

COMMENTARY

The critical role of clinical champions: Commentary on “Establishing and sustaining high-quality services for people with young-onset dementia: The perspective of senior service providers and commissioners”

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Introduction

Delivery of high-quality and age-appropriate care for the estimated 3.9 million people living with young-onset dementia (YOD; with symptom onset prior to 65 years of age) (Hendriks *et al.*, 2021) is a global challenge. In YOD, symptom onset occurs “off-time” and earlier than is expected in the population. As such, most dementia care is designed for older people and is integrated into existing elder and/or health care systems (Draper and Withall, 2016). It is well established that specialized services designed for and delivered to meet the unique experience of YOD are most effective and preferred by people with YOD. For example, Stamou, La Fontaine, Gage, *et al.* (2021) identified that specialized YOD services performed better on all indicators of care quality than other care providers (e.g. general practitioners). People with YOD and their families consistently report a preference for services designed with their unique needs in mind (Bannon *et al.*, 2022; Carter *et al.*, 2018; Cations *et al.*, 2022; Mayrhofer *et al.*, 2018). Indeed, many people with YOD and their families choose not to access a dementia service recommended to them because of concerns about the service being able to meet their needs (Cations *et al.*, 2017).

Barriers to the delivery of YOD-specific health and care services occur at the individual, provider, and system levels. For example, delayed help seeking can occur due to fear, stigma, and lack of insight into impairments (O’Malley *et al.*, 2021). Health and social care professionals rarely receive training about YOD, and most provide care to a person with YOD only infrequently without ready access to mentors with expertise in the area (Couzner *et al.*, 2022). At the system level, establishing the cost-effectiveness of specialized services can be challenging especially where people with YOD are spread across a large geographical area (Burkinshaw *et al.*, 2023). Because YOD care is

delivered across services (and in some countries, sectors), fragmentation can limit care quality (Day *et al.*, 2022). Even where adequate funding is available, people with YOD face difficulties finding appropriate services with which to use their funding (Cations *et al.*, 2022). These and other factors mean that access to specialized YOD services is patchy and inequitable in most countries (Bakker *et al.*, 2021).

Missing from the literature has been an exploration of factors that may enable the establishment and sustainment of YOD-specific services. This gap in the literature leaves service designers and funders to implement change without evidence-based guidance. As such, Oyeboode *et al.*’s (2023) recent qualitative study exploring key facilitating factors for professional engagement in delivering YOD-specific services in the United Kingdom is well timed.

Chief among the themes identified by Oyeboode *et al.* (2023) is that an experienced and committed champion of change is very often required to trigger the establishment of YOD-specific services. Clinical champions can be credited for many advances in healthcare delivery that are now embedded in systems across the world (Santos *et al.*, 2022). Evidence from implementation science literature shows that the adoption of innovation in healthcare is improved when devoted champions facilitate implementation, though the quality of evidence remains mixed (Santos *et al.*, 2022). Theoretical models suggest that champions promote the engagement of their peers in a cause and build buy-in for change (Morena *et al.*, 2022). They help to shape positive attitudes toward the planned change (and intention for action) by exerting their “power” cultivated via being trustworthy, credible, and well-liked. This can facilitate a shift in professional perceptions about what should be considered “core business” (Morena *et al.*, 2022).

Given the value of clinical champions in establishing high-quality YOD care services, determining how to identify and/or develop such champions is

the critical next step. Effective champions tend to have excellent communication and interpersonal skills, can develop meaningful relationships with their peers, retain high levels of technical expertise, and may have some prior experience with successfully implementing change (even if only minor; Miech *et al.*, 2018). They also have usually worked within a service or sector for a long time, allowing them to understand how the service works and identify the available levers for change (Morena *et al.*, 2022). In the recruitment, identification, and training of champions, attention should be paid to the relationships that exist within services. Champions are often not in formal positions of power but rather hold informal “power” based on their trust and influence (Valente and Pumpuang, 2007). As noted by Oyeboode *et al.* (2023), potential champions may also need empowerment to recognize their own ability to enact change (Morena, *et al.*, 2022).

In the context of YOD care, cultivating champions may be assisted by ensuring that motivated professionals working within existing services have access to existing champions working in other services. A “hub-and-spoke” model may be most appropriate where it is not feasible to establish large service centers in all regions. In this model, remote service providers (“spokes”) have access to expertise and mentoring from professionals working at centralized and well-developed specialized YOD services (“hubs”) (Bakker *et al.*, 2021; Cations *et al.*, 2021). The development of strong and active networks of YOD-informed professionals can promote the sustained enthusiasm required to implement change (Day *et al.*, 2022). Within local areas, open and regular communication between potential YOD champions can promote service integration and streamlined care (Stamou, La Fontaine, O’Malley, *et al.*, 2021; Day *et al.*, 2022). Potential champions may also need resources to build their knowledge and skills in driving and implementing change (Bonawitz *et al.*, 2020). These resources should include access to patient and public involvement, as lived-experience voices can empower champions, promote their enthusiasm, and influence leadership decision making (Pizzo *et al.*, 2015).

Of course, the need for champions implies that specialized YOD services continue to be delivered outside “business as usual” and beyond the remit of a universal healthcare system. Indeed, access to specialized services remains the exception rather than the norm for most people with YOD (Bakker *et al.*, 2021). A major consequence is inequity in care and, by extension, outcomes. Inequity will be present anywhere that a passionate clinical champion is needed to drive the implementation of a

service for which there is clinical demand and an established evidence base. Oyeboode *et al.* (2023) also note the critical risk to the sustainability of specialized services where they are reliant on individual champions and time-limited funding. This message is echoed by Burkinshaw *et al.* (2023), who describe the inherent tension between the priorities of policy makers and service planners (e.g. cost-effectiveness and efficiency of care) and the needs of people with YOD (e.g. thorough and often time-intensive assessment and care). Striking a balance in this context will be crucial toward the goal of embedding specialized YOD services into “business as usual.”

