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Family experience of young-onset dementia: the perspectives of spouses and children

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1 **Family experience of young-onset dementia: the perspectives of spouses and children**

2 Running title: Family experience of young-onset dementia

3

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13

14 **Abstract**

15 **Objectives:** Although young-onset dementia (YOD) affects the whole family system, this
16 population is still under-represented in literature, and no progress in care provision has been
17 made. Hence, additional evidence is necessary to understand how family and social
18 relationships are affected by YOD and care challenges, as to provide recommendations for
19 clinical practice and service improvement from a family perspective.

20

21 **Method:** Family carers were recruited via one memory clinic and the local Alzheimer's
22 Associations in Italy. Semi-structured interviews explored their experiences with YOD, the
23 impact of the condition on their lives, family and social relationships, and the support and care
24 they received. Transcripts were coded by three researchers and analysed using inductive
25 thematic analysis.

26

27 **Results:** Thirty-eight interviews were conducted with 26 spouses and 12 adult children. Three
28 themes emerged: 1) Problems around diagnosis, 2) Lack of post-diagnostic support, and 3)
29 Living with YOD as a family. Overall, problems occurred across the dementia pathway.
30 Without appropriate support, it was difficult for families to adjust to living with YOD and to
31 the associated changes in family roles and relationships.

32

33 **Conclusions:** Since optimal care depends on good family relationships, better support for
34 families in the adaptation to condition would likely benefit patient care while ensuring social
35 inclusion and health equity for vulnerable groups.

36

37 **Keywords:** young onset dementia; patients; spouses; adult children; caregivers; family
38 relations; delayed diagnosis; adaptation, psychological; social isolation; delivery of health care

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43

44 **Introduction**

45 Young-onset dementia, commonly known as YOD, affects people's behaviours and cognitive
46 functions under the age of 65 years (Draper & Withall, 2016). Although dementia mainly
47 affects older than younger adults, increasing attention is being devoted to YOD due to the
48 profound impact of the condition on patients and their families (Richardson et al., 2016).

49 The prevalence of YOD is challenging to estimate, as epidemiological studies are scarce,
50 and most of them are registry-based (Millenaar et al., 2016). On their basis, the proportion of
51 YOD varies from 5% to 10% of all dementias (Prince et al., 2014). However, these estimates
52 might be lower than actual since many people do not ask early for help, thus preventing timely
53 access to treatment and care (Carter et al., 2018; van Vliet et al., 2013). Furthermore, making
54 a diagnosis of YOD is not easy since it is more likely to be inherited and has a variety of
55 aetiologies and clinical presentations (Rossor et al., 2010). Indeed, younger people living with
56 dementia are less likely to have memory problems as their first symptoms (Koedam et al.,
57 2010). In the early stages of the condition, neuropsychiatric symptoms (e.g., personality
58 changes, loss of empathy, diminished motivation) are common and can be difficult to recognise
59 (Woolley et al., 2011). Misdirected referrals and misdiagnosis can occur and are associated
60 with a lack of specialist knowledge by healthcare practitioners (Bakker et al., 2013; Mendez,
61 2006). Notwithstanding, the progression of YOD seems to be relatively rapid, thus underlining
62 the importance of earlier diagnosis and intervention (Kuruppu & Matthews, 2013).

63 Once obtained the diagnosis, people living with YOD and their families need specialist
64 counselling and support to adapt to the condition (Millenaar et al., 2016). Indeed, people living

65 with YOD are often working and are physically active, without any other serious or long-term
66 health conditions (Mayrhofer et al., 2018). They can have financial and family responsibilities,
67 such as mortgages, young children, and/or dependent parents to care for (Svanberg et al., 2011).
68 Dementia symptoms can adversely impact all these roles and responsibilities, thus leading to
69 difficulties surrounding employment, changing social roles and family relationships, poor self-
70 esteem, and a reduced sense of purpose in life (Richardson et al., 2016).

71 Family carers, mostly spouses, often provide an intensive level of caring which can last
72 several years, thus leading, in the absence of support, to adverse consequences on their
73 emotional and physical health (Cabote et al., 2015; van Vliet et al., 2010). In accomplishing
74 various daily tasks, such as working, raising children, and managing finances, they may not
75 feel confident and prepared to play the role of carers (Wawrziczny et al., 2018). Furthermore,
76 dementia at a younger age, because of its non-normative nature, impacts the entire family unit,
77 including children and young people who are at risk of lasting psychological distress (Chirico
78 et al., 2021a). Indeed, they can struggle to balance caring tasks and their own needs, thus
79 compromising their development, future planning and success in life (Chirico et al., 2021a).

