriate support has been  
88 highlighted as a critical element to facilitate the transition of people with YOD and their families  
89 to living with the diagnosis (Pipon-Young, Lee, Jones, & Guss, 2012; Westera et al., 2014).

90 Indeed, during the last three decades, the number of studies highlighting the need for YOD-  
91 specific services has been continuously increasing (Beattie et al., 2002; Cox & Keady, 1998;  
92 Livingston, 2020). To date, most of the studies have provided recommendations for age-specific  
93 needs-based services by reporting on the experiences and perspectives of people with YOD  
94 and their caregivers (Mayrhofer et al., 2018; Stamou et al., 2020). In contrast, there is a  
95 significant scarcity of data regarding the views and perspectives of health care professionals  
96 and practitioners on the challenges they experience when delivering services to people with  
97 YOD and caregivers (e.g., Curran, Grimshaw, Hayden, & Campbell, 2011; Spreadbury & Kipps,  
98 2018). Professionals' and practitioners' points of view are integral for service development and  
99 evaluation due to their unique experience and understanding of barriers and facilitators involved  
100 in real-life practice. (Curran et al., 2011). Furthermore, services are delivered by professionals  
101 with varying background, experiences, perceptions, feelings and ways of reasoning, which need  
102 to be considered during service design and remodelling (Naylor, 1995; Pawson et al., 2005),

103 mainly when the work of improvement aims at translating research evidence into practice  
104 (Curran et al., 2011; Thornhill and Conant, 2018), This study aimed to explore service delivery  
105 for YOD through the unique perspectives of professionals, to identify the challenges, barriers  
106 and facilitators involved and provide recommendations for service improvement.

## 107 **Ethics approval**

108 The UNIBO Ethics Committee approved this study in November 2017. All study participants  
109 provided written, informed consent to be interviewed outside working hours.

## 110 **Methods**

111 Consistent with the aim and the nature of the study, a grounded methodology was employed  
112 (Corbin & Strauss, 1990), with particular attention paid to data collection methods, sampling  
113 strategy, categorisation, abstraction, interpretation, and reporting (Elo et al., 2014; Neuendorf,  
114 2017). After coding all the concepts identified in the interviews, these were grouped into  
115 categories and themes, which informed the study recommendations for service improvements.

## 116 **Participants, Recruitment and Data Collection**

117 Study participants were professionals and practitioners who had worked with people with YOD  
118 and their families for at least two years. Participants were recruited from 14 sites in and around  
119 three urban cities of Italy. The sites included health care agencies, welfare agencies, and  
120 Alzheimer's associations (see Table 1). Service managers circulated the study advertising  
121 material via staff mailing lists while the study flyers were also available in the services.  
122 Qualitative interviews took place with participants who were willing to report their experiences  
123 of working with people with YOD and their families in their respective services.

124 Interviews were semi-structured and conducted by two of the study authors (LDR, LA). None of  
125 the participants were acquainted with the interviewers. Each interview lasted between 30 and  
126 60 minutes and comprised open-ended questions (see Appendix), as well as the collection of  
127 socio-demographic data on participants' age, education, occupation, and work experience. After  
128 being fully informed about the study and its aims, all participants signed a consent form.

129 The authors determined the interview questions after a preliminary focus group discussion,  
130 which took place prior to the interview phase with a psychologist, a neurologist, a social worker,  
131 and two health service coordinators who provided services/support for people with YOD. The  
132 focus group aimed to identify specific areas of interest from healthcare professionals'  
133 perspective, which would be further explored during the interview phase. The identified areas  
134 were (i) service organisation and structure and (ii) professionals' involvement.

135 Consistent with the grounded methodological approach, recruitment for the interviews ceased  
136 once no additional themes emerged during the analysis of three consecutive interviews, at  
137 which point it was determined that saturation had been reached (Corbin & Strauss, 1990; Hsieh  
138 & Shannon, 2005; Neuendorf, 2017). This was the only criterion we employed to cease  
139 recruitment. All participants were thanked for their participation and were offered the option to  
140 receive a brief study report upon the end of the study and the opportunity to be contacted for  
141 future research.

## 142 **Data analysis**

143 The study interviews were transcribed verbatim and analysed via content analysis (Corbin &  
144 Strauss, 1990; Hsieh & Shannon, 2005). Four researchers (LDR, LA, RC and GO) read one  
145 interview transcript each time and employed a feed-forward strategy to extract research-related  
146 codes; these constituted the conceptualisations extracted from the data. Following the steps  
147 indicated by Corbin and Strauss (1990), the codes about the same phenomenon were clustered  
148 into categories and then into themes by each researcher. Through the feed-forward strategy,  
149 the development of categories and themes evolved until it was finalised. The consistency of  
150 coding and clustering processes was discussed and reviewed after each interview by four  
151 researchers (LDR, LA, IC and GO). In cases of discrepancy, additional peer input was sought  
152 from the remaining authors until a consensus was reached (Hickey & Kipping, 1996).

