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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 pragmatical 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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Introduction

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

Many factors hinder both a timely YOD diagnosis and post-diagnostic care access (Beattie, Daker-White, Gilliard, & Means, 2002). People with YOD might experience symptoms that differ from typical memory loss observed in Alzheimer's disease, such as changes in behaviour and mood, speech disorders or decision-making difficulties (Woolley, Khan, Murthy, Miller, & Rankin, 2011). Furthermore, health care practitioners may not be aware that dementia can occur at a younger age, which often results in misdirected referrals and misdiagnosis for depression, stress, menopause or other conditions linked to changes in personal life, such as loss of employment or relationship breakdown (Bakker et al., 2013; Mendez, 2006). Arguably, misdiagnoses resulting from insufficient or inadequate investigation of symptoms may be preventable via the education and specialist training of care physicians, general practitioners and dementia specialists involved in primary and secondary care. Enabling a timely diagnosis could not only protect people with YOD from experiencing long periods of confusion without understanding the underlying cause (van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010). Still, it could further prevent unnecessary service costs and precipitate post-diagnostic care access (Carter et al., 2018).

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

Indeed, during the last three decades, the number of studies highlighting the need for YOD-specific services has been continuously increasing (Beattie et al., 2002; Cox & Keady, 1998; Livingston, 2020). To date, most of the studies have provided recommendations for age-specific needs-based services by reporting on the experiences and perspectives of people with YOD and their caregivers (Mayrhofer et al., 2018; Stamou et al., 2020). In contrast, there is a significant scarcity of data regarding the views and perspectives of health care professionals and practitioners on the challenges they experience when delivering services to people with YOD and caregivers (e.g., Curran, Grimshaw, Hayden, & Campbell, 2011; Spreadbury & Kipps, 2018). Professionals' and practitioners' points of view are integral for service development and evaluation due to their unique experience and understanding of barriers and facilitators involved in real-life practice. (Curran et al., 2011). Furthermore, services are delivered by professionals with varying background, experiences, perceptions, feelings and ways of reasoning, which need to be considered during service design and remodelling (Naylor, 1995; Pawson et al., 2005), mainly when the work of improvement aims at translating research evidence into practice (Curran et al., 2011; Thornhill and Conant, 2018), This study aimed to explore service delivery for YOD through the unique perspectives of professionals, to identify the challenges, barriers and facilitators involved and provide recommendations for service improvement.

Ethics approval

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

Methods

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

Participants, Recruitment and Data Collection

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

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

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

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

Data analysis

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

Results

Socio-demographic information of participants

Thirty-one participants participated in the study (see Table 1); 27 participants were female, and 4 were male. Participants' age ranged from 29 to 74 years (M = 47.9, SD = 12.5), while average years of education were 19.2 (SD = 3.2). The sample comprised three social-workers, two nurses, two geriatricians, two neurologists, one psychiatrist, one physician, one music therapist, one nursing assistant, fourteen psychologists, one service manager and three volunteers, whose professional experience ranged between 3 and 50 years (M = 18.6, SD = 11.8). Participants used to work with a mean of 17.5 people with dementia per week (SD = 21.1), of whom 7.1 were people with YOD (SD = 8.9). Two participants further reported having a relative living with YOD.

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

Qualitative findings

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

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

Service complexity and responsiveness

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

Time availability

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

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

Network of services

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

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

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

Matching constraints, offers and needs

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

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

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

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

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

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

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

Counselling

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

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

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

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

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[1] 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)