Oyeboode *et al.* (2023) present elegant examples of how YOD-specific services have been established and maintained within existing health and social care systems. Scaling these achievements out to other regions and settings will in part rely on the continued dedication of existing and emerging clinical champions. Future research that examines the characteristics of clinical champions in YOD care, as well as factors that empower them to step into action, will help to drive the expanded availability of best practices to all those living with YOD.

Conflicts of interest

None.

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References

- Bakker, C., Verboom, M. and Koopmans, R.** (2021). Reimagining postdiagnostic care and support in young-onset dementia. *Journal of the American Medical Directors Association*, 23, 261–265.
- Bannon, S. M., Reichman, M. R., Wang, K., Uppal, S., Grunberg, V. A., Vranceanu, A.-M.** (2022). A qualitative meta-synthesis of common and unique preferences for supportive services among persons with young onset dementia and their caregivers. *Dementia*, 21, 519–539.
- Bonawitz, K. et al.** (2020). Champions in context: which attributes matter for change efforts in healthcare? *Implementation Science*, 15, 62. <https://doi.org/10.1186/s13012-020-01024-9>.

- Burkinshaw, K., Tsourtos, G. and Cations, M.** (2023). System and policy-level barriers and facilitators for timely and accurate diagnosis of young onset dementia. *International Journal of Geriatric Psychiatry*, 38, e5859.
- Carter, J. E., Oyeboode, J. R. and Koopmans, R. T. C. M.** (2018). Young-onset dementia and the need for specialist care: a national and international perspective. *Aging & Mental Health*, 22, 468–473. <https://doi.org/10.1080/13607863.2016.1257563>.
- Cations, M. et al.** (2017). Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. *PLOS ONE*, 12, e0180935. <https://doi.org/10.1371/journal.pone.0180935>.
- Cations, M. et al.** (2021). A call to action for the improved identification, diagnosis, treatment and care of people with young onset dementia. *Australian & New Zealand Journal of Psychiatry*, 55, 837–840. <https://doi.org/10.1177/00048674211037542>.
- Cations, M., Day, S., Laver, K., Withall, A., Draper, B.** (2022). Post-diagnosis young-onset dementia care in the National Disability Insurance Scheme. *Australian & New Zealand Journal of Psychiatry*, 56, 270–280. <https://doi.org/10.1177/00048674211011699>.
- Couzner, L. et al.** (2022). What do health professionals need to know about young onset dementia? An international Delphi consensus study. *BMC Health Services Research*, 22, 1–12.
- Day, S., Couzner, L., Laver, K. E., Withall, A., Draper, B., Cations, M.** (2022). Cross-sector learning collaboratives can improve post-diagnosis care integration for people with young onset dementia. *Health & Social Care in the Community*, 30, e6135–e6144. <https://doi.org/10.1111/hsc.14051>.
- Draper, B. and Withall, A.** (2016). Young onset dementia. *Internal Medicine Journal*, 46, 779–786.
- Hendriks, S. et al.** (2021). Global prevalence of young-onset dementia: a systematic review and meta-analysis. *JAMA Neurology*, 78, 1080–1090.
- Mayrhofer, A. M. et al.** (2018). Young onset dementia: public involvement in co-designing community-based support. *Dementia*, 19, 1471301218793463–1066.
- Miech, E. J., Rattray, N. A., Flanagan, M. E., Damschroder, L., Schmid, A. A., Damush, T. M.** (2018). Inside help: an integrative review of champions in healthcare-related implementation. *SAGE Open Medicine*, 6, 2050312118773261.
- Morena, A. L., Gaias, L. M. and Larkin, C.** (2022). Understanding the role of clinical champions and their impact on clinician behavior change: the need for causal pathway mechanisms. *Frontiers in Health Services*, 2, 1–14. <https://www.frontiersin.org/articles/10.3389/frhs.2022.896885>
- O'Malley, M., Carter, J., Stamou, V., LaFontaine, J., Oyeboode, J., Parkes, J.** (2021). Receiving a diagnosis of young onset dementia: a scoping review of lived experiences. *Aging & Mental Health*, 25, 1–12.
- Oyeboode, J. R. et al.** (2023). Establishing and sustaining high quality services for people with young onset dementia: The perspective of senior service providers and commissioners. *International Psychogeriatrics*, 1–10 (Preprint).
- Pizzo, E., Doyle, C., Matthews, R., Barlow, J.** (2015). Patient and public involvement: how much do we spend and what are the benefits? *Health Expectations*, 18, 1918–1926. <https://doi.org/10.1111/hex.12204>.
- Santos, W. J., Graham, I. D., Lalonde, M., Demery Varin, M., Squires, J. E.** (2022). The effectiveness of champions in implementing innovations in health care: a systematic review. *Implementation Science Communications*, 3, 80. <https://doi.org/10.1186/s43058-022-00315-0>.
- Stamou, V., La Fontaine, J., O'Malley, M. et al.** (2021). Helpful post-diagnostic services for young onset dementia: findings and recommendations from the Angela Project. *Health and Social Care in the Community*, 30, 142–153.
- Stamou, V., La Fontaine, J., Gage, H. et al.** (2021). Services for people with young onset dementia: the 'Angela' project national UK survey of service use and satisfaction. *International Journal of Geriatric Psychiatry*, 36, 411–422.
- Valente, T. W. and Pumpuang, P.** (2007). Identifying opinion leaders to promote behavior change. *Health Education & Behavior*, 34, 881–896.