

Young-onset dementia – possible causes and effects on patients’ lives

Demencja o wczesnym początku – prawdopodobne przyczyny i wpływ choroby na życie pacjentów

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Abstract

For years, there has been an ongoing myth that dementia diseases affect only elderly people. However, in recent years, with the development of medicine and growing awareness of “new” diseases, more and more cases of the so-called “young-onset dementia”, also known as “early-onset dementia” or even “working-age dementia” have been described. The disease can lead to job loss, changes in relationships with loved ones, and the necessity of providing constant care. The story of a 19-year-old boy from China who has been recently diagnosed with Alzheimer’s disease (Jia *et al.*, 2023) inspired us to find out more about that condition, as there are still gaps in knowledge about that topic and a lot to discover, especially among people outside the medical environment. Despite claims that most of the information about this condition so far comprises theories, and there is still extensive research to be done, the authors decided to gather the key data and summarise them in this narrative review, with a view to raising awareness about this growing problem and about the lack of correct diagnosis, help for the patients, and the effects this condition has on the daily life of young people.

Keywords: Alzheimer’s dementia, early-onset Alzheimer’s disease, late-onset Alzheimer’s disease, frontotemporal dementia, neurocognitive disorders

Streszczenie

Przez wiele lat panowało przekonanie, że choroby otępienne dotyczą wyłącznie osób starszych. W ostatnich latach, wraz z postępem medycyny i podnoszeniem świadomości na temat „nowych” chorób, opisuje się coraz więcej przypadków tzw. otępienia o wczesnym początku, znanego także jako otępienie wczesne. Jako że opisywana choroba dotyka osoby w wieku produkcyjnym, stanowi spore wyzwanie dla całego społeczeństwa. Może prowadzić do utraty pracy, zmiany relacji z bliskimi oraz konieczności zapewnienia stałej opieki. Historia 19-letniego chłopca z Chin, u którego niedawno zdiagnozowano chorobę Alzheimera (Jia *et al.*, 2023), zainspirowała autorów do zgłębienia tego tematu. Wciąż niewiele wiadomo na temat etiopatogenezy otępienia o wczesnym początku, wiele pytań pozostaje bez odpowiedzi. Chociaż większość informacji na temat tej choroby ma na razie charakter przypuszczeń, autorzy postanowili zebrać najważniejsze doniesienia i podsumować je w formie przeglądu narracyjnego. Celem jest podnoszenie świadomości wśród pracowników ochrony zdrowia oraz pacjentów i ich rodzin na temat demencji o wczesnym początku oraz wpływu tej choroby na codzienne życie młodych ludzi. Niniejszy przegląd skupia się zatem na czynnikach mających potencjalny wpływ na rozwój chorób otępiennych u osób poniżej 65. roku życia, problemach diagnostycznych, a także na konsekwencjach dla pacjentów, ich rodzin oraz całego społeczeństwa, wynikających z rosnącej zapadalności na demencję.

Słowa kluczowe: otępienie typu alzheimerskiego, choroba Alzheimera z wczesnym początkiem, choroba Alzheimera z późnym początkiem, otępienie czołowo-skroniowe, zaburzenia neuropsychiczne

INTRODUCTION

The recently described case of a young boy from China shows that Alzheimer's disease can affect even someone as young as a 19-year-old. The patient concerned started experiencing the symptoms when he was 17, and his tests for any known genetic markers of early Alzheimer's disease were negative (Jia et al., 2023). Dementia is generally perceived as a condition affecting older people, and the estimated frequency of late-onset dementia (LOD) increases exponentially with age. This is accompanied by an impairment in cortical functions such as memory, orientation, counting, thinking, understanding, and learning. At later stages, patients might experience disturbances in behaviour and emotional perception, delusions, and hallucinations. The condition can also result in personality changes and social withdrawal (Fatima et al., 2022). The disorder increasingly affects younger people (under 65 years old), which can lead to the so-called "young-onset dementia" (YOD), also known as "early-onset dementia" (EOD), which currently affects about 8% of the population (Pawlowski et al., 2020).