## 153 **Results**

### 154 **Socio-demographic information of participants**

155 Thirty-one participants participated in the study (see Table 1); 27 participants were female, and  
156 4 were male. Participants' age ranged from 29 to 74 years ( $M = 47.9$ ,  $SD = 12.5$ ), while average

157 years of education were 19.2 (SD = 3.2). The sample comprised three social-workers, two  
158 nurses, two geriatricians, two neurologists, one psychiatrist, one physician, one music therapist,  
159 one nursing assistant, fourteen psychologists, one service manager and three volunteers,  
160 whose professional experience ranged between 3 and 50 years (M = 18.6, SD = 11.8).  
161 Participants used to work with a mean of 17.5 people with dementia per week (SD = 21.1), of  
162 whom 7.1 were people with YOD (SD = 8.9). Two participants further reported having a relative  
163 living with YOD.

164 ---- Please Insert Table 1 about here -----

### 165 **Qualitative findings**

166 Analysis of qualitative interviews resulted in four recurring themes representing service  
167 functionality: 'Service complexity and responsiveness', 'Knowledge and education on YOD',  
168 'Staff support', and 'Proposals for improvement' (see Table 2). The first theme describes the  
169 level of complexity and responsiveness of services, with a particular focus on how services  
170 responded to the needs of people with YOD. The second theme focuses on the importance of  
171 YOD-related knowledge, mainly regarding the level of professionals' education on YOD and  
172 raising awareness among the public. The third theme focuses on the burden and difficulties  
173 experienced by professionals during service provision. The last theme encompasses the  
174 proposals of professionals on service development to enable the provision of needs-appropriate  
175 support for people with YOD and their families.

176 ---- Please Insert Table 2 about here -----

### 177 **Service complexity and responsiveness**

178 Participants described the challenges associated with the complexity of the health  
179 service system when delivering support to people with YOD. The lack of YOD-specific  
180 services led those living with the condition to generic dementia services designed for older  
181 people, which often resulted in assessments and care delivered by professionals with very  
182 little knowledge of YOD. This appeared to be a significant factor related to a delayed  
183 diagnosis and the lack of age-appropriate post-diagnostic support. Despite this inconsistency,

184 services were described as the essential sites of service receipt and support for people with  
185 YOD and their families.

### 186 ***Time availability***

187 Limited time availability resulting from heavy workloads appeared to be a significant challenge  
188 preventing the development of a meaningful relationship between the professionals and people  
189 with YOD and their families. Participants emphasised the negative impact of limited time slots  
190 and long waiting lists in both diagnosis and care. They questioned the capacity of professionals  
191 to facilitate service recipients' understanding of the condition and their transition to life with the  
192 diagnosis under these conditions:

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193 *On the first visit, you collect the person's history. The problem arises at the*  
194 *control meeting. It must last half an hour. [...] And I must communicate the*  
195 *diagnosis. And we have half an hour. I mean, I have to share the diagnosis. I*  
196 *have to evaluate if the person is alone or if she/he is accompanied by someone*  
197 *else. People have a lot of questions to ask. They are anxious. [...] We have to*  
198 *quickly give a lot of information, as we must respect the number of people we*  
199 *are asked to see according to statutory constraints. Often the family has no*  
200 *time to process what we say.*

---

### 201 ***Network of services***

202 The majority of services are designed to respond to the needs of older people with dementia.  
203 As a result, people with YOD often moved from one service to another and struggled to find  
204 age-appropriate support. The lack of collaborative infrastructures in the service system  
205 appeared to be a critical missing element:

---

206 *The most frequent question that family members of a young person ask me is,*  
207 *"where can I leave my loved one? Which is the service that fits the most with*  
208 *him/her?" [...] A wife told me that she contacted—several services, but she*

209 *couldn't find any. [...] It is not just a demand of assistance, but of an ecosystem*  
210 *capable of responding to their needs.*

---

211 ***Matching constraints, offers and needs***

212 The lack of age-appropriate services further resulted in bureaucratic, time-consuming  
213 challenges. Participants reported the need to modify official documents, such as informed  
214 consent or insurance reports, to make them suitable for younger people.

---

215 *We also had to change many of our formal papers. When we started, there was*  
216 *the reference "aged" person on the documents.*

---

217 In functional terms, matching people of different ages appeared to elicit adverse outcomes and  
218 age-specific challenges. People with YOD struggled to develop or maintain a sense of  
219 connectedness with older people, and such interactions exacerbated the psychological impact  
220 of diagnosis at a younger age.