80 It seems evident that both people living with YOD and their carers experience various
81 psychosocial problems that require specialist support and appropriate treatment and care
82 throughout the entire course of the condition (Stamou et al., 2021a, b). Indeed, due to their
83 age, people living with YOD can prefer less sedentary activities or want more help surrounding
84 the environment. At the same time, carers can need improved access to respite care and
85 psychological support (Giebel et al., 2020, 2021). Despite it, no standard model of care
86 provision exists, and most services are designed for older people and, therefore, are
87 inappropriate for this population's needs (Ottoboni et al., 2021a). In this context, insufficient
88 attention has been paid both by Higher Education and current policies, thus resulting in a lack
89 of specialist knowledge on how to manage the psychosocial consequences of YOD, as well as
90 in a low level of public awareness (Chirico et al., 2021b; Ottoboni et al., 2021a, b).

91 Despite the potential and multiple adverse outcomes of dementia in midlife, this
92 population is still under-represented in literature, and no progress in care provision has been
93 made (Livingston et al., 2020; Roach et al., 2008). Since the impact of YOD on families is
94 enormous, it is crucial to understand how family relationships are affected by YOD in order to
95 provide adequate care and services designed upon both patients and families' needs (Roach et
96 al., 2012). Hence, this study aimed to investigate the experience of dementia in midlife through
97 the perspectives of family members. Findings will inform both researchers and practitioners

98 about the needs of this population by providing recommendations for clinical practice and
99 service improvement from a family perspective.

100

101 **Methods**

102 **Participants and recruitment**

103 Family carers were eligible to take part if they had a relative with a diagnosis of YOD (i.e.,
104 under the age of 65 years) of any type. Participants were recruited via convenience sampling
105 via one memory clinic and the local Alzheimer’s Association of five urban cities in three
106 regions of Italy. At first, professionals and volunteers contacted potential participants directly
107 via telephone or met them in person, thus sharing information about the study and asking
108 whether they wanted to be involved. Once researchers obtained a list of participants, they called
109 them to set up interview details (date, time, interviewer, location).

110 Recruitment ceased once no additional themes emerged during the analysis of three
111 consecutive interviews, at which point it was established that saturation had been reached
112 (Saunders et al., 2018). Participants were thanked for their involvement in the study singularly
113 and offered the options to receive a brief research report and be contacted for future research.

114

115 **Data collection**

116 Ethical approval was obtained from the Ethics Committees of the University of Bologna [Ref:
117 116887], and of the University Hospital Sant’Orsola-Malpighi of Bologna (Italy) [Ref: 18148].
118 Written informed consent, including confidentiality and the participant’s right to withdraw at
119 any time, was obtained before participation in the study.

120 Data were collected between October 2019 and February 2020 through semi-structured
121 interviews which were conducted face-to-face or by telephone with geographically dispersed
122 participants. Interviews were carried out by two of the study authors (IC and EM) who have
123 experience in qualitative data collection. During each interview lasting between 30 and 45
124 minutes, participants were encouraged to describe their experience with YOD, the impact of
125 the condition on their lives, family and social relationships, and the support and care they
126 received. When necessary, the interviewer asked participants to add some details or to clarify
127 their answers. Prior to the interviews, socio-demographic characteristics about participants and
128 their relatives living with YOD (e.g., age, gender, education), as well as information about the
129 condition (e.g., first onset symptoms, time and type of diagnosis) were collected.

130

131 **Data analysis**

132 The audiotapes of all interviews were transcribed verbatim and analysed via inductive thematic
133 analysis (Braun & Clarke, 2006). Data analysis was performed independently by three
134 researchers (IC, RC, GO) experienced in analysing qualitative data. This analysis consisted of
135 firstly gaining familiarity with the transcripts through repeated readings of the interviews. Each
136 researcher individually employed a feed-forward strategy to extract relevant codes representing
137 the main units of content. Codes about the same issue were clustered into subthemes and, then,
138 into themes by each researcher. The clustering process evolved until it was finalised. It was
139 discussed after each interview with the remaining study authors, until a consensus about its
140 consistency was reached and any discrepancies were solved (Hickey & Kipping, 1996).

141

142 **Results**

143 **Background characteristics**

144 Thirty-eight interviews were undertaken. These included 26 spouses and 12 adult children
145 coming from different families. Spouses' ages ranged between 55 and 75 years ($M = 65.1$, SD
146 $= 5.5$), while children were on average $35.5 (\pm 9.4)$ years old (range 21 to 47). Most participants
147 were female (68.4%) and married (78.9%). They finished secondary (44.7%) or middle
148 (26.3%) school, while smaller percentages obtained an academic degree (23.7%) or just
149 completed primary school (5.3%). Most spouses (65.4 %) were retired, while the majority of
150 children were working (83.3%) and living outside the family home (75%).

