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Special Article

Reimagining Postdiagnostic Care and Support in Young-Onset Dementia



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Although dementia has a profound impact in general, young-onset dementia causes additional problems and challenges as people are affected in their prime years. Awareness has increased that people with young-onset dementia and their families have specific care needs and dedicated services are necessary to accommodate those needs. However, in many countries, age-appropriate care and support for people with young-onset dementia is still largely unavailable. In this special article, barriers as well as facilitators for the development of postdiagnostic care and support in young-onset dementia are addressed. Drawing from the experiences in the Netherlands, the establishment of an appropriate infrastructure has proven a corner stone in service development in young-onset dementia. The establishment of a center at the national level for the development and dissemination of knowledge and affiliated regional centers that coordinate and offer care and support at the regional level has helped to reimagine, redefine, but more importantly also rearrange, postdiagnostic care and support in young-onset dementia in the Netherlands. This has resulted in care standards for service provision in young-onset dementia that have been incorporated in the dementia standard at the national level. Also, a quality hallmark has been developed to guide the arrangement of age-appropriate services at the local level. Moreover, specific training programs are in place for health care professionals involved in young-onset dementia. To be able to prioritize topics in research for the upcoming years, a scientific agenda has been established. The strong collaboration between organizations that provide a voice for people with dementia, care providers and research centers, that all strive to support people to live well with young-onset dementia has boosted these developments and may inspire other countries searching for ways to improve post-diagnostic care and support in young-onset dementia.

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In the past decades, awareness has increased among health care professionals, researchers, and policy makers that people living with dementia at a young age have specific care needs that are specifically linked to the different life phase in which the dementia occurs.¹ Young-onset dementia, in which first symptoms occur

before the age of 65 years, impacts largely on family relationships, parenthood, work, and social life,² causing a significant loss in sense of self and identity, high levels of caregiver burden, and a delay in the initiation of appropriate care and support because of misdiagnosis.^{3–6} Although dementia has a profound impact in general, people who develop dementia before the age of 65 years often find the changes that occur due to dementia particularly distressing and life-changing.⁷ Moreover, in many countries age- and needs-appropriate services are still scarce, suggesting that there are barriers that impede the development of dedicated young-onset dementia services. In this special article, we address some of these barriers as well as prerequisites for the development

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of postdiagnostic care and support in young-onset dementia. For this purpose, we draw from the experiences in the Netherlands with the development of dedicated services in the past 2 decades that may help reimagine postdiagnostic care and support in young-onset dementia in other countries with similar care systems.

Service Provision in Young-Onset Dementia

A recent systematic review investigated available evidence for age-appropriate services for younger people living with dementia as well as the perceived effectiveness of current interventions.⁸ It showed that in most countries these services are often still fragmented, geographically dispersed, variable, and often short-term because of project-based funding. Moreover, although many of the included articles identified the need for specific support concerning employment, legal, and financial issues and this was recognized as critical in young-onset dementia, such services appear scarce and highly under-researched. This is troubling, because the first articles that identified the mismatch between mainstream dementia services and the needs and preferences of young individuals and their families date back more than 20 years ago. Care costs in young-onset dementia are almost twice as high when compared to these costs in late-onset dementia and are heavily inflated by indirect (economic) costs, such as by the loss of employment.⁹ Moreover, a recent survey in the United Kingdom showed that family care highly contributes to indirect care costs in young-onset dementia,¹⁰ through the loss of even more productive individuals to society. Experiences in the Netherlands are that service providers are also hesitant to design services for a “new” target group, because of the initial increase in costs that accompany the development of dedicated services. Also, the fact that the target group of these services is only an approximate 5% of all people living with dementia¹¹ probably further raises barriers for the establishment of such services.