---

221 *We tried to include a young man in the usual activities, but he stopped turning*  
222 *up. He [...] told us that he liked the other people, but he had a more profound*  
223 *discomfort to accept himself, as so young, catapulted into an age to which he*  
224 *did not belong. He told us that the other participants looked at him and said,*  
225 *"But do we have the same disease? At least it happened to me when I was 80*  
226 *years old, look at how bad you are, poor fellow". There is nothing worse than*  
227 *seeing the sorrow in the other's eyes or words.*

---

228 Services were set up to offer activities for people with dementia to preserve their residual skills  
229 irrespective of their age and functional or cognitive abilities. This resulted in professionals  
230 struggling to meet the expectations and needs of people with YOD:

---

231 *I realise that [...] the cognitive stimulation groups can only work if participants*  
232 *can work together according to their age, the level of cognitive decline and*  
233 *education. [...]. On the other hand, during the moments of confrontation, when*

234 *we can talk about personal issues, difficulties, and differences emerge. [...] The*  
235 *activities must be created ad-hoc because they are young people who have*  
236 *worked until a short time before the diagnosis, so they cannot be involved in*  
237 *usual activities that take place in day centres and care homes with older people,*  
238 *such as manual work or recreational activities.*

---

## 239 **Counselling**

240 Participants reported the need to establish services that support the entire family living with the  
241 condition. They described the challenges they faced in helping family members to understand  
242 and accept the changes brought about by the diagnosis and empowering them to cope with the  
243 declining nature of the condition:

---

244 *[...] a vital need is [to make them feel] that they are loved as much as before*  
245 *even with the disease[...] Family members must work a lot on themselves to*  
246 *accept the condition. This step is the first and the most difficult one. Secondly,*  
247 *they must find the desire to stay with the person who has become different,*  
248 *with whom it is possible to do fun things too".*

---

249 Participants also described the legislative restrictions preventing services from providing  
250 families with the support they needed, such as practical information and financial advice:

---

251 *In my opinion, spouses should also be supported with both practical and*  
252 *economic needs by laws capable of guaranteeing something more besides law*  
253 *number 104<sup>1</sup>: in fact, this law ensures only four hours of spare time per month,*  
254 *which is not enough at all.*

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<sup>1</sup> The Italian Law number 104 of 1992 represents the main framework for all disability issues. As it is well described here: “it guarantees specific rights for people with disabilities and their families, provides assistance, stipulates full integration and the adoption of measures for prevention and functional recovery, and also ensures social, economic and legal protection.” (<https://www.european-agency.org/country-information/italy/legislation-and-policy>)

255 **Respite**

256 Participants reported that, while family members face dementia, they find themselves  
257 constrained between providing care and the time they dedicate themselves. Dementia strongly  
258 affects the entire family system by interrupting people's life trajectory with YOD and the present  
259 and the future of the whole family. In light of the significant challenges elicited by dementia, any  
260 services providing respite become essential as they can promote informal caregivers' well-being  
261 by providing the time and space needed to balance their priorities.

---

262 *"They need to rest. They don't have to be around these people 24 hours a day.*  
263 *They need to be with other people too, because they have to recharge their*  
264 *batteries.*

---

265 Again, participants discussed that when dementia affects young people, they usually hold active  
266 roles within the family and work. Moreover, it is likely that the family is intact and comprises  
267 dependent family members living at home. Hence, many caregivers are spouses, under-aged  
268 sons or daughters, or both. Young carers can count on personal resources that older carers  
269 cannot employ. By relying on them, they ask for less external help while keeping the problems  
270 within the family walls. On the other hand, when they decide to rely on services, they receive  
271 support to alleviate the burden associated with care duties. Unfortunately, however, this is  
272 usually limited-in-time.

---

273 *Often the person is directed to a daycare centre because the caregiver cannot*  
274 *make it.*

---

275 Participants highlighted the contribution of private services, such as home care assistants and  
276 key workers who enable families of people with YOD to find needs-appropriate support:

---

277 *This project [Teniamoci per mano] was born to provide immediate support to*  
278 *the family. It begins with analysing family needs and then attempting to find the*  
279 *most suitable service, either public or private, within the dedicated network.*

---

280 On the other hand, in cases where care is provided by caregivers living with the person  
281 with dementia and/or with the entire family, significant challenges may arise daily.

---

282 *Behavioural problems come from there. Because these caregivers, with a tone*  
283 *of voice that sounds like they want to argue. They trigger behavioural reactions.*  
284 *Because they ... they don't do it on purpose. They say "put your hat on" with*  
285 *their tone of voice ... Which sounds like a command. And the person perceives*  
286 *it this way. "You're ordering me to put my hat on, and I won't wear it, and I'm*  
287 *taking it off".*

---

288 Participants also described the challenges of developing meaningful relationships with service  
289 recipients. The effectiveness of formal caregiving relies on the development of strong  
290 relationships based on shared knowledge and understanding.

---

291 *Briefly, if I wash you, I cook for you, feed you, and keep the house clean. What*  
292 *is the personal relationship based on? By assisting older people with cognitive*  
293 *impairments, you [caregiver] can catch some aspects suggesting that the*  
294 *person itself cannot express if you know their history and habits. But up to what*  
295 *extent can a merely formal caregiver get to know about the person? Almost*  
296 *nothing. It impoverishes the relationship with the person even more actually.*  
297 *Family members know how to interpret needs because they know their people's*  
298 *whole history and habits. In short, it is very different here.*

---

299 Participants also reported voluntary services' contribution as a complementary resource and  
300 how the nature of these enables those offering support to overcome the time restraints  
301 characterising formal services and provide needs-appropriate support.