Respite

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

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

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

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

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

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

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

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

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

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

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

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

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

Knowledge and education

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

Guidelines

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

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

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

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

Education

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

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

Public awareness

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

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

Staff support

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

Professionals' burden

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

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

Mirroring

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

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

Proposals for improvement

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

Non-statutory services

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

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

Advance Care Planning

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

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

Discussion

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

Service complexity and responsiveness

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

An important aspect to consider when evaluating services' responsiveness is that most of them were initially designed for older people with dementia, who embody stories grounded on entirely different time frames. For instance, the psycho-social activities offered to people with YOD should be carefully designed; stimuli such as music, videos and images should be selected based on relevance, particularly given the fact that it may be hard to maintain control over both types of memories and the behavioural responses elicited by these stimuli. People with YOD find it challenging to benefit from group interventions developed for older people, whose symptoms and activity levels could differ (Aplaon, Belchior, Gélinas, Bier, & Aboujaoudé, 2017). The mismatch between needs and offer decreases the access of people with YOD and their families to services (Green & Kleissen, 2013). On the contrary, it should be fostered by planning activities with people of the same age or cooperation with non-statutory services. Middle age is firmly located in a social context (Erikson, 1950), and group activities represent a real opportunity for people with dementia. Social activities decrease the social discontinuity while facilitating their attempts to cope with the disease by acquiring a new sense of agency (van Vliet et al., 2017). Simultaneously, though, the needs of people with YOD change rapidly as the disease progresses. Services should be ready to accommodate such a dynamic transformation. In this vein, one of the suggestions which emerged in the interviews regarded the activities that can be organised either together or with non-statutory services (Kinney, Kart, & Reddecliff, 2011). By continuing to participate in activities which require a similar effort to the activities people with YOD are used to, they feel in control of their life (Richardson et al., 2016). People with YOD can still rely on higher perceptual and motor abilities than their older peers (de Dieuleveult, Siemonsma, van Erp, & Brouwer, 2017), they are still powerful and active, and this is the reason why they need to be involved in activities appropriate to their age (Carone, Tischler, & Dening, 2016; Clarke & Korotchenko, 2011). In general, people with YOD and a family struggle to cope with their new future: the diagnosis causes people with dementia to change their representations of themselves and their future; they must reshape self-awareness while reformulating plans and programs. Indeed, people with YOD are often young spouses in the middle of their lives: they use to work and look after their old parents or their children, whose capability to be independent is still insufficient, in most cases. As a consequence of such a diagnosis and prognosis, sons and daughters are prompted to review their life plans, and spouses have to re-program many of their habits to adapt to the new situation (van Vliet et al., 2010; Chirico, Ottoboni, Valente, & Chattat, In press).

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

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

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

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

Knowledge and education

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

In Europe, services are often committed to providing information and education to the public about dementia and its health-related concerns (Chirico et al., In press). In the public sphere, dementia is equated with Alzheimer's disease, which, in turn, is assumed by the public to cause memory decline in the elderly (Sikes & Hall, 2018). The effort spent to improve the public's level of education on this matter can surely increase the general level of well-being. Firstly, higher education raises the quality of the care outcomes; then it can reduce the stigma surrounding the people living with the disease and promote dementia-friendly communities blooming (Herrmann et al., 2018; Mukadam & Livingston, 2012).

Staff support

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

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

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

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

Proposals for improvement

In the amelioration of the service, one of the solutions capable of balancing the negative impacts is the capability to exert control over the working environment (Ajzen, 1985; Grol, Wensing, Hulscher, & Eccles, 2010). In this light, the proposals advanced by our participants represent a few good examples. To implement health services while respecting their constraints and limits, one solution may be characterised by the involvement of non-statutory services. For many economic and structural reasons, services cannot afford many activities. The change to organise with other non-profit service provider activities as baking, fishing, walking, art or evening out, among the others, has been proven beneficial in the development of those social networks so paramount to maintain the sense of dignity and social inclusion (Mayrhofer et al., 2018).

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

All the aspects discussed here can be grouped according to a pragmatical framework suggested to represent how health services can be improved independently of their intrinsic nature (Grol, 2010). The framework argues that the actions of improvements entail external and internal instances at the same time (Grol, 2010). To improve clinical services, any manager or political stakeholders should consider the level of motivation featuring professionals and workforces and design plans for its improvement, even via the account of the problems they are used to face. At the same time, professionals and the workforce must be provided with the most recent information about the issues they can expect to encounter. Again, the needs and the wishes of the target population must be considered while analysing the surrounding setting around which the services is located. Hence, the analysis would facilitate the plan or develop alliances with supporting networks operating in the surrounds. From the inner side, the instances that must be valued concern the provision of feedback about professionals and workforces' performance, together with the weighing of the social interactions underpinning service or the network of services. In keeping with the internal instances, a general evaluation of the situation and the proposal for future changes are other key elements. At this level, it is essential to keep on managing service quality while being focusing on continuous improvement. Finally, it is fundamental to evaluate professional effort in terms of earnings and benefits: in this light, legislation, budgeting and disciplinary jurisdiction must be known and managed while keeping these procedures directed towards ameliorating the service status quo (Grol, 1997). The evidence reported in this work matches more than others depicted in the pragmatic conceptual framework (Mayrhofer et al., 2018; Stamou et al., 2020), as they are a mixture of internally and externally driven instances.

Limitations and recommendations for future research

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

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

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

Conclusion

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

Appendix

1. **Tell me about YOD**
    a. How would you define it?
2. **Tell me about your work (while caring for people with YOD)**
    a. Talk about how both your service and the territorial ones are organised and structured
    b. Talk about the diagnosis (time, place, to whom it is told)
    c. Talk about the available interventions
    d. Talk about the people you meet: YOD patients and caregivers
    e. Which are the expressed needs?
3. **Tell me about your personal aspects**
    a. Do you like your job, or would you like to change it?
    b. How do the people you care for behave to you?
    c. Does work atmosphere has an effect on your personal life?

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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

Table 2. Themes and categories as identified by participants.

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