Worldwide, only a few countries have incorporated specific recommendations on postdiagnostic care and support in young-onset dementia in their dementia strategies. In countries that do have more inclusive dementia strategies in place, age-appropriate services and access to these services appear to have developed at a much higher rate. For instance, in Australia, people with young-onset dementia can now be assisted through the Australian National Disability Insurance Scheme (NDIS) owing to recent changes in government policy. This is rather unique as care in Australia for people with young-onset dementia can be delivered within a disability system. The structure of the NDIS facilitates that care can be delivered to young people that promotes self-management, autonomy, and independence.¹² In the Netherlands, last year young-onset dementia has been appointed an overarching theme in the National Dementia Strategy, to support both research into young-onset dementia, further improve the diagnostic trajectory as well as to ensure people with young-onset dementia have access to dedicated postdiagnostic care and support. Although for each country there will be differences in what issues need to be addressed to better accommodate the needs of young individuals and their families, there are several aspects that should at least be addressed in dementia strategies. For instance, recommendations should be included to improve diagnosis in young-onset dementia. It takes approximately 2.9 to 5.5 years until a diagnosis can be established in young-onset dementia.^{5,6,13,14} This is a significant delay compared to the time to diagnosis in old age. Moreover, misdiagnosis is common in young-onset dementia related to the larger variety in potential causes, misinterpretation of early signs and symptoms, and often atypical presentation,⁶ adding to the burden already felt by these families and resulting in a delay in the referral to appropriate care and support. Also, recommendations

should be included about the development of age- and needs-appropriate services and how to secure access to such services.

A recent UK study, the Angela Project, focused on positive experiences of people with young-onset dementia and their families with dedicated postdiagnostic support.¹⁵ Conclusions were that postdiagnostic services should focus on enabling young people with dementia to understand young-onset dementia and how to cope with any consequential changes. The authors also concluded that age-appropriate services should be accommodated suitable for their social, physical, and mental health needs and support to maintain or regain a sense of connectedness and reciprocity within family and age-appropriate social contexts. Studies such as the Angela Project should be of particular interest to policy makers and health care professionals because the perspectives of both people living with dementia and their families and those of health care professionals were explored. With that, the chances increase that services can be designed that match care needs and can also be attuned to the changes that occur during the disease trajectory.

There are several good examples of support that address the specific themes that have been identified in the Angela Project. For instance, recently several promising interventions have been developed, such as the SPAN intervention that focuses on current capacities of people with young-onset dementia that allow them to engage in meaningful activities and feel useful.¹⁶ The intervention emphasizes the importance of support for persons with young-onset dementia in how to regain a sense of usefulness in daily life to preserve self-esteem and to feel engaged in society. Another recent study positively evaluated the use of Twitter by people with young-onset dementia and found that Twitter could be an important source of postdiagnostic support as participants felt it helped them to counter a loss of identity through community membership and by regaining a sense of purpose.¹⁷ Another intervention is Partner in Balance, which has been specifically tailored to support family members of young people living with dementia and incorporates self-management principles to help family members find a balance between caregiving and daily life.¹⁸ These interventions are characterized by a complementary nature, building on what people with young-onset dementia and their family members can do themselves, and appear to be easily accepted by young people living with dementia and their family members. However, it is of little use offering such interventions without embedding them into a service model to ensure that people will have access and interventions can be offered at the most appropriate time during the caregiving trajectory as well.

The service model for postdiagnostic care and support for younger people living with dementia and their families in the Netherlands that has been established in the past 2 decades has proven a solid model, and this model may also be a template for service arrangements for other countries (Table 1). Based on a recent meta-analysis of international prevalence studies, estimates can be made that currently 14,000 to 17,000 people live with young-onset dementia in the Netherlands.¹¹ Because of the low prevalence, in the Netherlands postdiagnostic care and support in young-onset dementia is organized at the regional level with a hub-and-spoke approach in which one of the larger health care organizations together with smaller local partners offer services and support after the diagnosis. Guidelines and care standards are developed at the national level. In 2003, a steering committee was initiated by 2 health care provider organizations already providing care for young people living with dementia at that time. Aims of the steering group were to advocate for a timely diagnosis in young-onset dementia, support the development of age- and needs-appropriate postdiagnostic services, and to obtain financial resources to provide such services. The efforts of the steering committee resulted in a young-onset dementia care program based on best practices and the available scientific evidence at that time how to