---

302 *However, I believe that since we are volunteers, we must not set any time*  
303 *limits. Of course, we must give a good service, but in short, we can leave*  
304 *productivity a little aside for a moment. Firstly, it comes to us to listen and to*  
305 *know how to grasp the problem of those in front of us, so I never limit myself to*

306 *the time. [...] someone says, “but lady, it is a long time that you have been with*  
307 *me”. Eh... I see, but I feel good this way. I feel like giving a good service, a*  
308 *service appropriate for the person in front of me.*

---

## 309 **Knowledge and education**

310 YOD's scientific and clinical understating is still in development; YOD began to interest  
311 scholars and professionals relatively recently compared to late-onset dementia. This has  
312 impacted both the number of official written resources and the translation of knowledge into  
313 education and practice.

### 314 ***Guidelines***

315 Participants stressed the lack of guidelines or best practice recommendations which hinders the  
316 development of services capable of offering appropriate care.

---

317 *... it is a problem that does not have a linear [clinical] path at the moment, as*  
318 *we have for other diseases.”*

---

319 Professionals also reported how advances in research and knowledge are not timely translated  
320 into practice to inform the necessary service changes and enable them to meet the age-specific  
321 needs of people with YOD and slow down the progression of the condition:

---

322 *They are young but with a level of cognitive impairment that is no longer*  
323 *adequate for the cognitive stimulation groups, in the sense that it is quite*  
324 *severe. [...] They are people who were diagnosed to have dementia at 60 years*  
325 *old. Still, in only 2 or 3 years, they have such noticeable difficulties that they*  
326 *can no longer fit into any other group that they had attended at an early stage*  
327 *of the disease.*

---

328 **Education**

329 Participants emphasised the need for critical professionals for YOD-specific training and  
330 education, particularly general practitioners who are the first point of contact and often tend to  
331 underestimate YOD symptoms:

---

332 *Surely, GPs are in an ideal position to make an early diagnosis, to act as first*  
333 *sentinels. Still, I don't think they have the tools to make a differential diagnosis*  
334 *between a depressive pathology, a psychiatric one and a problem of this type.*  
335 *I think they struggle a lot. I think they need more specific training on the topic*  
336 *of YOD.*

---

337 **Public awareness**

338 Services are committed to inform the general population about health-related issues. However,  
339 public awareness campaigns on YOD do not seem to be a priority as the primary focus is on  
340 diseases affecting more extensive parts of the population. As a result, the consequences of  
341 YOD remain widely unknown to the public, which can increase social stigma and reinforce  
342 negative attitudes towards people with YOD:

---

343 *I realise that there is a lot of confusion in the community, and fear too. Many*  
344 *people are scared as soon as they hear the term Alzheimer's. Many think that*  
345 *dementia and Alzheimer's are entirely different, they tell me: "Dementia is a*  
346 *normal ageing condition; Alzheimer's is a bad disease" [...] We should create*  
347 *a culture of education, starting with primary and elementary schools, to try to*  
348 *spread a culture of acceptance [...]. Dementia is not infectious. We must not*  
349 *treat them as lepers, they are unfortunate people, but they have intact feelings.*

---

350 **Staff support**

351 Professionals play an active role in the process of care delivery. The way they deliver care  
352 influences service recipients' well-being. In dementia, professionals' well-being seems to be  
353 more negatively affected by care provision to people with YOD than their older counterparts.

354 **Professionals' burden**

355 Formal caregivers appeared to experience a heavy burden that they were not equipped to face;  
356 this, in turn, impacted the quality of the services they provided and their quality of life.

---

357 *In my opinion, the development of support strategies for home care assistants*  
358 *are necessary. Especially when the service is 24/7, the home carer feels really*  
359 *trapped. I see it this way, [...] and with a person who gives you trouble; that's*  
360 *when there are situations of opposing people, it's really a disaster.*

---

361 **Mirroring**

362 Professionals might experience vigorous psychological exchanges while providing care to  
363 people with YOD. This seems to be mediated by a mirroring mechanism through which  
364 professionals may identify themselves in people with YOD due to similarities in age,  
365 background, or family situations. This can lead to increased empathy but also potential anxiety.

---

366 *Surely, as operators, we have a broader understanding of people's difficulties*  
367 *because many of these are spouses, but most of the people we follow have our*  
368 *age. I always think it could happen to me, and it's a matter of luck. It didn't*  
369 *happen.*

---

370 **Proposals for improvement**

371 Service improvement requires professionals and services revising and refining their care  
372 delivery. The development of new or improved age- and needs-appropriate services involves  
373 innovation in redesigning and planning new care strategies.

