



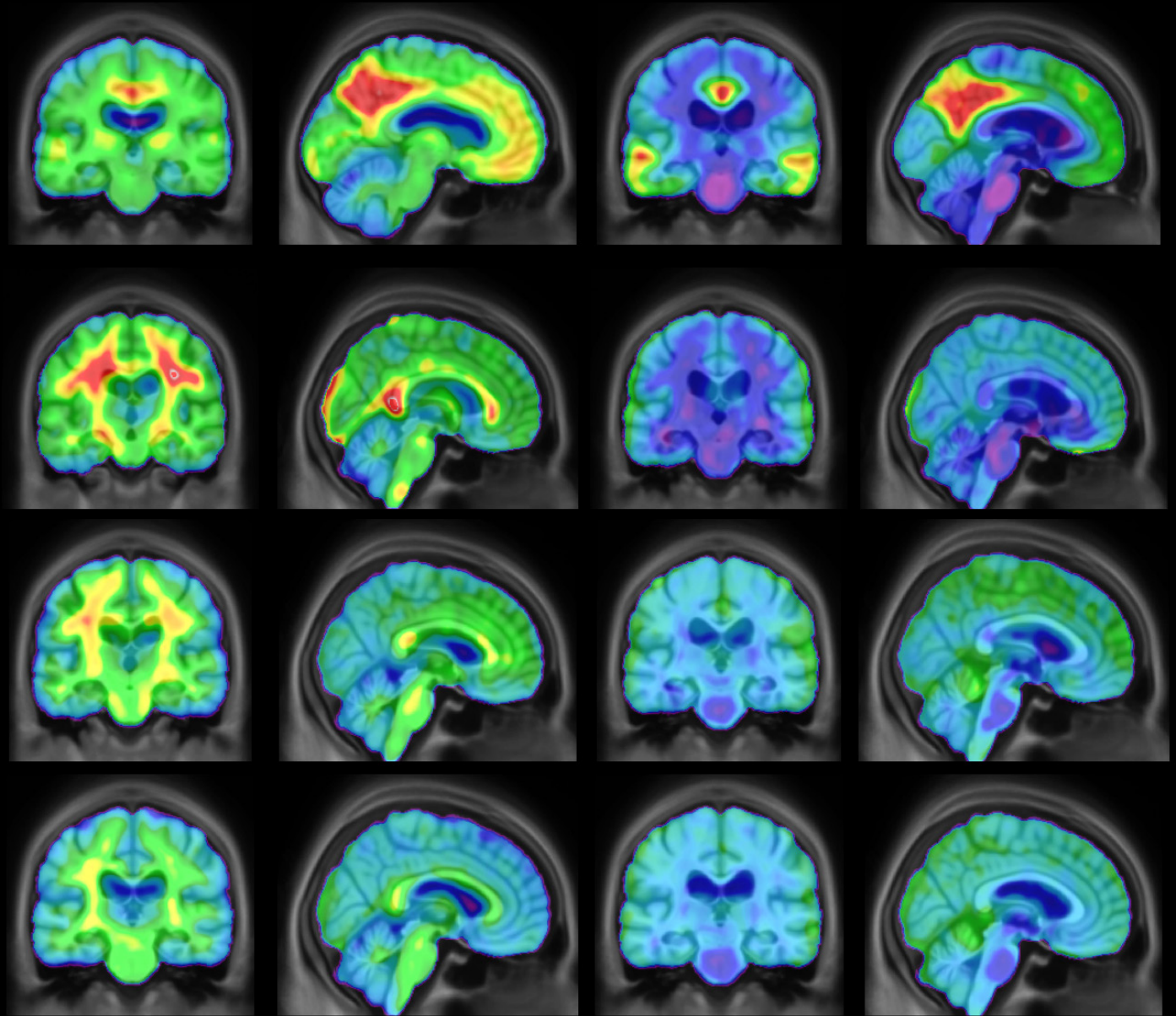
**Alzheimer's Disease
International**

The global voice on dementia

World Alzheimer Report 2021

Abridged version

Journey through the
diagnosis of dementia





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To access the full report please visit:

<https://www.alzint.org/resource/world-alzheimer-report-2021/>

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Foreword

Paola Barbarino, Chief Executive Officer, Alzheimer's Disease International

In 2018 I was invited to a meeting of the Innovative Medicines Initiative of the European Commission to talk about innovation in diagnostics. It was then, while studying wearables to detect early symptoms of Alzheimer's disease and big data, that I came across some really fascinating studies. These were signposted to me by the omniscient Serge Gauthier, then Chair of our Medical and Scientific Advisory Panel. They talked about people who suspected they had dementia and were desperate for a diagnosis, but too ashamed or scared to go to the doctor, were using bogus Internet sites promising equally bogus treatments or cures.