Table 1
Components of the Dutch Young-Onset Dementia Care Model

Topic	Key Components
National level	
Acknowledge special needs in YOD	The inclusion of YOD as an overarching theme in the Dutch Dementia Strategy. The incorporation of specific recommendations to improve diagnosis and postdiagnostic support in the national dementia standard. These developments have allowed for <ul style="list-style-type: none"> - promoting awareness of YOD in the community; - providing guidance regarding important prerequisites to improve diagnosis and service provision in YOD; - increasing chances to allocate funds to not only further develop but also maintain the existing dedicated YOD care infrastructure; and - allocating funds for scientific research on YOD.
Innovation and service development	A Knowledge Center at the national level that is tasked with <ul style="list-style-type: none"> - raising awareness on YOD and advocating for the specific needs of young people living with dementia and their families; - warranting that the voices of people with YOD and their families are heard and are used to guide policy and service development; - developing YOD care standards and facilitating the development of interventions and services that meet the needs of YOD families; and - establishing a scientific research agenda on YOD as well as the promoting and supporting scientific research to improve diagnosis and postdiagnostic care and support in YOD. <p>The Knowledge Center was acknowledged by the Dutch government as center of preference regarding matters in YOD. A research consortium was initiated by the Knowledge Center and Dutch Alzheimer's Society that includes all 5 academic research centers and important stakeholders, tasked with carrying out the scientific research agenda.</p>
Education of health care professionals	The establishment of accredited YOD training programs for nurses and case managers and an interprofessional training program for elderly care physicians, psychologists, specialist nurses and physician assistants.
Lack of fit between needs and services	A quality hallmark to aid health care organizations to attune services to the needs of YOD families.
Regional level	
Availability of services	Regional centers throughout the country that are tasked with providing dedicated YOD services.
Access to appropriate care and support	Regional centers are stimulated to also deliver services in more remote areas and to work in close collaboration with local partners to ensure that families will have access to appropriate services and support nearby.
Coordination of care and support	Case managers specialized and trained in the support of YOD families. Quality indicators have been developed to guide service delivery post diagnosis.
Local level	
Continuity in care	Regional centers together with local partners provide care and support throughout the entire caregiving trajectory, including <ul style="list-style-type: none"> - case management, - multidisciplinary YOD teams, - respite options, - psychosocial support of family members (ie, peer support groups, e-health, or educational program), and - Day care centers and residential care facilities attuned to the needs of younger people living with dementia.

YOD, young-onset dementia.

address the needs and preferences of people with young-onset dementia and their families. This also resulted in acknowledgement by the Dutch government that there was a need for such services and that more knowledge was necessary on how to improve diagnosis and postdiagnostic care and support. Also, additional reimbursement from the national health insurance was obtained to compensate for the higher costs of care in young-onset dementia.

In 2013, the Young-Onset Dementia Knowledge Center was founded. At that point, the organization had already grown to 8 health care organizations offering dedicated services. Currently, the Knowledge Center is recognized by the government as a partner in the development of services and support in young-onset dementia. The number of members has grown to approximately 40 health care organizations providing dedicated services throughout the country, composed of dedicated services, including case management, home and day care, respite care, and residential care. Also, the Dutch Alzheimer's Society and the 5 academic Alzheimer research centers have joined the Knowledge Center to improve diagnosis and postdiagnostic support in young-onset dementia. In 2020, a research agenda was issued by the scientific advisory board of the Knowledge Center to identify research priorities, and currently a research consortium is being established to carry out this agenda. Focus of the Knowledge Center has always been to improve the quality of life of people living with young-onset dementia and their relatives by supporting scientific research, develop standards for high-quality care and educate health care professionals involved with people with young-onset dementia. For this purpose,

the Knowledge Center offers a learning community to allow for the exchange of knowledge but also supports projects aimed at the development of services at the regional level. For example, a business case has been established for dedicated case management, defining quality indicators as well as the budget needed to offer case management that can accommodate the needs of young people living with dementia. Similarly, educational programs for health care professionals generally do not address young-onset dementia and do not prepare these professionals for how to best offer support in young-onset dementia. Therefore, the Knowledge Center has supported the development of several dedicated training programs that are now offered at the national level, for instance, for nurses and case managers but also an interprofessional training program for elderly care physicians, psychologists, nurse practitioners, and physician assistants.