374 **Non-statutory services**

375 Participants expressed their hope to develop services that can offer activities suitable for people  
376 with YOD and their families. They supported the idea that existing services and non-statutory  
377 ones should collaborate to constitute an integrated, comprehensive care network.

---

378 *I think that museums, art, concerts or even gardening- where one can go and*  
379 *find vegetables- could be beneficial activities. Indeed, indoor activities are*  
380 *usually organised in noisy, crowded places. No matter how the coffee is, to go*  
381 *to the museum, listening to a short concert, or going to eat vegetables from the*  
382 *plants and something else is entirely different.*

---

### 383 **Advance Care Planning**

384 Due to younger age, people with YOD's autonomy level may not be severely affected when they  
385 receive the diagnosis. Nevertheless, participants highlighted the need for services to provide  
386 advance care planning to ensure that people with YOD receive the care they prefer.

---

387 *Think about the possibility of compiling the living will for a person who is still*  
388 *lucid and deciding how he wants his own things to be managed [...] because*  
389 *this is a disease that will take away the ability to choose consciously. [...] But*  
390 *suppose I tell you that you are going to lose your decisional skills, and I give*  
391 *you the possibility to “remain” in control of that, in my opinion. In that case, it is*  
392 *the best way to develop a personal form of adaptation to the disease.*

---

### 393 Discussion

394 The present study aimed to explore service delivery for YOD through professionals' unique  
395 perspectives to identify the challenges, barriers, and facilitators involved and provide  
396 recommendations for service improvement. Analysis of the interviews revealed four significant  
397 themes about the complexity and responsiveness of services, the level of education and  
398 knowledge on YOD, the impact that supporting people with YOD has on practitioners, and a  
399 series of proposals on improving services to offer people with YOD and families the provision  
400 of care they deserve. The themes identified in our study are, to a large extent, consistent with  
401 previous findings (Baptista et al., 2016A; Mayrhofer et al., 2018; Millenaar et al., 2016;  
402 Spreadbury & Kipps, 2018). Our study participants emphasised the need for a more organised  
403 and well-structured network of collaborative services, advocated for YOD-specific education  
404 and training, and provided specific service improvement proposals.

## 405 **Service complexity and responsiveness**

406 As previously reported in the literature (Beattie et al., 2002; Mendez, 2006; Stamou, Fontaine,  
407 Gage, et al., 2020; Van Vliet et al., 2013), one YOD-specific key aspect of service  
408 responsiveness relates to the disclosure of the diagnosis, which appears to be challenging to  
409 deliver in a timely and appropriate manner. People with YOD have previously reported that  
410 timely and open communication around diagnosis can facilitate the transition to life with the  
411 condition (Van Vliet et al., 2013). Our study confirmed that this process necessitates the  
412 availability of time and resources and a well-structured network of collaborative services  
413 (Johannessen, Helvik, Engedal, & Thorsen, 2017; Robinson et al., 2013). Recent studies have  
414 highlighted the crucial role of YOD specialists (O'Malley et al., 2019; Ottoboni et al., Under  
415 Review) and staff with YOD-specific training and education, which need to be higher education  
416 standards to constitute a highly influential factor in the development of appropriate services.

417 An important aspect to consider when evaluating services' responsiveness is that most of them  
418 were initially designed for older people with dementia, who embody stories grounded on  
419 entirely different time frames. For instance, the psycho-social activities offered to people with  
420 YOD should be carefully designed; stimuli such as music, videos and images should be selected  
421 based on relevance, particularly given the fact that it may be hard to maintain control over both  
422 types of memories and the behavioural responses elicited by these stimuli. People with YOD  
423 find it challenging to benefit from group interventions developed for older people, whose  
424 symptoms and activity levels could differ (Aplaon, Belchior, Gélinas, Bier, & Aboujaoudé, 2017).  
425 The mismatch between needs and offer decreases the access of people with YOD and their  
426 families to services (Green & Kleissen, 2013). On the contrary, it should be fostered by planning  
427 activities with people of the same age or cooperation with non-statutory services. Middle age is  
428 firmly located in a social context (Erikson, 1950), and group activities represent a real  
429 opportunity for people with dementia. Social activities decrease the social discontinuity while  
430 facilitating their attempts to cope with the disease by acquiring a new sense of agency (van Vliet  
431 et al., 2017). Simultaneously, though, the needs of people with YOD change rapidly as the  
432 disease progresses. Services should be ready to accommodate such a dynamic transformation.  
433 In this vein, one of the suggestions which emerged in the interviews regarded the activities that  
434 can be organised either together or with non-statutory services (Kinney, Kart, & Reddecliff,  
435 2011). By continuing to participate in activities which require a similar effort to the activities