As Hrinco, Fisk and Robillard state in this report *'Ease of information-sharing via websites and social media can perpetuate misinformation, which can undermine the relationship between people living with dementia and their healthcare providers. These issues stemming from an unregulated online environment are particularly troubling for vulnerable individuals, as some sites promote non evidence-based treatments that may lead to financial loss and negative health outcomes.'* [Page 39 of the full report].

As Alzheimer's Disease International (ADI) is an organisation first and foremost about protecting vulnerable people, this troubled me a lot. Why aren't governments providing reliable online resources or redirections to Alzheimer's and dementia associations as a first port of call? Why aren't there trustworthy online tests provided by national healthcare systems to give worried individuals a sense of whether they should go to see their doctor or not? Can we not create the equivalent of an online BMI (Body Mass Index) to test for dementia? Can we overcome any technical, ethical and cultural challenges?

“ There is a perfect storm gathering on the horizon and governments all over the world should get to grips with it.

As I shared some of these questions with Serge, I realised the diagnostic issue really is at the core of everything we do. Healthcare professionals themselves need to believe that Alzheimer's (and related dementias), is a disease and that it is their job to diagnose it. As Louise Robinson puts so eloquently in the report *'Healthcare professionals can be reluctant to speak openly and honestly about dementia, especially with the person concerned, with some reluctant to use the actual 'D' word'*.

Diagnosis and stigma go hand in hand. There is a direct link between our 2019 World Alzheimer's Report on stigma and this report.

Dementia is now the 7th leading cause of mortality globally and, as we know from previous World Alzheimer Reports, one of those with the highest cost to society. There are 55 million people living with dementia as we speak, and as this report indicates, probably less than 25% globally are actually diagnosed. In lower income countries this percentage may be as low as 10%.

There is a perfect storm gathering on the horizon and governments all over the world should get to grips with it.

New therapeutic breakthroughs are starting to appear on the market. These require a confirmatory diagnosis of Alzheimer's or dementia to be prescribed. At the same time, there seems to be a link between COVID-19 and the development or acceleration of cognitive deterioration. There is also, at last, a concrete possibility of a plasma biomarker that would make diagnosing Alzheimer's much easier and quicker. Last, but not least, the number of those who sadly develop dementia is growing, with age being the biggest risk factor and globally ageing populations.

On the other side of the scale (and you will see this clearly in the report) there are still too few primary healthcare practitioners able, willing or with the means to perform all the tests required to ascertain whether a person has dementia. This is not just in lower income countries but all over the world. In some countries there are no scanners, or professionals who can perform cerebrospinal fluid tests, or specialists to interpret the results.

This report is complex because diagnosing dementia is difficult. There are many grey areas and the report does not shy away from them. It aims to intersect race, gender, social, scientific, technological, economic and geopolitical issues with layers of medical information.

It also tackles complex areas, for example the fact that diagnosis is still a hit or miss affair. The report explains that up to 30% of people are actually misdiagnosed. This is why we urgently need better diagnostic systems, as in the case of the biomarkers mentioned earlier.

Healthcare practitioners need to be better educated to understand what is expected of them. In the words of Emily A. Largent *'Regrettably, older adults are often inadequately assessed for cognitive decline during primary care visits due to limitations on clinician time as well as lack of clinician expertise.'* [Page 143 of the full report]

The report also tackles the issue of disclosure of the diagnosis and why this is such a difficult area for doctors. In the words of Serge Gauthier, *'[...] many people with dementia due to Alzheimer's disease, have a lack of awareness regarding their cognitive and functional decline (this phenomenon is called 'anosognosia') that makes them uninterested in the diagnosis and its likely causes. On the other end of the spectrum are those people who are so anxious about their diagnosis that a catastrophic reaction such as severe depression, and even suicidal thoughts are possible.'* [Page 176 of the full report]

For those who are still wondering why diagnosing dementia is important even if there is no cure yet (a belief sadly shared by 33% of clinicians responding to our questionnaire), I suggest they read the words of Jose Antonio Garcia, a person living with dementia, *'Early diagnosis is very important because at this age, we still have responsibilities to our children and our elders. Our capabilities must be kept intact so that we can maintain our independence*

for as long as possible. Both our healthcare professionals and society in general need to provide us with maximum knowledge of the disease and with the means to improve it.' [Page 154 of the full report]

In the words of a former carer, and one of this report's authors, Claire Webster, *'Only by learning to adapt to all the cognitive and physical changes brought on by this condition will a carer be able to manage effectively.'* [Page 191 of the full report]

People have a right to know, to learn, to understand, to make their own choices. Presuming otherwise is condescending and wrong.

