

Chapter 8: International differences in best practice for young onset dementia

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Abstract

The focus of national and international health and social care policies on the impact of young onset dementia has increased during the recent decades. National dementia strategies have aimed to recognise the distinct needs of younger people with dementia and their families and promote evidence-based age-appropriate services via recommendations of good practice. This chapter provides an overview of the differing international approaches to provision of post-diagnostic support, along with examples of good practice across Europe and Australia. Despite the remaining gaps in research and practice, current evidence suggests that significant progress has been made towards establishing the basic principles of good practice in young onset dementia and the fundamental attributes of age-appropriate needs-led services. The increasing pockets of good practice around the world allow for an optimistic view regarding more effective services for young onset dementia in the future.

Key learning points

The fundamental elements of best practice comprise:

- personalised age-appropriate needs-led services delivered in a timely and uninterrupted manner and using a person-centred approach
- family-oriented services which address the individual and collective needs of all those affected by young onset dementia
- clear, affordable, effective, and easily accessible diagnostic and post-diagnostic care pathways across the experience with young onset dementia
- coordination and collaboration between services, to provide continuity and address the changing needs of younger people and their families over time

Transferring research evidence on good practice from one country to another may be a highly complex task. Evaluation models are needed for the implementation of national guidelines on good practice.

There is little knowledge about good practice in palliative or end of life care for young onset dementia.

The needs of under-represented groups, such as younger people with dementia who live alone or come from Black, Asian and Minority Ethnic communities, have not been sufficiently explored and identified.

A substantial number of studies worldwide have explored the needs of younger people with dementia (YPD) and their families and provided recommendations of good practice to improve post-diagnostic services for young onset dementia (YOD). In this chapter, we will provide an overview of the differing international approaches to provision of post-diagnostic support for YPD and will highlight examples of best practice across Europe and Australia. For reasons of brevity, international examples from the US and Canada will not be covered as these can be found elsewhere in the literature (Alzheimer Society of Canada, 2017; Morhardt et al., 2015; Shnall, 2015).

Definition of best practice

The need to establish specialised services for YOD has been previously highlighted (National Institute for Health and Care Excellence, 2018). Recent advances in research across different countries have identified a universally accepted approach on which good practice for YOD post-diagnostic support should be based. This advocates national governmental bodies and international organisations involved in policy-making to adopt a needs-led framework for service design and provision (European Parliament, 2011). Currently, there is limited empirical evidence with respect to widely accepted models of best practice.

International perspectives on YOD

In 2011, the European Parliament convened to discuss the European initiative on Alzheimer's disease and other dementias. In its resolution, the Parliament recognised the differential pathological and clinical profile of YOD and advocated for the right of YPD to access appropriate post-diagnostic care and support. The Parliament officially called on the European Union and Member States to adapt post-diagnostic services to the needs of YPD (European Parliament, 2011). In the following sections of this chapter, we will explore the evidence-based guidelines of good practice in different countries, as well as real-life examples of best practice in cases where the guidelines have been implemented.

United Kingdom

There are approximately 42,000 YPD in the UK (Alzheimer's Society, 2014). The *Prime Minister's Challenge on Dementia 2020* (Department of Health, 2015) highlighted the age-specific needs of YPD and their families. Similarly, the *UK National Dementia Strategy* (Department of Health, 2009) underscored the importance of enabling YPD and their families to access dementia services which are specific to their needs, age and diagnosis, and the National Institute for Health and Care Excellence recognised the need for specialist multidisciplinary services to be developed to this end (National Institute for Health and Care Excellence, 2006; 2018). Despite the current lack of comprehensive evidence-based guidelines for YOD service models, there is a wide range of collaborative initiatives involving lay and professional YOD networks, charity organisations and health and social care authorities, which have enabled the development of pockets of good practice in the UK.