436 people with YOD are used to, they feel in control of their life (Richardson et al., 2016). People  
437 with YOD can still rely on higher perceptual and motor abilities than their older peers (de  
438 Dieuleveult, Siemonsma, van Erp, & Brouwer, 2017), they are still powerful and active, and this  
439 is the reason why they need to be involved in activities appropriate to their age (Carone,  
440 Tischler, & Dening, 2016; Clarke & Korotchenko, 2011). In general, people with YOD and a  
441 family struggle to cope with their new future: the diagnosis causes people with dementia to  
442 change their representations of themselves and their future; they must reshape self-awareness  
443 while reformulating plans and programs. Indeed, people with YOD are often young spouses in  
444 the middle of their lives: they use to work and look after their old parents or their children, whose  
445 capability to be independent is still insufficient, in most cases. As a consequence of such a  
446 diagnosis and prognosis, sons and daughters are prompted to review their life plans, and  
447 spouses have to re-program many of their habits to adapt to the new situation (van Vliet et al.,  
448 2010; Chirico, Ottoboni, Valente, & Chattat, In press).

449 In talking about the sense of usefulness, it is worth considering that it should be kept high in  
450 informal carers. Carers deserve to receive a specific education about providing assistance in  
451 many aspects of life for people with YOD (van Vliet et al., 2017). Besides learning how to foster  
452 a sense of utility in their beloved ones, informal carers need to be enrolled in psycho-education  
453 activities where they can learn how to cope with the entire trajectory of the disease, what to  
454 expect and when, how to deal with the symptoms and changes, and where and when to start  
455 seeking help (Spreadbury & Kipps, 2018).

456 All the reported shortages project apparent low levels of service appropriateness in the eyes of  
457 people who abruptly must cope with unpredictable difficulties until the diagnosis. However,  
458 when counselling paths are available, people with YOD and their families can take advantage  
459 of such facilities (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Brodaty, Green, &  
460 Koschera, 2003; Richardson et al., 2016). A recent study aimed at exploring the attempts of  
461 children of people with YOD's to cope with dementia-related difficulties indicates that children  
462 with higher levels of empowerment showed higher levels of well-being than the ones recorded  
463 at the disease onset time (Johannessen, Engedal, & Thorsen, 2016a; Chirico, Ottoboni,  
464 Valente, & Chattat, In press). In this light, counselling needs to be focused on resilience and  
465 empowerment by accepting the situation and obtaining psycho-social support.

466 One of the most important functions of many services was respite (Beattie et al., 2002; Stamou  
467 et al., 2020). The chance to accommodate the loved one in convenient services is essential for  
468 many caregivers. The free time such accommodations provide is vital to fulfilling those personal  
469 needs that cannot be satisfied while providing care. Voluntary services can facilitate respite,  
470 too, as the far less demanding time/cost trade-off positively impacts the perceived quality of the  
471 provided service (Johannessen, Engedal, & Thorsen, 2016b; Öhman, Nygård, & Borell, 2001).

472 Another type of service often reported to be very important, regarded the chance to rely on  
473 home care services (Johannessen, Engedal, & Thorsen, 2016b. Having someone taking care  
474 of the person with YOD within the home setting is essential for both the person with YOD and  
475 the carer, as the carer might rely on the patient's context and habits. Notwithstanding these  
476 significant positive impacts, most of the time, to capitalise on home care services, both caregiver  
477 and family have to accommodate each other. If this does not happen, people with YOD might  
478 exert behaviours that can be challenging for the caregivers to interrupt the home care  
479 assistance.

## 480 **Knowledge and education**

481 YOD has begun to attract scholars' and experts attention recently; its knowledge is still in  
482 development, and neither higher education nor European dementia national plans provide  
483 professionals with adequate information on such a complex disease at a younger age (Chirico  
484 et al., In press; Ottoboni et al., Under Review: Hvalič-Touzery et al., 2018). Moreover, apart  
485 from improving YOD-related knowledge, further legislative initiatives to acknowledge the  
486 financial impact of the condition on people with YOD and their families could be beneficial, as  
487 those affected by the disease are in significant need of practical support. Services that provide  
488 legal advice could also be helpful to this end.

489 In Europe, services are often committed to providing information and education to the public  
490 about dementia and its health-related concerns (Chirico et al., In press). In the public sphere,  
491 dementia is equated with Alzheimer's disease, which, in turn, is assumed by the public to cause  
492 memory decline in the elderly (Sikes & Hall, 2018). The effort spent to improve the public's level  
493 of education on this matter can surely increase the general level of well-being. Firstly, higher  
494 education raises the quality of the care outcomes; then it can reduce the stigma surrounding

495 the people living with the disease and promote dementia-friendly communities blooming  
496 (Herrmann et al., 2018; Mukadam & Livingston, 2012).

#### 497 **Staff support**

498 One of the aspects that deserve special attention concerns the impact of working with YOD on  
499 staff's well-being and the care they provide (Miyamoto, Tachimori, & Ito, 2010). As it also  
500 emerged in our interview, professionals and people with YOD are often of the same age. Via a  
501 mirroring mechanism, this similarity can elicit psychological concerns as it increases an  
502 emotional connection that is witnessed during the process of care. The same mirroring  
503 mechanism can also bring about a greater sense of responsibility towards the people and their  
504 families, which, in turn, can exacerbate these psychological issues. In response to this, services  
505 should organise more internal case meetings, where team members exchange professional  
506 opinions, concerns, and ideas for coping. Structured meetings where team attention is directed  
507 towards emotionally driven issues are also worth considering (Reuther et al., 2012).