In conclusion, I think the world is still in denial about diagnosing dementia. We cannot ignore the problem in the hope that it will go away. The phrase 'conspiracy of silence' might sound a tad melodramatic, but I have often felt like this when speaking to Health Ministries worldwide. Dementia is everywhere in the world and the case for the cost effectiveness of diagnosis versus not doing anything is clear, as Anders Wimo and Serge Gauthier articulate so cogently at the end of the report.

This work aimed to bring out into the open every little myth around diagnosis and I feel strongly it has succeeded. We hope it will offer people living with dementia, carers, researchers, physicians and policymakers a solid foundation for their journey or their practice. We also hope it will also act as a call to action to those governments that are yet to embrace the realities of what is coming. You can all help by making sure this report lands where it is needed. If you have read this far, please help us by sharing and disseminating this important piece of work into the right hands across all corners of the globe. As ever, we count on you.



Paola Barbarino

CEO, Alzheimer's Disease International
London 2021

Introduction

Overview

This is an abridged version of the [World Alzheimer Report 2021, Journey through the diagnosis of dementia](#). For ease of reading and translation, this version has been edited by ADI and made available alongside individual pdfs of each chapter which can be downloaded from <https://www.alz-int.org/resource/world-alzheimer-report-2021/>

The World Alzheimer Report 2021, developed by McGill University, Montreal, Canada, is a comprehensive and candid report that brings together the different voices

impacted by a dementia diagnosis. The list is a long one – individuals living with dementia, their friends, families and carers, advocates, laboratory researchers, academics, general practitioners and specialists – and collectively, they create an inclusive account of the diagnosis journey of dementia ranging from new and emerging diagnostic techniques through to best practises of disclosing a diagnosis. By definition, this abridged version can present only a snapshot of the larger volume.

Expert contributions from practice and lived experience

Please see the full report, or individual chapters, to read the expert essays from health and social care professionals globally. The full text was reviewed by two persons living with dementia.

Case studies from eleven people living with dementia can be found in full taking us from the clinical world and theoretical concepts to real-life transformative situations and genuine experiences. Extracts can be read below.

'Some (specialists) told us that my Mom had depression, and some told us it was normal for her age.' América Velasco Amador, Mexico.

'Some of the sickness is taboo, so when we just first heard about it, it was really a shock, and we were then in denial.' Anoud Hariri, Jordan.

'We left the neurologist's office with no information. I had no real understanding of what it all meant.' Carmel Geoghegan, Ireland.

'Healthcare professionals, please avoid the tendency to pigeonhole patients with dementia. Get to know your patients and take the time to understand their history.' Emily Ong, Dementia Alliance International, Singapore.

'In terms of things that could have been done differently, maybe the follow-up by the neurologist should be at least annually, with the necessary tests to find out the progression of the disease.' José Antonio García, Spain.

'My diagnosis was transparent, open, and professionally given.' Roger Marple, Canada.

'For nine years, my family has been learning every day to live with this condition. At first, it was very hard because we refused to accept it. We did not know what to do or how to deal with it.' Perla Echeverria Cuidador, Venezuela.

'The stigma of being too young to have dementia clouded the opinions of the experts' Mary Beth Wighton, Dementia Advocacy Canada and Dementia Alliance International, Canada.

'He gave her medication and told me nothing else... however, when she went home, she probably didn't take the medication because she forgot.' Véronica Frias Salinas, Mexico.

'I think doctors should have a big role in educating the public about Alzheimer's disease. I am sure that many people had Alzheimer's disease before and didn't know it.' Ranaivosoa Nancy Prisca, Madagascar.

'It was nearly two or three years prior to the official diagnosis that I figured out something was going wrong.' Sarmistha Dutta Gupta, India.

Survey results

Data from three surveys is incorporated throughout the full report. This includes evidence from 1,111 multidisciplinary clinicians, 205 people with dementia, 2,122 carers, and 101 ADI member associations. In summary, findings suggest:

- Just 45% of people with dementia and carers felt they were given adequate information at the point of diagnosis, identifying a major gap in clinician signposting.
- Conversely, clinicians do have a source to refer to, as 98% of 101 Alzheimer's and dementia associations stated that they maintain and update information on diagnosis on their webpages.
- Key barriers to diagnosis identified by people with dementia and carers included lack of access to trained clinicians (47%), fear of diagnosis (46%) and cost (34%).
- Key barriers to diagnosis identified by clinicians included lack of access to specialised diagnostic tests (38%), lack of knowledge in making a diagnosis (37%) and the widespread belief that nothing could be done (33%).
- 75% of clinicians ranked the increasing number of people seeking a diagnosis as a major challenge in the future, followed by people seeking diagnosis due to self-testing (with the proliferation of online and at home tests), and an increase in disease-modifying treatments.
- 77% of clinicians in the survey said they would be interested to use a new blood test to increase diagnostic precision of the cause of dementia (those that didn't cited cost barriers, belief they would need further validation, or time pressures with extra time required to explain results).
- 83% of clinicians maintain that the COVID-19 pandemic delayed access of people with cognitive decline for assessment.
- Personal testimonies from people with dementia and carers consistently indicate the lengthy time taken before being given a diagnosis, as well as a lack of information at the point of diagnosis about specific types of dementia, progression and available support.