The authors of this paper analysed the available literature with the aim of:

1. dispelling the myth that neurodegenerative/dementia diseases occur in elderly people only;
2. outlining the epidemiology of YOD;
3. presenting the existing hypotheses about possible aetio-pathogenesis of YOD;
4. discussing the influence of YOD on people's lives.

MATERIALS AND METHODS

In March 2023, a literature search was performed to conduct this systematic review. The authors searched through the PubMed and Google Scholar electronic databases. Only these two databases were used, as the aim was to focus on the most accessible journals and search engines. The authors did not exclude any type of articles. No particular language was set. The keyword used was: "young-onset dementia". On Google Scholar, no particular language was chosen, the results were sorted by accuracy, and no specific type of publication was picked. The keywords used were: "young-onset dementia" and "working-age dementia".

Inclusion criteria:

1. focusing on neurodegeneration affecting young people;
2. bringing up the subject of growing prevalence and detectability of dementia diseases among young adults.

Exclusion criteria:

1. articles focused only on LOD;
2. articles about cortical changes in non-neurodegenerative disorders.

No restrictions for age (other than younger than 65-year-olds according to the definition of YOD), sex, ethnicity etc. of people described in the papers was set.

RESULTS

In order to adapt to the requirements of the paper concerning the limit of no more than 30 references, a total 26 articles were identified and synthesised in this review. The articles found on Google were included as well, as they discussed the outlook of the people outside the medical world.

DISCUSSION

Statistics

It needs to be stressed that YOD tends to be misdiagnosed, which can lead to a possible underestimation of existing statistics. Harvey et al. (2003) have reported that YOD affects 54.0 people per 100,000 population, but an underestimation was likely, as people with the disease were identified retrospectively, with a register-based approach. Also, many new diagnostic criteria were introduced during the 2010s, so the increase in the neurodegenerative conditions over the decades cannot be determined with an absolute certainty. Compared to LOD, patients with YOD are diagnosed with a greater delay, and they are more likely to be misdiagnosed because physicians rarely see such cases in their practice (Novek and Menec, 2021). Hendriks et al. (2021), in their systematic review and meta-analysis, gathered the statistics of age-standardised prevalence that estimates an increase from 1.1 cases per 100,000 population in the group aged 30 to 34 years to 77.4 cases per 100,000 population in the group aged 60 to 64 years. Another global age-standardised prevalence reported in the same review was 119.0 cases per 100,000 population in the maximum age span of 30 to 64 years, which corresponds to an absolute number of 3.9 million people living with YOD worldwide. New findings show that 70,800 people with YOD live in the UK alone, which is already called a "hidden population" – a rise of 28,800 (69%) since 2014 (Dementia UK, 2022).

Aetiology

The aetiology of YOD does not usually vary from LOD. Most of elderly patients' diseases are caused by neurodegeneration progressing with age or cerebrovascular disorders. Cognitive function loss in younger patients is due to factors that can be divided into several categories outlined below.

Primary neurodegenerative diseases

All neurodegenerative conditions can occur not only in elderly patients, but also younger individuals. Examples include Alzheimer's disease, frontotemporal lobe degeneration, dementia with Lewy bodies, motor neuron disease, Huntington's disease, amyotrophic lateral sclerosis, Parkinson's disease dementia, and hereditary hemochromatosis (Loi et al., 2023; van de Veen et al., 2021). Genetic factors can be involved in the development of some of these

conditions (Devenney et al., 2019; Sivasathaseelan et al., 2019), and all of them may also occur in older age, highlighting the similarity between YOD and LOD. Overall, the genetic origin is important both in YOD and LOD.

Cerebrovascular disorder

Vascular dementias in younger individuals, including LOD, are among the most common causes of cognitive impairment. They lead to decreased cerebral blood flow, haemodynamic impairments and, ultimately, brain hypoxia. It is worth mentioning that cardiovascular risk factors, such as hypertension or hypercholesterolaemia, influence the brain vessels as well, and can accelerate the development of cerebrovascular diseases, including YOD (Ridley et al., 2013). Hypertension seems to be particularly dangerous with respect to cognitive impairment, as it leads to blood vessel remodelling and a significant reduction in their lumen.