508 Overall, suppose professionals are not trained to manage the emotional aspects carefully. In  
509 that case, the associated burden will affect their well-being and the quality of the care they  
510 provide. Compassion fatigue, i.e., the deteriorating inability to care well for others and to  
511 maintain a meaningful intimate relationship, is described as being triggered by factors, which  
512 produced both physical and emotional symptoms, in turn (Nolte, Downing, Temane, & Hastings-  
513 Tolsma, 2017). Some of the triggering factors are related to the work environment: limited  
514 opportunity in their professional development (Drury, Craigie, Francis, Aoun, & Hegney, 2014),  
515 staff shortage, and challenging workload can all impact negatively on the workforce. Moreover,  
516 such problems and the lack of support from managers and administrators make the crew feel  
517 alone while facing patients and families' expectations (Austin, Goble, Leier, & Byrne, 2009). In  
518 the same vein, anxiety negatively correlates with the responsiveness of the services to people's  
519 request and with the increasing effort, the complexity of the work environment requires.  
520 However, as our participants declared, the emotional involvement professionals have with the  
521 people they care for can either help them to be emotionally sympathetic and empathetic or  
522 spillover in their life refraining them to escape from their personal and professional issues (Drury  
523 et al., 2014).

524 On the one hand, the level of stress is higher when professionals care for people affected by  
525 incurable disease with a short end (Abendroth & Flannery, 2006), on the other hand, the same  
526 level can be modified in several manners. One of the factors refers to the fortune to rely on  
527 peers and family's supportive help, who can provide support to overcome part of the stress.  
528 However, even incidental debriefs occurring inside the services or activities of support precisely  
529 planned can modify professionals' strategies of coping positively. Similar beneficial effects can  
530 also be exerted by recalling professionals the boundaries inside which they are expected to do  
531 and how (Melvin, 2012). Finally, self-care strategies, as exercise, reflection, self-analysis,  
532 balancing work and personal life and spirituality, are part of the copying strategies identified to  
533 be at the disposal of healthcare professionals (Nolte, Downing, Temane, & Hastings-Tolsma,  
534 2017).

535 In the interviews, volunteers were referenced as being a crucial complementary resource.  
536 Volunteers' impact can be analysed according to very different perspectives. From a social  
537 standpoint, volunteering represents a way to encourage community involvement to improve  
538 social capital. From the health system perspective, they can grant services with levels of quality  
539 that are dissimilar to what professionals do, only when the tasks to accomplish are very complex  
540 (Woldie et al., 2018). From caregivers' perspective, the services provided by the volunteers can  
541 alleviate tension and fatigue and set professionals and family members free to accomplish other  
542 tasks in ways modulated by other factors (Choi, Burr, Mutchler, & Caro, 2007). From a personal  
543 point of view, volunteering is stated to increase volunteers' quality and length of their life  
544 (Jenkinson et al., 2013). Although the long list of beneficial effects, this service's gratuity has  
545 begun recently to be discussed (South, Purcell, Branney, Gamsu, & White, 2014). Volunteering  
546 seems to be underpinned by many implicit and explicit rewards. However, without a structured  
547 reimbursement system, people featured of low incomes cannot afford the cost addressed by  
548 the service commitment. South and al. (2014) highlighted how sessional payment could not  
549 economically support volunteering engagement. On the other hand, people often expect to  
550 receive more professional services in return for economic exchange.

### 551 **Proposals for improvement**

552 In the amelioration of the service, one of the solutions capable of balancing the negative impacts  
553 is the capability to exert control over the working environment (Ajzen, 1985; Grol, Wensing,

554 Hulscher, & Eccles, 2010). In this light, the proposals advanced by our participants represent a  
555 few good examples. To implement health services while respecting their constraints and limits,  
556 one solution may be characterised by the involvement of non-statutory services. For many  
557 economic and structural reasons, services cannot afford many activities. The change to  
558 organise with other non-profit service provider activities as baking, fishing, walking, art or  
559 evening out, among the others, has been proven beneficial in the development of those social  
560 networks so paramount to maintain the sense of dignity and social inclusion (Mayrhofer et al.,  
561 2018).

562 Another exemplar suggests the discussions about end of life that services should facilitate and  
563 organise to occur among people with dementia, family members, medical professionals,  
564 psychologists and social workers (Cheong et al., 2015; Song et al., 2018). Such discussions  
565 are more useful when they are timely delivered. According to the personal and relational  
566 characteristics of the person with YOD and of the family, it might be helpful to start it as early  
567 as after disclosure of the diagnosis (Kumar & Kuriakose, 2013), or even along with the  
568 development of a personalised care pathway (Beauchamps & Childress, 1994).