Guidelines on best practice

Within the past 15 years, a growing body of evidence has provided important insights into the service needs of YPD and their families and highlighted the lack of clear pathways into

age- and needs-specific care (Alzheimer's Society, 2014). The Young Dementia Network (YDN; <https://www.youngdementiauk.org/young-dementia-network>) - which is composed of YOD experts, including YPD and their families/supporters, researchers, clinicians and service providers who work together to develop guidance and influence policy - produced a care pathway for YOD which was endorsed by the Royal College of Psychiatrists (Royal College of Psychiatrists, 2018). Due to the often-fragmented service provision and commissioning in the UK, the report emphasised the need for clear locally-agreed referral pathways and for specialist key workers, who will link health services with third-sector organisations and statutory providers, to enable YPD and their families to receive needs-appropriate support at home and in their communities for as long as possible. By assigning a key worker who will monitor and coordinate long-term access to needs-led services, YPD will be enabled to receive timely support across their experience with dementia from a range of professionals, including dementia advisors, specialist dementia nurses such as Admiral Nurses, social workers, psychiatric nurses, occupational therapists, speech and language therapists, clinical psychologists, and physiotherapists. The YDN report identified these professionals as the specialised staff that can meet the needs of YPD and their families for:

- information and guidance regarding the condition and how to cope with the symptoms,
- support to maintain individual cognitive functions and social and family relationships,
- emotional support, and
- help with issues related to employment, accommodation, driving, mobility, finances, and legal arrangements.

Of importance, the YDN recommendations included guidance on needs-appropriate support towards the end of life, which is an area largely under-investigated. The report emphasised the need to:

- enable YPD and their families to plan their care in advance, so that the support offered is consistent with their needs and wishes,
- provide short-time respite, appropriate acute care in dementia-friendly wards, and age-sensitive long-term residential care within distance that allows the family to maintain contact with YPD, and
- offer age-appropriate palliative care to YPD at home or in residential care, and bereavement support to families and supporters.

Example of best practice

Younger People With Dementia Berkshire (<http://www.ypwd.info>) is a charity organisation which provides YPD and their families with ancillary support, to fill the unfunded gaps in local post-diagnostic services across the Berkshire region. The charity is funded mainly via grants and donations and employs its own staff to provide support - including out of hours services - alongside statutory services, such as the memory service and local primary care physicians. Referrals can be made to the memory service for adapted cognitive stimulation therapy to improve cognitive and brain functions and, depending on needs across the care pathway, YPD and supporters have timely access to a wide range of useful forms of support, as summarised in Figure 1.

<Fig. 1 here>

Figure 1. Presentation of the post-diagnostic support available via YPWD Berkshire.

The collaboration between services for the timely provision of support and the person-centred approach of the professionals and volunteers involved, ensure that services are delivered in a well-coordinated manner which enables YPD and their families to meet their needs and live well with the condition.

Netherlands

According to Alzheimer Nederland (<https://www.alzheimer-nederland.nl/dementie/jongdementie>), the number of YPD in the Netherlands is approximately 12,000, the majority of whom are between 55 and 65 years old. In 2004, a national task force on YOD developed the national *YOD Care Programme* based on evidence on best practice. The programme aimed to improve the care for YPD and their families, advocate for their social recognition, and argue for a financial boost in YOD service provision. The Dutch government recognised in 2006 the special care needs of YPD and their families and introduced additional funds for YOD-specific services (Carter, Oyeboode, & Koopmans, 2018). In 2008, the State Secretary of Health, Welfare and Sport expressed the ambition to improve dementia care and in her letter to the Dutch House of Representatives included a special mention to YOD (Dutch State Secretary of Health, Welfare and Sport, 2008). The letter underscored the need for services that are specific to the age and needs of YPD and their families and emphasised the imperative for rapid knowledge acquisition and dissemination to improve diagnosis and post-diagnostic support.

In 2013, the Dutch YOD Knowledge Centre (<https://www.kcdementieopjongeleeftijd.nl>) was founded by representatives of eight care organizations in the Netherlands that were among the first to offer YOD-specialist services across the country. The aim of the YOD Knowledge Centre was to improve health care and support for YPD and their families on a national level, via the exchange of knowledge and expertise on best practice between representatives from the member organizations. The number of organizations grew from eight in 2013 to 31 today, and is continuing to grow as more Dutch care organizations are interested to know how YOD services can be designed, financed and offered to YPD in the Netherlands.