Inflammation

Inflammatory diseases, especially systemic or neurological disorders, have also been claimed as possible causes of YOD. Researchers have identified a string of those conditions, including multiple sclerosis, chronic meningitis, autoimmune connective tissue disorders, polyarteritis, neurosarcoidosis, hepatic encephalopathy, coeliac disease, and Sjögren's syndrome (van de Veen et al., 2021). A very interesting aspect is the role of the gut–brain axis in the development of neurological conditions. Researchers have pointed out that gut microbiota composition may correlate with dementia morbidity, while rich gut microflora could have a positive influence on brain functions (Cryan et al., 2020).

Infections and prions

Diseases caused by microbiological factors are also being considered as possible YOD triggers. For example, some authors have mentioned neurosyphilis, human immunodeficiency virus (Loi et al., 2023), transmissible spongiform encephalopathy, cytomegalovirus encephalitis, Lyme disease, tuberculosis, fungal infection, toxoplasmosis, and other conditions in this context (van de Veen et al., 2021). Regarding neurosyphilis, it may cause a condition called dementia paralytica – a progressive disease presenting with memory loss, constricted judgment, disorientation and even seizures. Also, human immunodeficiency virus (HIV) infection may induce the so-called HIV dementia, consisting in basal ganglia neurodegeneration. Patients affected by this condition have proper recognition, but suffer from motor slowness, depression, and disrupted hand-eye coordination and memory (Pluta et al., 2018; Almeida and Lautenschlager, 2005).

Toxic and metabolic diseases

The most common disorders leading to cognitive impairment are related to heavy alcohol abuse (Loi et al., 2023; van de Veen et al., 2021). High consumption of ethanol can affect many parts of the brain, such as frontal cortex,

hippocampus, hypothalamus, amygdala, and even cerebellum (Cations et al., 2019), by causing oxidative stress, and disturbing neurogenesis and metabolism of brain tissue. On the other hand, alcoholism often leads to malnutrition and vitamin deficits. Microelements such as thiamine, niacin, vitamin E or D are crucial for the human nervous system, so their deficiencies yield severe disturbances in neuronal functioning (Ridley et al., 2013). Luckily, alcohol abuse seems to be one of the modifiable factors. It has been proved by neuroimaging that abstinence could reverse white matter loss to some extent (Ridley et al., 2013). Moreover, brain atrophy can also be induced by drugs (hashish, cocaine, barbiturates) as well as heavy metal (lead, mercury, arsenic, aluminium) and carbon monoxide poisoning (van de Veen et al., 2021). Also, metabolic intoxication could be dangerous concerning YOD development and harmful metabolite accumulation resulting from conditions such as uraemia, porphyria, Wilson's disease, hyperammonaemia or homocystinuria (van de Veen et al., 2021).

Mitochondrial disorders

Examples of disorders affecting brain condition include mitochondrial myopathy and encephalopathy, lactic acidosis and stroke (MELAS) and myoclonic epilepsy with ragged-red fibres (van de Veen et al., 2021). MELAS is a rare, monogenic disease, but it is highly associated with YOD, as it leads to stroke episodes before the age of 40, encephalopathy and cognitive function loss (Almeida and Lautenschlager, 2005).

Lysosomal disorders

For instance, Tay–Sachs disease, a genetic storage disorder with shortage of β -hexosaminidase A, a lysosomal enzyme, can lead to brain tissue damage because of ganglioside GM2 aggregation (van de Veen et al., 2021). The disorder is associated with acute neurodegeneration.

Leukodystrophies

Leukodystrophies are hereditary white matter diseases affecting astrocytes, oligodendrocytes, and microglial cells, disturbing myelination and, consequently, nerve impulse conduction (van de Veen et al., 2021). For example, cerebral adrenoleukodystrophy leads to quick cognitive function loss, ataxia and even seizures.

Head/brain injuries

Injuries of the central nervous system have a really strong correlation with dementia development in young individuals (Loi et al., 2023; van de Veen et al., 2021). For example, chronic traumatic encephalopathy is one of conditions commonly observed after repeated head injuries, especially among combat sport players (Cations et al., 2019). However, single brain traumas may also affect cognitive skills. Mendez (2017) indicated that moderate to severe head injury correlates with higher risk of developing neurodegenerative disorders, including Alzheimer's disease. Cerebral

tumours and abscesses or subdural haematoma can also impact brain conditions involving dementia (van de Veen et al., 2021).