151 Concerning their relatives living with YOD ($n=38$), their ages ranged between 50 and 76
152 years ($M = 62.03$, $SD = 5.3$), and more than half were male (55.3%). They finished middle
153 (47.4%) or secondary (31.6%) school, while smaller percentages obtained an academic degree
154 (18.4%) or just completed primary school (2.6%). Most of them (81.6%) were retired. The
155 mean time lag between symptom onset and diagnosis was $1.6 (\pm 1.2)$ years (range 6 months to
156 5 years). Diagnoses of YOD were Alzheimer's disease (65.8%) or frontotemporal dementia
157 (23.7%), and the remaining were unknown (10.5%). All people living with YOD were under
158 medication, and 34.2% did not receive any benefits related to their condition. While 71% of
159 them were attended by unpaid family carers only, smaller percentages received home paid care
160 (15.8%), followed day-care centers (7.9%) or lived in a nursing home (5.3%).

161

162 **Qualitative findings**

163 Three themes were identified from the interviews: 1) Problems around diagnosis; 2) Lack of
164 post-diagnostic support; 3) Living with YOD as family. Each theme is described in detail
165 below, with verbatim extracts of participants' responses.

166

167 **Table 1.** List of themes and sub-themes from interviews

Themes	Sub-Themes
1. Problems around diagnosis	Difficulty in pre-diagnostic phase Delayed diagnosis Inappropriate communication Need of counselling
2. Lack of post-diagnostic support	Financial barriers Lack of case management Geographic barriers Care needs
3. Living with YOD as family	Couple relationships Parent-child relationships Social isolation

168

169 **THEME 1: Problems around diagnosis**

170 **Difficulty in pre-diagnostic phase**

171 The pre-diagnostic phase was characterised by changes in mood, personality and behaviours
172 or, sometimes, by increasing memory problems. It was difficult for people living with YOD
173 and family members to seek help with symptoms being ascribed to stress due to issues related
174 to work, ageing and retirement, and life events.

175 *“It took over 1 year before we sought help. He didn’t accept the condition, he still used to drive
176 and ride the bike. <My friends forget things too> he kept saying. I’m not ill, I don’t want to go
177 to the psychiatrist, I’m not crazy” (wife, 69 yrs).*

178 *“We were aware that there was something wrong, but we didn’t want to accept it. Those signs
179 that I initially misinterpreted as due to work overload were instead symptoms of the condition”
180 (husband, 70 yrs).*

181

182 Sometimes, a point of crisis such as economic losses forced participants to ask for a diagnostic
183 consultation.

184 *“We couldn’t understand this condition until we realised we were in an economic crisis
185 because of him” (wife, 68 yrs).*

186

187 **Delayed diagnosis**

188 Participants reported that people living with YOD experienced delays before receiving a
189 correct diagnosis due to having their concerns neglected or being misdiagnosed. General
190 practitioners tended to underestimate symptoms and give misdiagnoses such as depression or
191 stress. Age seemed to be a factor contributing to the missed diagnosis of dementia.

192 *“Our general practitioner has learnt about YOD thanks to me. She’s a doctor, but she was
193 asking me for information about this condition since she had no previous experience with it”*

194 **(wife, 73 yrs).**

195 *“[...] I was crying in front of the doctor <Doctor, what can I do with my husband? He’s
196 worsening day by day and no one can tell what condition it is. Could it be Alzheimer's? There’s
197 another man with Alzheimer’s and his symptoms remind me of my husband>. <Can’t be, your
198 husband’s too young for Alzheimer's, he’s probably just tired> the doctor said - he was 60
199 years old at that time”* **(wife, 69 yrs).**

200

201 Before receiving the correct diagnosis, participants often sought the advice of more than one
202 professional (psychiatrists, neurologists) with additional costs due to private visits and time off
203 from work. At the same time, relatives were increasingly frustrated and worried about their
204 loved one’s health and were uncertain about the future. Furthermore, misdiagnoses often led to
205 inappropriate drug prescriptions.

206 *“Medical visits were a journey of hope”* **(son, 38 yrs).**

207 *“At first, the doctor visited her ensuring me that it was just anxiety or depression. He gave her
208 psychiatric drugs, anxiolytics and antidepressants but, instead of improving, she was
209 worsening”* **(son, 46 yrs).**

210

211 **Inappropriate communication**

212 Many participants reported that the the YOD condition was not named clearly to their relatives,
213 but rather euphemisms and vague words such as memory problems were used. Such a choice
214 aimed to minimise the emotional impact due to receiving a diagnosis of dementia at a younger
215 age.

216 *“She thinks she’s depressed and has some problems with memory and language. That’s what
217 she knows, nothing more”* **(daughter, 21 yrs).**

218 *“We haven’t clearly told him it, we’ve tried to sweeten the deal”* **(wife, 55 yrs).**

219

220 In a few cases, when diagnosis was clearly stated, participants reported that people living with
221 YOD lacked awareness or capacity to remember it.