Guidelines on best practice

Based on the national *YOD Care Programme*, quality indicators for best practice were developed, which were published by the YOD Knowledge Centre in 2015 as ‘care standards’ for YOD (Kenniscentrum Dementie op Jonge Leeftijd, 2015) and are expected to be officially incorporated into the national dementia standards. The main objective of the associated guidelines is to promote the effective coordination of and cooperation between care providers involved in different levels of service provision, to facilitate the delivery of multidisciplinary person-centred needs-led care which will enable YPD to live autonomously in their home for as long as possible and maintain their quality of life across their experience with YOD. In this context, the standards highlight the need for early recognition of symptoms and referral to

YOD-specialist services for assessment and diagnosis. At the same time, the standards call for provision of support to be initiated, to ensure that the diagnostic process takes place in a way supportive to the needs of YPD and their families and minimise its impact. At this stage, the role of a case manager is pivotal in coordinating the collaboration between services to provide access to a clear needs-led care pathway. A multi-disciplinary YOD-specialist team consisting of professionals from medical and psychological disciplines, in collaboration with a memory clinic and/or mental health care unit, need to be available to this end. Depending on individual and family needs and the stage of the condition, a wide range of services should be available to YPD and families across their experience with dementia, as shown below:

- YOD-specific mental health services with specially trained staff,
- advance care planning,
- appropriate medical care (including care for comorbid conditions),
- physiotherapy/occupational therapy,
- speech therapy,
- YOD-specific day-care programmes,
- age-appropriate daytime activities, such as fitness and walking, woodcarving, creating artwork, and other group-based interventions,
- outreach care,
- peer support groups,
- music therapy,
- family support to enhance relationships and roles within the family,
- support with finances and legal issues,
- support groups, psychoeducation and case-specific information/advice for family members,
- guidance for family carers to prevent overburdening due to caring tasks,
- specialised nursing homes with dedicated YOD units where YPD live together, and
- grief counselling for caregivers and families of YPD.

Example of best practice

The Florence Centre is one of the eight pioneer care organizations which founded the YOD Knowledge Centre. The Florence Centre (<https://www.florence.nl/aandoening-specialist/aandoeningen/dementie-op-jonge-leeftijd.htm>) has been an established YOD-specialist service for almost 20 years and offers a full range of services, including diagnosis, information services, day-time activities and programs, treatment and support, respite, and residential care. The Florence Centre employs YOD specialists for diagnosis and assigns a case manager, who is responsible for coordinating the timely provision of needs-appropriate post-diagnostic services to both YPD and their caregivers/families across their experience with YOD. The case manager monitors the needs of service users and initiates access to services complementing informal care, while also functioning as a link between different services to facilitate interagency collaboration. With a special focus on monitoring the clinical progress and challenging behaviours of YPD, the case manager also facilitates the provision of appropriate psychosocial support and information.

The Florence Centre offers a modular care program which can be tailored to the individual needs of YPD and their caregivers/families. YPD and their caregivers are supported by the case manager to choose those modules from the program that fit their individual situation and care needs. For instance, at a particular time in the caregiving trajectory YPD might want to focus on meaningful daytime activities, social company and dealing with cognitive changes and loss. At that point, the case manager could offer specific modules, such as attending a support group for YPD or a day care centre, following the SPANkracht program which is aimed at empowering YPD to regain a sense of self and identity through daytime activities (van Vliet et al., 2017). During the caregiving trajectory the individualised treatment plan is jointly adjusted by the care provider and the person with dementia.

With regard to the families of YPD, the Florence Centre offers a three-component program of support. First, there is an introduction course, which provides information on dementia symptoms and how to cope with them. It also addresses legal and financial issues and potential relationship difficulties. The second component of the program comprises support to various separate groups of relatives, partners and children, which enable:

- meeting and sharing experiences with other YOD caregivers/families in an accepting environment,
- having social company and experiencing social intimacy and communication,
- understanding and adapting to changes brought by the condition as they occur (including changes in roles and issues related with loss of identity or self),
- exchanging knowledge about managing behavioural symptoms,
- gaining insight into the formal support available,
- enhancing a sense of competence in caregivers.

Finally, individual counselling is also available for family members of YPD to address potential mental health problems and/or offer grief counselling; this is available face-to-face, as well as via an e-health intervention which includes meetings with a coach.

The YOD day-care centre of the Florence Centre has flexible opening hours and specially trained staff to employ programs that meet the needs of YPD. Overnight and weekend stay services are also available for respite. When community care options are no longer effective, residential care and sheltered living are available. In these cases, the care program continues with a focus on creating a ‘home’ within an institution and includes the caregivers/families of YPD in the provision of support.