In 2015, care standards have been developed by the Knowledge Center to guide the arrangement of postdiagnostic care and support in young-onset dementia, and these standards have recently been incorporated as recommendations into the national dementia standard. The recommendations address the need for early recognition and referral to specialized diagnostic facilities in young-onset dementia, timely access to age- and needs-appropriate care and support, and the introduction of a trained young-onset dementia case manager following diagnosis. Aims were to minimize the impact of the diagnosis, support the family in adjusting to the changes caused by the dementia, to live well with dementia, and support advance care

planning. This requires multidisciplinary person-centered and needs-driven care. Therefore, case managers either cooperate or are affiliated with the health care organization that provides specialist young-onset dementia services in the region. The Knowledge Center supports health care organizations that want to specialize in young-onset dementia and the development of local learning communities to translate the care standards to the local context and improve collaboration between health care organizations at the regional level. Recently, a quality hallmark to guide best practice has been developed together with people living with dementia, their caregivers, and health care professionals of the organizations affiliated with the Knowledge Center. The quality indicators of the hallmark reflect the needs and preferences of younger people living with dementia and their families during the entire caregiving trajectory. As a result, these indicators can guide health care organizations to adapt their multidisciplinary care and the way it is delivered to accommodate those needs and make the necessary changes to, for instance, their day care center or nursing home. Health care organizations affiliated with the Knowledge Center can obtain the quality hallmark through an independent audit. The hallmark allows for people with young-onset dementia and for those who refer them to ascertain whether the organization provides age-appropriate and high-quality care for both the person with young-onset dementia and other family members.

Implications for Practice and Policy

The infrastructure that has been established for young people living with dementia in the Netherlands, with a center at the national level for the development and dissemination of knowledge and the affiliated regional centers that coordinate and offer care and support at the regional level, has helped to not only reimagine and redefine but also rearrange postdiagnostic care and support in young-onset dementia in the Netherlands. The model has also inspired policy makers to arrange long-term care for other similar target groups.

However, when arranging specific services for people with young-onset dementia, we have learned that there are several barriers that must be addressed. First, the government must acknowledge that people with young-onset dementia have different needs compared to people with dementia in old age. Given the fact that a family-oriented approach is needed in young-onset dementia, this also requires that services are developed from this perspective, and this requires that the government is willing to fund both research into diagnostic and postdiagnostic services and the infrastructure to provide them. The inclusion of young-onset dementia in the national dementia strategy has proven an important step.

Another important barrier refers to the delay between diagnosis and the initiation of postdiagnostic support. When memory clinics are aware of care options that specifically target people with young-onset dementia, this lowers the threshold to initiate appropriate services. However, this requires an overview of available services nationwide that memory clinics can access and that health care providers with dedicated services for people with young-onset dementia for instance establish service level agreements with memory clinics to arrange for appropriate referral after diagnosis. Especially in regions where a young-onset dementia case manager also works at the memory clinic, the gap between diagnosis and initiation of appropriate services has been reduced to a minimum.

To allow for a timelier initiation of appropriate care and support, the delay in the time to diagnosis also must be addressed. This requires a better understanding of disease mechanisms that underlie the causes of dementia in younger people and ways to improve early detection. At the same time, we have learned that it is important to include information about young-onset dementia in the curricula of educational programs for general practitioners, occupational

physicians, and other professionals who may encounter people with young-onset dementia in an early stage to raise awareness on possible first symptoms of dementia in younger people. Also, raising awareness on young-onset dementia among the general public through different media channels has helped. However, given the low prevalence of young-onset dementia, this remains an important challenge.

In more scarcely populated areas, people with young-onset dementia will not have access to dedicated services, including access to residential care. This will likely also be related to regional differences in the willingness of local partners and regional centers to work together in providing continuity in care. Currently in the Netherlands, a change in the system is being considered to financially stimulate regional centers to address this issue and cooperate with local partners.

Despite these barriers, we have learned that the cohesion between different organizations, ranging from organizations that provide a voice for people with dementia and care providers to research centers that all strive to support people to live well with young-onset dementia, has benefited the individual organizations but also the group as a whole. It shows that a group of organizations working together can achieve far more than one organization working alone. Also, the learning community has proven an important facilitator in the past 2 decades. The learning community has played a key role in the development of postdiagnostic care and support in the Netherlands, because it has strengthened the connection between research and clinical practice, provided opportunities to share best practices, and has accelerated the development of tools for the improvement of service provision in young-onset dementia that could also be used to inform policy makers. The developments in the past decades in the Netherlands described in this special article may also inspire other countries searching for ways to improve postdiagnostic care and support in young-onset dementia.

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