222 *“He does realise that he has something...but he doesn’t want to know it, or he doesn’t realise,*
223 *or he’s pretending, who never knows” (wife, 58 yrs).*

224 *“He was there when they told us the diagnosis, but he doesn’t remember it” (wife, 72 yrs).*

225

226 **Need of counselling**

227 Receiving the diagnosis came as a shock, and information and guidance by professionals on
228 how to manage this condition were minimal.

229 *“When the diagnosis was told, we didn’t know anything about dementia. We didn’t know what*
230 *it would have implied, how the condition would have developed and how much time it would*
231 *have lasted. It was shocking. I had to learn all by myself, and it wasn’t easy at all. There’s the*
232 *need for someone teaching you how to cope with this condition” (husband, 70 yrs).*

233 *“Practitioners are not informed enough and they don’t have the necessary empathy to manage*
234 *the situation. Information is just the first step, someone should help us with practical*
235 *implications and suggestions. How can we do if he doesn’t take the pills? Such ordinary things*
236 *are the most important ones to deal with this condition in the everyday life” (wife, 62 yrs).*

237

238 Some participants acknowledged that, without any advice, they made wrong choices, thus
239 increasing their psychological distress.

240 *“I had to do all by myself with him and I made many mistakes. I wasn’t prepared for it and no*
241 *one helped me” (wife, 68 yrs).*

242

243 Whether some information was provided by professionals, it seemed quite narrow in scope
244 and, therefore, was combined with other sources of information, such as the Internet or asking
245 people with similar experiences.

246 *“The doctor helped me with a small number of issues related to the condition. I had to study*
247 *on my own even during night-time. Internet is a pot of knowledge nowadays, but you have to*
248 *know how to use it” (husband, 62 yrs).*

249

250 **THEME 2: Lack of post-diagnostic support**

251 **Financial barriers**

252 Participants experienced great frustration accessing financial aids or funding assessments due
253 to a slow and excessive bureaucracy. They had to wait several months and filled out plenty of
254 documents before obtaining the help they needed. These challenges were difficult to reconcile
255 with carers' work and life commitments.

256 *"[...] I'm still waiting for the assessment by social workers...He's 65 years old, so they're*
257 *having trouble comparing him to older people"* (wife, 63 yrs).

258 *"The economic support comes too late. Many families haven't received it yet, even though their*
259 *relative with dementia is already at a moderate stage. The support should come earlier to cope*
260 *with the first condition challenges"* (wife, 73 yrs).

261

262 Financial barriers also occurred when people affected by YOD had to stop working some years
263 before being eligible for an age pension.

264 *"At the time of the diagnosis he was currently working as a teacher, that was the main problem.*
265 *It was hard for him to get retired due to the education policy, so he had to be off sick for a*
266 *couple of years. Finally, after that, they let him retire"* (wife, 70 yrs).

267

268 **Lack of case management**

269 Participants complained about the lack of a 'case manager' aimed to coordinate health and
270 social care services, and to link people with service upon request.

271 *"There is a lack of coordination among services. There is the need of a person helping you*
272 *with every aspect of the condition"* (daughter, 42 yrs).

273

274 Only few participants received the information they needed to identify service resources and
275 facilitation, although it appeared to be due to chance.

276 *"I was really lucky because a neurologist gave me all the information about the available*
277 *services and resources for the condition"* (wife, 62 yrs).

278

279 **Geographic barriers**

280 Participants perceived geographical disparities in the distribution of services across the city.
281 This limited access to services, since many people living with YOD stopped driving, and they
282 relied upon the carer, in the absence of dedicated transports. While some participants
283 experienced extra-burden, others ultimately gave up due to a difficult balance between daily
284 duties and their loved ones' needs.

285 *“We have to consider another service because it’s too far from home. It’s on the other side of*
286 *the city and it’s unrealistic for me to reach it twice a week, considering that we’ve got already*
287 *many visits and everyday issues” (wife, 65 yrs).*

288

289 **Care needs**

290 Participants spoke about the little and expensive help provided by the national health services,
291 which was partially compensated by local associations. These latter offered a range of social
292 activities such as Alzheimer cafés and carer support groups.

293 *“Public services are ridiculous [...] Associations are much better, they compensate for the*
294 *lacking public health system” (son, 38 yrs).*

295 Although associations played an important role in supporting families making them feel
296 socially connected, there appeared to be limitations in the activities provided to younger people
297 living with dementia. Participants mainly complained about the low frequency of activities and
298 the group composition. The latter was largely represented by older people with activities less
299 convenient for younger people or, alternatively, it was quite heterogeneous in terms of age and
300 level of impairment. Furthermore, some participants perceived a sort of gender imbalance in
301 groups, with men being under-represented.