Norway

It is estimated that up to 1,400 younger people are diagnosed with dementia in Norway (Johannessen & Möller, 2013). The *Dementia Plan 2020 - A More Dementia-friendly Society* issued by the Ministry of Health and Care Services (Norwegian Ministry of Health and Care Services, 2016), focuses on facilitating the provision of needs-led health and social care services at a national level. The plan has been developed in collaboration with people with dementia and their families as a continuation of the *Dementia Plan 2015* (Norwegian Ministry of Health and Care Services, 2008). Among the programmes included, one specifically focuses on improving services for YOD.

Guidelines on best practice

The *Dementia Plan 2020 - A More Dementia-friendly Society* recognises the age-specific needs of YPD and the importance of interagency collaboration between health and social care services. Although there are no comprehensive YOD-specific guidelines, the plan provides recommendations for YOD services. Starting with diagnosis, the plan emphasises that assessments need to be carried out within specialist health care services, such as memory clinics, by professionals with YOD-specialist knowledge. Measures are proposed to ensure that YPD and their families receive YOD-specific information and advice after diagnosis, by professionals and other families living with YOD. The need to enable YPD to continue working and be treated as equals to people with other disabilities in the working environment is also highlighted in the plan. Work managers are encouraged to cooperate with health services and the person living with the diagnosis to enable YPD to continue feeling useful and maintain their financial income. Finally, measures are recommended to ensure the provision of systematic follow-ups that will promote needs-led support, such as meaningful activities, help to cope with the symptoms, and respite care.

Example of best practice

There are currently more than 30 Green Care Farms offering day care in Norway (Ibsen, Eriksen, & Patil, 2018). As a result of the *Dementia Plan 2015* recommendations, Green Care Farms are now small-scale farms (de Bruin et al., 2017) funded by Norwegian municipalities, which provide complementary day-care services to promote physical and mental health in different population groups, including YPD. The staff comprises farmers and often members with health care education, who use farm resources, such as farm buildings, gardens, green houses, stables, farm yards, work sheds, animals, outdoor areas, and the agricultural landscape, to organise meaningful activities tailored to the needs and preferences of YPD on a daily basis. The farms have a home-like character and may include different types of farming, such as woodland, dairy farm or industrial livestock, crops and subsistence production, combined with health, social and/or educational services. The internal and external spaces are well-organised to provide a secure and safe environment, while transport to and from the farm is also available. The needs-led physical and social activities and the accepting environment of the farms enable YPD to experience meaningful real-life participation and achieve personal growth, instead of feeling stigmatised or embarrassed. The activities take place in an accessible way, which enables participants to learn new skills, experience mastery, and teach others (Sudmann & Børsheim, 2017). Within the social context of the farms, participants can experience social roles, such as those of the work leader or the host, and an enhanced sense of identity which may counteract the impact of dementia on self-image and promote a sense of purpose and social well-being (de Boer et al., 2017). Of particular importance appears to be the exposure to nature, animals and the associated daily life stimuli; these create a supportive and often familiar natural environment which facilitates physical and social engagement and may help to reduce behavioural symptoms. Finally, the farms offer communal meals which promote a sense of community within the day-care settings.

France

There are approximately 32,000 YPD in France today, 5,000 to 8,000 of whom are less than 60 years old (French Ministry of Social Affairs, Health and Women's Rights, 2008; Paulin & Pasquier, 2012). The *Plan for Neurodegenerative Diseases 2014-2019* issued by the French Ministry of Social Affairs, Health and Women's Rights (2014), focuses on adjusting national health services across the country to the needs of service users. The plan clearly includes dementia and specific measures for YOD services, and is based on the following four axes:

- delivering care and support that will promote the quality of life of service users across their experience with the condition,
- facilitating society's adaptation to the challenges of neurodegenerative diseases, to reduce the impact on personal and social aspects of daily life,
- developing and coordinating research plans to inform improvements in services, and
- using the *Plan for Neurodegenerative Diseases 2014-2019* as an innovative tool to steer public policy and promote democracy in health services.