Endocrine diseases

Endocrine malfunctions (i.e. diabetes mellitus, thyroid, parathyroid or adrenal diseases) are believed to be other risk factors for developing dementia at an early age (van de Veen et al., 2021). For instance, diabetes mellitus, especially type 1, affects patients' brain functioning for decades through fluctuations in blood glucose levels (hyper- or hypoglycaemia) and their implications. Early-onset diabetes correlates with higher risk of cognitive decline. On the other hand, hypo- and hyperthyroidism affect patients' psychological functioning and can induce not only anxiety disorder, mania or depression, but memory, response time and concentration impairments as well (Przybylak et al., 2021).

Psychiatric conditions

Depression, anxiety, conversion disorders, mania and schizophrenia (van de Veen et al., 2021) also affect the condition of the central nervous system and may have some contribution in developing dementia diseases. Depression seems to be comorbid with dementia in many cases, however, it is not always obvious which of the conditions occurs first. Researchers, in their efforts to determine whether depression is a cause or effect of cognitive impairment, have discovered that early-life depression significantly increases the risk of developing dementia. Nevertheless, some authors point out that this mental condition could be also prodromal to some neurodegenerative diseases or even their complication (Bennett and Thomas, 2014).

Genetic and autoimmune disorders

It is worth mentioning that many patients with Down's syndrome under the age of 65 show dementia symptoms (Loi et al., 2023; van de Veen et al., 2021), though not every patient with Down's syndrome lives long enough to develop dementia. The fact that every patient with Down's syndrome will develop Alzheimer's disease is caused by the overproduction of amyloid precursor protein (APP) as a result of chromosomal changes. Although the retardation of intellectual development does not fit into the definition of dementia, so Down's syndrome cannot be considered as its type, the authors decided to include it in the discussion because of a significantly young age Alzheimer's disease occurs in those cases. On the other hand, patients suffering from autoimmune disorders can also be afflicted by cognitive decline – a relevant example of such a disease is an autoimmune encephalitis, leading to the so-called autoimmune dementia (AiD). A string of autoantibodies relevant to this disorder have been identified: ANNA-1, ANNA-2, ANNA-3, PCA-2, NMDAR, and many others. In contradistinction to typical LOD, autoimmune one is more likely to emerge in younger age (<45), especially in patients already suffering from autoimmune disorders (Long and Day, 2018).

It needs to be highlighted that some of the causes and risk factors for YOD are more frequently identified than others. Van de Veen et al. (2021) summarise the most common reasons of EOD in their review from 2021: "The most frequently mentioned aetiologies included Alzheimer's disease (35 publications), frontotemporal dementia (30), Huntington's disease (22), alcohol-related dementias (21), and infectious diseases (26), such as human immunodeficiency virus (HIV) and prion diseases" (p. 1908). Nevertheless, other factors mentioned above are also prominent and should not be overlooked, as their impacts may aggregate and raise the risk of developing a neurodegenerative disease.

Consequences and influence on people's lives

Emotional condition

The consequences of YOD affect not only the diagnosed person, but the whole family (Svanberg et al., 2011; Wiggins et al., 2023). Crucially, many people learning about the diagnosis of YOD, or even finding out that they have or soon will have a cognitive impairment at a young age, become depressed, which decreases their ability to cope with their lives. Sometimes, they feel guilty about the impact their condition has on their families, especially their children (Wiggins et al., 2023), fearing that they can pass their disability on their children. The spouses of patients with YOD are usually concerned about dependency, experience anxiety, and have increased risk of depression (Svanberg et al., 2011). It is also worth mentioning that emotional breakdowns, as well as impairments in cognitive functions may also lead to inappropriate behaviour, including psychotic symptoms and a tendency to aggressive behaviours, such as criminal and antisocial acts.