302 *“I’ve tried to bring her in 2 or 3 groups, but she was embarrassed because of the elderly*
303 *participants” (husband, 68 yrs).*

304 *“More time is needed and groups should be homogeneous. My wife cannot write, while the*
305 *other participants can do it. The group includes people in the 50-70 age range and 20 years*
306 *are too much. Someone is 50 years old, there are 2-3 men and now there are almost 8 people*
307 *aged 60 years old” (husband, 66 yrs).*

308 For what concerns the transition to residential care, participants complained about the
309 suitability of facilities and staff unwillingness to accept younger residents as being physically
310 agile yet.

329 *“[...] We looked for appropriate facilities, but most of them were not suitable for him [...]*
330 *Even the manager told us they couldn’t manage someone like him, as he was able to walk yet”*
331 *(daughter, 32 yrs).*

332

333 **THEME 3: Living with YOD as family**

334 **Couple relationships**

335 Since symptom onset, couple relationships seemed to experience several challenges. At the
336 beginning, a lack of understanding of the spouse's personality changes or the delays in
337 receiving the diagnosis put couple relationships under significant pressure. This, sometimes,
338 caused conflicts thus making it harder to get on, as they previously were used to.

339 *"I was angry because he didn't want to take care of himself, our relationship was*
340 *deteriorating... well I wanted to understand that it was the condition, he had nothing against*
341 *me, knowing earlier about the condition would have helped me a lot. I would have managed*
342 *it differently, instead of leaving home temporarily"* (wife, 58 yrs).

343 As the condition progressed, spouses had to assume increasing caring tasks to compensate the
344 multiple losses (autonomy, driving license) experienced by people living with YOD. In doing
345 so, spouses tried to protect their children, while having to learn new skills aimed to accomplish
346 those daily tasks that were previously carried out by people living with YOD. Providing
347 intensive care could even lead to symbiosis and feelings of being emotionally overwhelmed.

348 *"She had to stay with her boyfriend, she had her own life...I'm here for the dad. She couldn't*
349 *sacrifice her life to stay at home with her dad, for what? Washing and dressing her dad?"*
350 (wife, 72 yrs).

351 *"In 2014, when I realised that my husband's orientation was compromised and he couldn't*
352 *drive anymore, what did I do? I was 64-65 years old, I attended the driving school, I said <let's*
353 *see if I can do it>"* (wife, 69 yrs).

354 *"We've become addicted to each other because of this lack of social life, lack of recreation to*
355 *break the routine. The bond between us is like an umbilical cord"* (wife, 70 yrs).

356

357 The challenges of dealing with YOD radically changed the husband-wife roles as they were
358 before this condition. Spouses highlighted that, as symptoms worsened, romantic and intimate
359 relationships changed in favour of care relationships only (nurse-patient, mother-child). This
360 seemed to affect the marital quality and was accompanied by feelings of anticipated grief,
361 loneliness, lack of reciprocity and emotional responsiveness by the person living with YOD,
362 and sexual intimacy. Unlike in the past, participants had to make choices regarding family life
363 without their spouses' support. They also had to give up on their family dreams, plans for the
364 future and live day by day.

365 *"I'm grieved because I don't have a husband anymore. He complains when I touch him. I've*
366 *become his mother, his nurse. He gives me orders, he needs me. I'm there when he needs me,*
367 *when he needs drugs, when he needs everything, but I never receive satisfaction, never a sweet*

368 *gesture. I don't have a husband anymore, your life changes, the person with you is totally*
369 *different than was before, your life is different” (wife, 58 yrs).*

370 *“It's strange...You've been living for years, 40 years, with a person you could talk with, discuss*
371 *with, even argue with but then, out of the blue, you're alone. You suddenly have to choose just*
372 *by yourself, and you don't know if you're making the correct decision” (husband, 70 yrs).*

373

374 Only very few spouses were able to be still engaged in social life, and this allowed them to
375 better manage caring tasks thus preserving their mental health.

376 *“I've started to meet friends again. Actually, I've got my own space away from home, I would*
377 *probably freak out otherwise. My own space lets me survive and I can do things that I enjoy,*
378 *think less about the condition” (wife, 56 yrs).*

379

380 **Parent-child relationships**

381 In the beginning, children struggled to accept the diagnosis, thus experiencing negative
382 emotions such as anger, frustration and family conflicts. Hence, it took some time to re-
383 establish a relationship with their parent or, in extreme cases, they failed to accept the diagnosis.