Guidelines on best practice

The *Plan for Neurodegenerative Diseases 2014-2019* (French Ministry of Social Affairs, Health and Women's Rights, 2014) came as a continuation of the *Alzheimer Plan 2008-2012* (French Ministry of Social Affairs, Health and Women's Rights, 2008), which had provided specific measures to facilitate the provision of need-appropriate services for YPD. More precisely, it highlighted the need for early identification of the symptoms and proper medical assessments by specialised staff, either in older people geriatric services or in YOD-specialist services, to avoid delays in delivering a diagnosis. It emphasised that information and training should be offered to staff of the services involved, so that they are well equipped to identify the symptoms and refer YPD for further assessments. Information on YOD, how to cope with symptoms, and services that offer support, should also become available to YPD and their families at the stage of diagnosis. A National Reference Centre for YOD (<http://www.centre-alzheimer-jeunes.fr>) has been established to meet these objectives and is currently providing the related support. After diagnosis, appropriate and timely follow-up care should be available to YPD, which includes cognitive stimulation therapy groups and individual cognitive rehabilitation (Soins de Suite et de Réadaptation), to improve the cognitive and social functions of YPD and their ability to perform everyday tasks. Professionals involved in post-diagnostic services, such as occupational physicians and social workers, should receive special training and information on YOD, and services need to work collaboratively to address the needs of YPD and their families. For instance, the plan recognised that YOD has a significant impact on employment and family life. Regarding the former, the plan stresses the unique circumstances for each individual and the need to enable them to remain at work, if they choose or would prefer to do so. The person with the diagnosis should be assisted, accompanied and supported both within and outside the working environment to this end, and their rights should be respected by all parties involved. Options for part-time or remote working via assistive technology should also be available, to prevent a premature exit from the labour market which may have a negative effect on the financial income and self-esteem of YPD. Overall, services should focus on enabling YPD to maintain their autonomy and live at home for as long as possible; age-appropriate day care services should be offered to this end. Once it is not possible for YPD to remain at home, special accommodation and respite units should be

available. With respect to the family of YPD, specialist support is required to address the emotional difficulties and social isolation experienced by all those affected by the condition, and needs-appropriate support that considers the disturbance in family dynamics should be offered. Families affected by YOD should also be financially supported via disability allowance for YPD (Prestation de Compensation du Handicap) and by boosting carers' pensions, since they must usually stop working to care for YPD. Although the above recommendations have not evolved into official standards of good practice or shared tools for YOD service provision, pockets of good practice have emerged after the development of the national dementia plans.

Example of best practice

The nursing home AEDE La Résidence Le Chemin (<https://www.aede.fr/etablissement/residence-le-chemin>) was inaugurated in 2015 by the Minister of Social Affairs, Health and Women's Rights. It is situated in Cesson, Seine-et-Marne, in the south of Paris and offers permanent and temporary accommodation and day-care services for up to 50 YPD. The nursing home was made possible thanks to the *Alzheimer Plan 2008-2012*, which enabled the French state to create a specialised centre for YPD. The eco-responsible home is situated in a well-organised holding of 3,700 m² and the average cost per service recipient is €900 monthly, as part of the costs are covered by social security and departmental aids. There are two types of residence units (accommodating 7 and 14 individuals respectively) to create recognisable reference points, both of which create a home-like environment with home-style kitchens to support the residents' independence. The multidisciplinary team of specially trained staff comprises approximately 85 members, including:

- neuropsychologists,
- physiotherapists,
- occupational therapists,
- psychomotor therapists,
- social workers,
- art therapists,
- music therapists, and
- nurses, among others.

A range of different activities is offered in the nursing home, such as computer workshops, reminiscence groups, reading groups, therapeutic gardening, and balneotherapy with music, colourful lights and essential oils. Needs-appropriate personalised support is delivered in a person-centred manner as the staff members are specially trained to:

- employ positive person work by paying attention to the needs of YPD and enabling them to build on their strengths,
- treat all care recipients with respect and as equals,
- focus on creating an environment that is meaningful, inclusive, lively, safe and secure,
- work collaboratively to include the families of YPD and enable them to play an active role in the personalised project/care plan of their loved ones.

The overall aims of the nursing home are to (a) provide an accepting environment, which focuses on enabling YPD to maintain their abilities/functions and remain socially active, and

(b) promote the well-being of YPD by delaying the progression of the condition via medical and non-medical treatments and stimuli, which may further help to restore brain functions affected by YOD.