Relationships

Dementia at any age causes difficulties in daily living and relationships, but one of the reasons why it happens to be even harder for younger people is that it comes when it is least expected, and when most people expect to be in their prime. Another important reason is that young people tend to be misdiagnosed, which leads to many misunderstandings, while the uncertainty of diagnosis results in significant emotional impacts (Wiggins et al., 2023). Many spouses of individuals with YOD claim that they feel "robbed of their future" and need to assume the role of a parent rather than a partner, which includes issues with intimacy and sexuality (Svanberg et al., 2011). Importantly, the development of a neurodegenerative disorder is a prolonged process that includes behavioural changes that may not be recognised at first as symptoms of a neurological disease. Also, as mentioned above, the diagnostic process is long and requires a lot of involvement from the patients but also from their relatives.

Work and finances

Most people diagnosed with YOD admit that their first symptoms of dementia appeared while they were at work.

Patients report that they tended to forget about job assignments or simply were unable to carry on, which made some of them stop working due to feeling incapable of continuing. Still, there are patients who continued working for years after being diagnosed with YOD, though there are many reports about being treated unfairly by their employers who simply assumed that their job performance would decrease. Work is therapeutic, but there are ample reports about being abused or discriminated by both employers and co-workers because of YOD diagnosis (Alzheimer's Society, 2023). The lack of visibility in society is another cause of emotional issues mentioned by the individuals with YOD (Wiggins et al., 2023). Most individuals with YOD retire prematurely on medical grounds, which results not only in losing their income, but also their ability of making further contributions to their pension funds (Mayrhofer et al., 2021).

Care partners

As mentioned above, spouses turned into care partners tend to feel uncomfortable with their new role (Svanberg et al., 2011). Svanberg et al. also found that most spouses of patients with YOD develop mild to moderate depression, have high stress scores, and claim to receive little support from social services. Furthermore, they say their home turns into "an institution". Authors also implicate the lack of visibility in health care (Wiggins et al., 2023) and the fact that the age-appropriate health support in many countries is largely unavailable (Bakker et al., 2022). Another study (Kaiser and Panegyres, 2006) identified elevated levels of stress among care partners of individuals with YOD caused by the possible hallucinations, anxiety, and depression in patients. The main concerns reported by care partners include fear of dependency and increased depression, the latter being especially prevalent among the spouses of patients with frontotemporal lobar degeneration (Kaiser and Panegyres, 2006).

CONCLUSION

Every year, more and more people are diagnosed with dementia. When it occurs in patients younger than 65 years of age, the diagnosis is YOD. As mentioned above, YOD can affect individuals as young as 19-year-olds (Jia et al., 2023). Even though such extreme cases are rare, they cannot be ignored. The gap between the mentioned patient's first symptoms and the diagnosis proves extensive research still needs to be done to improve the process of diagnosing young people. Because of the persistent myth that dementia affects only elderly people, many young people with dementia are misdiagnosed. Therefore, it is hard to give precise statistics about how many people live with YOD.

The known aetiology of YOD includes primary neurodegenerative diseases, cerebrovascular disorders, inflammation, infections and prions, toxic and metabolic diseases, mitochondrial disorders, lysosomal disorders, leukodystrophies, head/brain injuries, and genetic and autoimmune

disorders. Since YOD affects cognitive functions, it has an impact on various aspects of people's lives, including their emotional status, relationships, work, and finances. In addition, it affects the lives of their families. Even though the prevalence is relatively rare, the diagnosis is more complex than in cases of late-onset dementia, which is why more research should be done in this area.

Conflict of interest

The authors declare that they have no conflict of interest related to the publication of this article.

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Author contributions

Original concept of study: JLew. Collection, recording and/or compilation of data: KKL, JLip. Analysis and interpretation of data: KKL, JLip, JLew. Writing of manuscript: KKL, JLip, JLew. Critical review of manuscript: KKL, JLip. Final approval of manuscript: KKL, JLip, JLew.