384 *“At the beginning, my daughter couldn't accept her mother's condition. There was a sort of*
385 *war and she left home. Then, slowly, she came back and now she's growing little by little”*
386 *(husband, 68 yrs).*

387 *“My son doesn't understand it. I mean, yes, he does understand his father's condition, but he*
388 *cannot accept it” (wife, 65 yrs).*

389

390 Children with caring responsibilities found it challenging to cope with the situation, as these
391 tasks were perceived as unexpected in relation to the life cycle stage. In accomplishing duties,
392 they were concerned about their healthy parent and made efforts to alleviate their emotional
393 discomfort. Relationship roles with their parent with YOD were reversed from what they were
394 previously, i.e. children became parents to their parents while communication gradually
395 decreased. Some children acknowledged that they lived in a limbo and even experienced an
396 ‘anticipatory grief’ as their parent’s condition worsened.

397 *“Honestly, I would have never thought to change my father's diaper at 25 years old...I would*
398 *accept it if I was 50-60 years old with my needy elderly parents, as it should usually occur”*
399 *(daughter, 28 yrs).*

400 *“He's not there anymore. He's out of our lives but, actually, he's always there and you always*
401 *think about him” (daughter, 42 yrs).*

402

403 Caring responsibilities strongly impacted children's lives concerning education/career,
404 interpersonal relationships and future life planning.

405 *"All these changes caused trouble in my personal life since my mother lives with me and my*
406 *partner. That brought a lot of problems, and now the relationship with my partner is completely*
407 *compromised. [...] I've lost my friends too. I hope I won't lose my job because I'm always tired*
408 *and nervous at work"* (son, 38 yrs).

409 *"You can't make any long-term plans, you have to live day by day and face the upcoming*
410 *demands. You don't know how it will carry on"* (daughter, 32 yrs).

411 However, some positive aspects seemed to coexist with the adverse outcomes of caring at
412 younger age, such as increased maturity, self-awareness and self-worth.

413 *"I feel stronger now, this experience brought out my determination. I was surprised about*
414 *myself. Despite this bad situation, I feel like my self-esteem has increased, I'm more aware of*
415 *myself now"* (daughter, 34 yrs).

416

417 **Social isolation**

418 Participants faced significant challenges in maintaining close social relationships. Conflicts
419 with family members often occurred due to having different views on how to manage this
420 condition. Simultaneously, most friends gradually disappeared due to the emotional impact of
421 this condition, difficulty in communication, and lack of knowledge on how to relate to a person
422 living with YOD.

423 *"I lost contact with his family. This condition broke our bonds. I've been accused of not caring*
424 *him enough by her sisters"* (wife, 68 yrs).

425 *"My mother suffered a lot because many people disappeared after the diagnosis. They had this*
426 *group of friends since they were 18 years old [...] but they drifted apart little by little*
427 *(daughter, 32 yrs).*

428 *"They don't know how to manage the relationship. It's embarrassing because they sometimes*
429 *ask something and then she answers about something else"* (husband, 62 yrs).

430 *"People that I know well genuinely told me <I'm scared she may not recognise me>. They're*
431 *in good faith, but they don't help us in this way. This increases family burden, our perceived*
432 *isolation, and my mother's complete loneliness"* (son, 38 yrs).

433

434 Participants felt stigmatised by society at large due to the lack of awareness about YOD, its
435 nature and strong impact on families. This could even lead them to avoid social interactions
436 because they felt ashamed of their relatives' behaviours, and were afraid of being bullied or
437 rejected.

438 *"I think that there is a social stigma yet due to lack of information about the condition. It's a*
439 *social problem that exists from a long time. You couldn't even mention oncological diseases*
440 *around 20-30 years ago, it's not that different from the stigma about homosexuality"* (**wife, 55**
441 **yrs**).

442 *"I notice a lack of knowledge, people don't know anything about this condition, how it destroys*
443 *our lives, how it breaks families and friendships. There is no adequate knowledge and support*
444 *for this specific condition, there are no advertisements as for other conditions, it's a bastard*
445 *condition"* (**husband, 64 yrs**).

446 *"It was annoying going outside with him because he acted weirdly and people chattered about*
447 *it. That's what annoyed me the most. I don't know if embarrassment is the correct word to*
448 *describe it [...] I didn't want him to be addressed as a dumb person, that's all"* (**wife, 68 yrs**).

449

450 **Discussion**

451 This study explored the experience of dementia in midlife from diagnosis to post-diagnostic
452 support. It provides evidence on how families touched by YOD face significant challenges to
453 adjust to living with such a long-term condition. Indeed, problems occurred across the course
454 of dementia, from the time required to obtain the diagnosis, to receiving post-diagnostic
455 support. Our results support previous studies (Giebel et al., 2020, 2021; Millenaar et al., 2017;
456 Rossor et al., 2010; van Vliet et al., 2013), suggesting several diagnostic challenges associated
457 with a lack of specialist knowledge by general practitioners and healthcare professionals. A
458 delayed diagnosis does imply that the person and their family don't get the support they need
459 at the right time. Furthermore, we found that the diagnosis was often not clearly told to people
460 living with YOD. This aspect should be carefully considered since there is empirical evidence
461 (Werbrouck et al., 2018) suggesting the need for patients to be told, since the early stages of
462 YOD, all relevant aspects of their condition, including its nature, expected outcomes and
463 available treatments. If such disclosure is made appropriately with sensitivity and tact, it
464 empowers patients to adapt to their situation while avoiding family tension due to a secret being
465 kept (Millenaar et al., 2017).