569 All the aspects discussed here can be grouped according to a pragmatical framework suggested  
570 to represent how health services can be improved independently of their intrinsic nature (Grol,  
571 2010). The framework argues that the actions of improvements entail external and internal  
572 instances at the same time (Grol, 2010). To improve clinical services, any manager or political  
573 stakeholders should consider the level of motivation featuring professionals and workforces and  
574 design plans for its improvement, even via the account of the problems they are used to face.  
575 At the same time, professionals and the workforce must be provided with the most recent  
576 information about the issues they can expect to encounter. Again, the needs and the wishes of  
577 the target population must be considered while analysing the surrounding setting around which  
578 the services is located. Hence, the analysis would facilitate the plan or develop alliances with  
579 supporting networks operating in the surrounds. From the inner side, the instances that must  
580 be valued concern the provision of feedback about professionals and workforces' performance,  
581 together with the weighing of the social interactions underpinning service or the network of  
582 services. In keeping with the internal instances, a general evaluation of the situation and the  
583 proposal for future changes are other key elements. At this level, it is essential to keep on  
584 managing service quality while being focusing on continuous improvement. Finally, it is

585 fundamental to evaluate professional effort in terms of earnings and benefits: in this light,  
586 legislation, budgeting and disciplinary jurisdiction must be known and managed while keeping  
587 these procedures directed towards ameliorating the service status quo (Grol, 1997). The  
588 evidence reported in this work matches more than others depicted in the pragmatic conceptual  
589 framework (Mayrhofer et al., 2018; Stamou et al., 2020), as they are a mixture of internally and  
590 externally driven instances.

### 591 ***Limitations and recommendations for future research***

592 Notwithstanding the data's significance, we prefer to discuss two limitations.

593 In our work, the dispersion featuring both the types of professions and their age, while recalling  
594 some of the limits featuring other studies facing services adequacy (Stamou et al., 2020),  
595 represent issues to consider accurately in the following research. As this study aimed to  
596 increase the spectrum of the knowledge on services adequacy, as soon as it has become  
597 comprehensive enough, the composing concepts could be stratified.

598 The other limit concerns the lack of feedback from a representative pool of interviewed  
599 participants. This part of the data analysis procedure is recommended to increase the data  
600 representativeness (Corbin & Strauss, 1990). However, both the adopted saturation criteria and  
601 the congruency with other independent works tend to decrease the doubt.

602

### 603 ***Conclusion***

604 Although YOD has been increasingly receiving attention during recent years, the focus of most  
605 research studies has been reasonably placed on the needs of people with YOD and their  
606 families. However, in improving services quality, the needs and perspectives of staff members  
607 delivering care to people with YOD must be considered. The current study offers some insights  
608 regarding centralised integrated diagnostic and post-diagnostic services, the promotion of YOD  
609 knowledge and education, either among professionals and the public, and the need for  
610 psychological support for professionals and practitioners involved in delivering care for people  
611 with YOD and their families.

612 **Appendix**

613 **1. Tell me about YOD**

614 a. How would you define it?

615 **2. Tell me about your work (while caring for people with YOD)**

616 a. Talk about how both your service and the territorial ones are organised and  
617 structured

618 b. Talk about the diagnosis (time, place, to whom it is told)

619 c. Talk about the available interventions

620 d. Talk about the people you meet: YOD patients and caregivers

621 e. Which are the expressed needs?

622 **3. Tell me about your personal aspects**

623 a. Do you like your job, or would you like to change it?

624 b. How do the people you care for behave to you?

625 c. Does work atmosphere has an effect on your personal life?

626

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**Table 1.** Summary of participants' socio-demographic characteristics.

		Frequency	Percent
Gender	Female	27	87,1
	Male	4	12,9
Formal education	Higher education degree	10	32,3
	Graduate degree	2	6,5
	Post graduate degree	18	58,1
	Other	1	3,2
Specializations	MD	6	19,4
	Nurses	2	6,5
	Nursing assistant	1	3,2
	Psychologist	14	45,2
	Service manager	1	3,2
	Social workers	3	9,7
	Therapist	1	3,2
	Volunteers	3	9,7
Service contexts	Urban	30	96,8
	Rural	1	3,2
Types of services	Health care agencies	13	41,9
	Alzheimer's associations	12	38,7
	Welfare agencies	6	19,4
N. of years in the service		M = 21,5	SD = 7,7
N. of people met per week		M = 40,1	SD = 36

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927 **Table 2.** Themes and categories as identified by participants.  
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Themes	Categories
I. Service complexity and responsiveness	1. Time availability 2. Network of services 3. Matching constraints, offers and needs 4. Counselling 5. Respite
II. Knowledge and education on YOD	6. Guidelines 7. Education 8. Public awareness
III. Staff support	9. Professionals' burden 10. Mirroring
IV. Proposals for improvement	11. Non-statutory services 12. Advance Care Planning

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