References

- Almeida OP, Lautenschlager NT: Dementia associated with infectious diseases. *Int Psychogeriatr* 2005; 17 Suppl 1: S65–S77.
- Alzheimer's Society: Living with dementia as a younger person. Available from: <https://www.alzheimers.org.uk/about-dementia/types-dementia/particular-issues-faced-younger-people-dementia#content-start> [cited: 1 June 2023].
- Bakker C, Verboom M, Koopmans R: Reimagining postdiagnostic care and support in young-onset dementia. *J Am Med Dir Assoc* 2022; 23: 261–265.
- Bennett S, Thomas AJ: Depression and dementia: cause, consequence or coincidence? *Maturitas* 2014; 79: 184–190.
- Cations M, Withall A, Draper B: Modifiable risk factors for young onset dementia. *Curr Opin Psychiatry* 2019; 32: 138–143.
- Cryan JF, O'Riordan KJ, Sandhu K et al.: The gut microbiome in neurological disorders. *Lancet Neurol* 2020; 19: 179–194.
- Dementia UK: New figures show 70,800 UK adults are affected by young onset dementia. Available from: <https://www.dementiauk.org/new-figures-adults-affected-young-onset-dementia/> [published: 14 September 2022; cited: 1 June 2023].
- Devenney EM, Ahmed RM, Hodges JR: Frontotemporal dementia. *Handb Clin Neurol* 2019; 167: 279–299.
- Fatima K, Mehendale AM, Reddy H: Young-onset dementia and neurodegenerative disorders of the young with an emphasis on clinical manifestations. *Cureus* 2022; 14: e30025.
- Harvey RJ, Skelton-Robinson M, Rossor MN: The prevalence and causes of dementia in people under the age of 65 years. *J Neurol Neurosurg Psychiatry* 2003; 74: 1206–1209.
- Hendriks S, Peetoom K, Bakker C et al.: Global prevalence of young-onset dementia: a systematic review and meta-analysis. *JAMA Neurol* 2021; 78: 1080–1090.
- Jia J, Zhang Y, Shi Y et al.: Erratum to: A 19-year-old adolescent with probable Alzheimer's disease. *J Alzheimers Dis* 2023; 92: 1501–1502. Erratum for: *J Alzheimers Dis* 2023; 91: 915–922.
- Kaiser S, Panegyres PK: The psychosocial impact of young onset dementia on spouses. *Am J Alzheimers Dis Other Demen* 2006; 21: 398–402.
- Loi SM, Cations M, Velakoulis D: Young-onset dementia diagnosis, management and care: a narrative review. *Med J Aust* 2023; 218: 182–189.
- Long JM, Day GS: Autoimmune dementia. *Semin Neurol* 2018; 38: 303–315.
- Mayrhofer AM, Greenwood N, Smeeton N et al.: Understanding the financial impact of a diagnosis of young onset dementia on individuals and families in the United Kingdom: results of an online survey. *Health Soc Care Community* 2021; 29: 664–671.
- Mendez MF: What is the relationship of traumatic brain injury to dementia? *J Alzheimers Dis* 2017; 57: 667–681.
- Novak S, Menec VH: Age, dementia, and diagnostic candidacy: examining the diagnosis of young onset dementia using the candidacy framework. *Qual Health Res* 2021; 31: 498–511.
- Pawłowski M, Johnen A, Duning T: Früh beginnende Demenzen [Young onset dementia]. *Nervenarzt* 2020; 91: 936–945.
- Pluta A, Łojek E, Habrat B et al. (eds.): *Życie i starzenie się z wirusem HIV. Podejście interdyscyplinarne*. Wydawnictwa Uniwersytetu Warszawskiego, 2018.
- Przybylak M, Grabowski J, Bidzan L: Cognitive functions and thyroid hormones secretion disorders. *Psychiatr Pol* 2021; 55: 309–321.
- Ridley NJ, Draper B, Withall A: Alcohol-related dementia: an update of the evidence. *Alzheimers Res Ther* 2013; 5: 3.
- Sivasathiaselan H, Marshall CR, Agustus JL et al.: Frontotemporal dementia: a clinical review. *Semin Neurol* 2019; 39: 251–263.
- Svanberg E, Spector A, Stott J: The impact of young onset dementia on the family: a literature review. *Int Psychogeriatr* 2011; 23: 356–371.
- van de Veen D, Bakker C, Peetoom K et al.; PRECODE Study Group: An integrative literature review on the nomenclature and definition of dementia at a young age. *J Alzheimers Dis* 2021; 83: 1891–1916.
- Wiggins M, McEwen A, Sexton A: Young-onset dementia: a systematic review of the psychological and social impact on relatives. *Patient Educ Couns* 2023; 107: 107585.