466 Families felt emotionally neglected from the time of diagnosis throughout the condition.
467 As found in the previous research (Millenaar et al., 2016; Roach et al., 2008, 2012),

468 professionals did not understand the enormous burdens associated with the experience of
469 dementia in midlife. Indeed, it was difficult for families to receive appropriate information and
470 timely support to adapt to the condition. They often faced a lonely journey of multiple and
471 overlapping difficulties. Among them, a lengthy bureaucratic process often hindered families
472 in their efforts to receive support and help, even modest, at the right time. Furthermore, families
473 were proactive in looking for information and support on their own, through the Internet or by
474 having the chance to meet people with similar experiences. However, without any advice, they
475 made some mistakes that increased their psychological distress while reducing the quality of
476 care for patients. In this regard, counselling for carers should be focused on improving their
477 resilience and empowerment as to deal with symptoms and cope with psychosocial problems
478 associated with YOD, while knowing how and where seeking help (Cabote et al., 2015;
479 Millenaar et al., 2017; Pinguart & Sørensen, 2006; Wawrziczny et al., 2018).

480 Even when some support was available, geographic barriers prevented access to care.
481 With previous studies (Bauer et al., 2019; Innes et al., 2011) suggesting that rural residents,
482 due to geographic distance, may be limited or unable to access healthcare services, similar
483 evidence was found even on a smaller scale. Indeed, services were not equally distributed
484 across the city, causing an additional burden on care provision, as patients had to rely on their
485 family members in the absence of dedicated transport. These gaps should be adequately
486 addressed by existing policies to design interventions for patients taking into consideration
487 family needs, thus avoiding that treatment course would cause a greater burden to patients'
488 relatives (Golics et al., 2013).

489 Interestingly, as compared to the little and expensive help provided by the national
490 healthcare system, local Alzheimer's Associations were able to provide support to families and
491 activities for people living with YOD, although with some limitations. As found in previous
492 studies (Cations et al., 2017; Giebel et al., 2020, 2021; Stamou et al., 2021a, b), many
493 participants highlighted the need for their relatives living with YOD to attend activities
494 specifically designed for their age. Indeed, groups composed of older people or mixed groups
495 seemed to create a mismatch in physical abilities and leisure interests. This even led to service
496 users' emotional discomfort and drop-out due to not having received the support they really
497 needed. Therefore, attention should be paid to provide age-appropriate respite care through a
498 careful design of therapeutic group composition, as well as appropriate activities for people
499 living with YOD aimed to strengthen their capacities while enhancing their social connectivity
500 (Aplaon et al., 2017; Green & Kleissen, 2013; Ottoboni et al., 2021a). Our study also
501 highlighted the need of accommodating residential facilities to younger residents as to increase

502 the chance of access. At this regard, the national health system should guarantee the continuity
503 of high-quality care in those situations where families cannot provide any support (Bakker et
504 al., 2013).

505 This study provides evidence on how YOD affects family and social relationships. As
506 increasing evidence points out (Golics et al., 2013), family members can be seriously
507 emotionally affected by this condition, even more than patients themselves. In our study,
508 family relationships were significantly challenged since the diagnostic period, during which
509 delays in diagnosis increased family conflicts with symptoms being blamed on the patient
510 rather than on dementia. In this regard, it is necessary to provide timely diagnosis and specialist
511 support to families to avoid the early potential worsening of family relationships and to
512 minimise the emotional impact of such a diagnosis (Roach et al., 2012). Indeed, we found that
513 radical changes occurred in spousal relationships throughout dementia. Among them were the
514 person living with YOD's increasing dependence on the spouse and the gradual shift of roles
515 and responsibilities. This led to lower quality of the relationship, increasing social isolation and
516 loneliness, lack of reciprocity and sexual intimacy. In extreme cases, there was risk of
517 symbiosis, which was fostered by social isolation. With lack of support, spouses felt
518 emotionally overwhelmed because of caring tasks and multiple roles associated with their
519 specific life stage. Future family plans were abandoned, and life was mostly restricted to
520 patients' needs with other vital areas of life being sacrificed. Furthermore, sexual activity,
521 which represents a crucial aspect of couple functioning, significantly reduced. Whilst for older
522 people, sexual intimacy often shifts towards other modalities of exchanging affection, for a
523 younger population, sexual activity is still important, with declines likely affecting self-esteem
524 and the emotional health of couples (Holdsworth & McCabe, 2018). Hence, beyond practical
525 needs, counselling should be provided to couples concerning relationships, intimacy, and
526 sexuality to ensure the adaptation of spousal relationships to the profound changes related to
527 YOD.