Australia

Current estimates suggest that there are between 24,700 and 26,443 YPD in Australia (Australian Institute of Health and Welfare, 2014; Dementia Australia, 2018). The *National Framework for Action on Dementia 2015 – 2019* (Australian Department of Social Services, 2015) was developed under the auspices of the Australian Health Ministers Advisory Council after consulting people with dementia, caregivers, and service providers. The framework is the continuation of the *National Framework for Action on Dementia 2006 –2010* (New South Wales Ministry of Health, 2006) and aims to promote research-informed actions that will improve the quality of life of service users. The 2015 – 2019 framework clearly recognises the different needs of YPD, compared to older people, and the barriers in accessing age-appropriate services. The impact of YOD on employment, family responsibilities and other life stage roles is highlighted, along with the need to provide YPD and their families with YOD-specific information, support and counselling, to enable them to share their concerns with their familial, professional and social environments, and discuss their abilities and changing needs. The framework stresses the critical role of clear and flexible referral and care pathways, as well as the importance of a key worker who will coordinate post-diagnostic care and will enable YPD and their families to maintain their independence, work arrangements, and social and community relationships for as long as possible. Measures are also proposed to meet the needs and preferences of YPD for age-appropriate home, acute, respite, and residential care. Finally, the framework underscores the need to move towards a person-centred approach linked with individualised funding options in care provision.

Guidelines on best practice

Although the *National Framework for Action on Dementia 2015 – 2019* provided recommendations for YOD services (Australian Department of Social Services, 2015), there are no official national care standards for YOD. Nevertheless, there have been comprehensive research reports, which informed the framework and provided detailed recommendations on best practice. Thompson (2011) identified a framework of best practice, which highlighted the importance of enabling YPD to live independently at home for as long as possible via:

- providing a timely diagnosis and early referral to post-diagnostic support,
- offering information to enable understanding of the condition and how to cope,
- facilitating timely access to needs-appropriate services,
- providing early intervention and support for transition points,
- offering opportunities for advance care planning,
- providing support for behaviour management,
- addressing the impact of YOD on lifestyle and family relationships,
- offering age-appropriate respite and residential care, when needed.

Additionally, the Australian Health Services Research Institute produced a comprehensive report on the needs of YPD and families and a feasibility assessment of YOD

services; the report provided a five-stage description of the experience with dementia, along with the systemic circles of impact and the key attributes of services involved in best practice (Westera et al., 2014). The findings of the report underscored the importance of a YOD-specific needs-led model of services, as summarised in Figure 2.

< Fig. 2 here >

Figure 2. Summary of the key characteristics of the YOD-specific model of services identified in the report of the Australian Health Services Research Institute.

The report also highlighted the need for the distinction between different diagnostic groups and their needs, as well as for specially trained staff with case management and effective interpersonal and communication skills, who will engage in well-coordinated interagency collaborations to address the needs of service users.

Example of best practice

The *National Younger Onset Dementia Key Worker Program* (Westera & Fildes, 2016) was launched by Alzheimer's Australia in 2013, to facilitate the provision of services tailored to the needs of YPD and their families/supporters and improve their quality of life. The program was funded by the Australian Government and until 2016 when the final evaluation report was released, 40 YOD key workers had provided support to 1,500 YPD and 2,000 caregivers and family members (Westera & Fildes, 2016), including local indigenous and culturally diverse community groups in rural areas. The key workers could be initially reached either via the National Dementia Helpline or via referral to Alzheimer's Australia by the general practitioner or another health specialist or community professional. The specially trained key workers worked closely with YPD and their families to set goals for the care needed and create individualised care plans. They then creatively navigated across health, ageing, disability, and community services to provide needs-tailored service planning and access to individualised support (Alzheimer's Australia, 2014). As a result of the program, YPD and their families were enabled to better understand the available services and receive individualised information and advice, education, and specialist counselling, while YPD were also offered new opportunities to remain active and socialise in their familial and community environments. The latter was often mediated by key workers' engagement in activities focused on raising awareness in other community groups, to promote the social inclusion of YPD. The consumer-directed approach of the program and the flexibility offered by the ongoing needs assessments and resulting service use enabled YPD and their families to practise individual control and choice over the types of support they received, and YPD to continue living at home for longer (Westera & Fildes, 2016).

An additional objective of the program was to enhance service efficiency by promoting capacity building and sector development. This was achieved via different actions taken by the key workers, such as assisting care organisations to better understand YOD and adjust their

services to the needs of YPD and their families, and working closely with medical professionals and various service providers to improve coordination of and collaboration between services at a local level.

The *National Younger Onset Dementia Key Worker Program* was evaluated against the recommendations on best practice provided by the Australian Health Services Research Institute (Westera et al., 2014). The official evaluation report (Westera & Fildes, 2016) highlighted the strengths of the program, which lie in:

- facilitating the provision of individualised needs-led support across the experience with YOD,
- empowering YPD and their families to access services themselves and remain socially active within their community,
- the expertise and enterprise of the program's staff in building capacity within local communities, to enable YPD and their families to live their lives in a meaningful way, and
- the consumer-directed approach, which not only promotes the quality of life of service users but also of the society as a whole.

Discussion and implications for the future

It is evident that a lot of progress has been made during the recent years in evidence-based practice for YOD. Although the extent of detail in national guidelines varies between countries, there are significant similarities which indicate a common understanding of best practice. Overall, the fundamental elements of best practice appear to comprise the following:

- personalised age-appropriate needs-led services delivered in a timely and uninterrupted manner and using a person-centred approach, to enable YPD to live well and independently at home and in the community for as long as possible,
- employing a family-oriented approach which also addresses the individual needs of caregivers and family members, the needs of the family as a whole, and the relational needs of those affected by the diagnosis,
- clear, affordable, effective, and easily accessible diagnostic and post-diagnostic care pathways across the experience with YOD, and
- appropriate coordination of and collaboration between services, to provide continuity and address the changing needs of YPD and their families over time.

Despite the high level of agreement on these elements, key issues remain to be addressed. Although it is legitimate to pool together empirical studies and YOD systematic reviews to inform national dementia strategies, transferring research evidence from one country to another is likely to be a highly complex task due to significant differences between countries in land mass, organisational structures, service commissioning, policies, available funds, economic environment, population composition, social norms, and cultural values. There is potential risk in adopting policies on paper which cannot be implemented in real life due to a lack of 'know-how', resources, shared tools, and understanding of country-specific factors that may have significant practical and financial implications. For instance, in the Netherlands, which is probably the leading country both in research and best practice in YOD, there is a well-coordinated and coherent approach towards establishing a self-sufficient system of services.

This may be very difficult to replicate in other countries with larger land mass or different population dispersion, such as the UK and Australia; it is not coincidental that, in most countries, best practice seems to be taking place close to urban centres, where more funds are available and the health care settings are relatively more stable compared to rural or remote areas with low population density. Furthermore, countries with significant variation in the ethnic, social or cultural background of their population, may need to consider the linguistic barriers and cultural prejudices that prevent YPD from Black, Asian and Minority Ethnic communities from accessing services (Osman & Carare, 2015), especially given the younger age profile of these communities (Dementia UK, 2007). Additional strategies may be needed to ensure that individuals and families are not socially marginalised or experience difficulty accessing formal services (Osman & Carare, 2015). In this context, it is reasonable to expect different challenges to emerge when implementing similar evidence-based guidelines in different countries.

Most evidence-based guidelines on needs of YPD and their families are partly informed by studies which have employed a problem-focused approach, to identify the shortcomings of services. Although these findings are useful, they cannot provide concrete evidence on the types of support that meet the needs of YPD and their families in real life and how exactly services should be delivered to ensure service efficiency. As national guidelines begin to be implemented in different countries, it will be useful to conduct studies, such as the Angela Project in the UK (Stamou et al., 2018), which gather detailed accounts of real-life positive experiences with services, to acquire a better understanding of ‘what works’ and why. Evaluation models will also be useful when national YOD care standards are developed and implemented. Additionally, research studies that have focused on caregivers’ perspectives, may not accurately depict all needs of YPD, particularly those of people who live alone and do not have access to informal care. Longitudinal studies, which will include groups under-represented in research, could enable a more thorough understanding of YPD needs and reduce health inequalities. For instance, studies on palliative or end of life care are currently scarce, which indicates an important gap in knowledge regarding critical stages in service users’ lives. Considering the ethical, cultural, legal, and social dimensions of palliative care, it is also questionable if research findings could be transferred from one country to another. Finally, given that alcohol use disorders constitute one of the strongest modifiable risk factors for YOD (Schwarzinger et al., 2018), alcohol policies need to be considered in dementia plans for the prevention and treatment of YOD.

Conclusion

Despite the gaps in research and practice, current evidence suggests that significant progress has been made towards establishing the basic principles of good practice in YOD and the fundamental attributes of age-appropriate needs-led services. The increasing pockets of good practice across the world allow for an optimistic view regarding more effective services for YOD in the future.

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