528 In such a family scenario, we found that children struggled to deal with the diagnosis so
529 much so that they could drift apart from families. This points out the importance of providing
530 tailored support since the early stages of this condition to safeguard the family unit. Over time,
531 children can assume increasing responsibilities as adults in the attempt to help their healthy
532 parents and keep the family together. However, as compared to adult carers, for a younger
533 population caring tasks and developmental needs can be difficult to reconcile (European
534 Association Working for Carers, 2017). Indeed, our results suggest that YOD impacts on
535 different areas of children's lives including education/career, interpersonal relationships, and

536 future life planning. Despite it, as a recent systematic review highlights (Chirico et al., 2021a),
537 caring at a younger age can be viewed as a natural extension of family relationship thus not
538 receiving specialist support and care. For example, the children's experience of 'anticipatory
539 grief' of their sick parent is often neglected or not recognised both by professionals and society.
540 Therefore, support is required, and psychoeducation, face-to-face groups, online forums and/or
541 blogs are recommended to ease children's burden (Chirico et al., 2021a; Pappadà et al., 2021).

542 A prominent theme emerging from interviews was the growing social isolation and
543 loneliness due to the loss of relationships, including with the extended family and friends, and
544 to increasing responsibilities. As previously discussed, dementia at a younger age is
545 challenging to cope with for both patients and families due to its non-normative nature. Its
546 psychosocial consequences are broader and less evident than in late-onset dementia. Therefore,
547 effective support and care should be based on a 'whole family' approach taking into
548 consideration both patients and family needs at the same time (Cabote et al., 2015; Roach et
549 al., 2012). This would require a network of collaborative services, including adult, child, health
550 and voluntary services (Chirico et al., 2021a). Professionals should be provided with YOD-
551 specific training and education and linked by the mean of a link contact, knowing the family
552 situation and able to coordinate care at the right time and in the right ways (Cations et al., 2017;
553 Ottoboni et al., 2021a). By providing support, positive aspects of caring such as personal
554 growth or improved self-efficacy could balance the adverse outcomes of care. In this view,
555 greater public knowledge and understanding about YOD, through the involvement of mass
556 media, may contribute to avoid family self-isolation while promoting social connectivity,
557 increased support at the policy level, and better emotional and practical support for patients
558 and families.

559

560 Limitations and proposals for future research

561 This is a study exploring the experience of YOD and, more specifically, its impact on family
562 and social relationships from the perspectives of spouses and children. Despite our findings
563 support and extend previous evidence from this field, findings are based on a small number of
564 interviews which were also conducted throughout three regions in Italy only. Therefore, since
565 dementia care is health system and culture dependent, the generalizability of this study is
566 limited by the small representativeness of participants.

567 Another limitation stems from the fact that diagnoses reported by participants were only
568 Alzheimer's disease and frontotemporal dementia. It would be interesting to obtain quantitative
569 longitudinal data on how YOD impacts on family relationships within different phases of child

570 development, type of YOD and parental condition stages. To gain a more comprehensive view
571 about the impact of YOD on family relationships, data might be collected from people living
572 with YOD as well as from their family members. Furthermore, family interventions could be
573 empirically evaluated to provide evidence on what works and why.

574

575 **Conclusions**

576 The impact of YOD is both profound due to the specific life cycle stage, and widespread as it
577 regards the overall family system. Despite it, family members' concerns could be neglected
578 or not understood. As known, one patient could create several more 'hidden patients' in the
579 family. In this regard, this study provides evidence for the need for age-appropriate support for
580 people living with YOD, which would take into consideration family needs and changing roles
581 and responsibilities within the family. Overall, results are in line with those from a recent, large
582 scale UK study (Stamou et al., 2021c) that identified the core features of optimum models for
583 service provision for people living with YOD and their families. Firstly, services staff should
584 adopt a person-centred approach, i.e. have a positive attitude, be collaborative and flexible, and
585 provide in-person support and user-friendly information for active middle-aged people.
586 Secondly, services should be organised taking into account the specific needs of this younger
587 population as well as those of the whole family, and be accessible and respond proactively to
588 their changing needs. Finally, specialist services should be guaranteed as well as the continuity
589 of care over time and integration across services. Since optimal care depends on good family
590 relationships, better support for families would likely benefit patient care while ensuring social
591 inclusion and health equity for vulnerable groups.

592

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596

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599

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601

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