Commentary and key points from the McGill University team are included in this abridged report covering five crucial areas of clinical assessment, laboratory tests, formulation of diagnosis, particular circumstances and the future of the diagnosis of dementia.

Executive summary

ADI estimates that globally 75% of people with dementia are not diagnosed, this may be as high as 90% in some low- and middle-income countries. Over 55 million people live with dementia worldwide. This is a staggering figure, made all the more striking as it rises on a daily basis, with forecasts reaching 78 million by 2030. The World Health Organization (WHO) Global action plan on the public health response to dementia targets at least 50% of countries to diagnose 50% of the estimated number of people with dementia by 2025. As most countries enforced lockdown measures to contain the spread of COVID-19 during 2020–2021, restriction of movement interrupted access to healthcare services for people with dementia symptoms; the full impact of this disruption to diagnosis is yet to be seen.

Clinical assessment

- ADI calls for governments to adopt a standardised approach to online cognitive assessment tools which are often unregulated, do not adhere to ethical standards and need government level control for best practice.
- Specialised assessment and advanced biomarker studies should be conducted where possible in individuals with atypical, early-onset and rapidly progressive dementias.
- Questions about changes in daily life may be more reliably answered by a family member, close friend or co-worker, especially if there is suspected anosognosia (someone who is unaware of their condition).
- Psychological symptoms associated with cognitive decline may be part of the disease process but may also be reactions to what is happening.
- Behavioural symptoms associated with dementia have a significant healthcare impact on carer fatigue, depression and possible burnout.

Laboratory tests

- ADI maintains that best practice is a combination of cognitive testing with confirmatory scan/cerebrospinal fluid (CSF), plus emerging biomarkers. Access to scanner technology and training for specialists is essential.
- Research has shown up to a 30% misdiagnosis rate post-mortem and 25% adjustment in Alzheimer's disease diagnosis following a PET scan, emphasising both the complexity of diagnosis and the need for the robust combination of laboratory and cognitive assessment.
- The performance of general blood tests is an important step in the diagnostic process to rule out other causes of cognitive changes.
- Head magnetic resonance imaging (MRI) or computed tomography (CT) should be considered as part of the initial laboratory evaluation of dementia.
- In complex cases, neuroimaging using PET or SPECT increases the diagnostic accuracy of Alzheimer's disease or of dementia with Lewy bodies.
- Under appropriate use criteria, neuroimaging using PET or SPECT may improve the diagnosis and care pathway of individuals by revealing the specific brain diseases underlying their dementia.
- Lumbar puncture (cerebrospinal fluid) is a safe and acceptable procedure aimed at a specific diagnosis in people with dementia of undefined aetiology, but its use is not currently widely adopted globally.
- Cerebrospinal fluid analysis biomarkers (phosphorylated tau (P-tau) and amyloid beta (A β 42 and A β 42/40 ratio) constitute an affordable alternative to imaging biomarkers, with excellent diagnostic properties.

- There is a need for cerebrospinal fluid biomarkers specific for dementias with causes other than Alzheimer's disease.
- Blood biomarkers now show diagnostic promise given their practical, scalable, and economic advantages.
- A structured genetic assessment is required if there is a suspicion of familial type of dementia.
- Although APOE4 is the major genetic risk factor for Alzheimer's disease, APOE4 geno-typing is not currently recommended in routine clinical practice.

Formulation of diagnosis

- ADI calls on governments globally to more accurately measure and record diagnosis rates not just in line with the WHO Global action plan on the public health response to dementia but universally – to enable better planning, treatment, care and support.
- As disease-specific blood biomarkers become available and machine learning is being developed to support clinical diagnosis, early identification of Alzheimer's disease will facilitate access to secondary prevention and disease-modifying therapies.
- Clinicians should promote informed decision-making, employ proven health communication techniques and provide guidance on appropriate next steps.
- Long-term follow-up of people with dementia is needed as new symptoms and physical signs may appear and lead to a change in diagnosis.
- As research is progressing on the biological definition of Alzheimer's disease, similar efforts are needed for non-Alzheimer dementias.

Particular circumstances

- ADI calls for the development of culturally appropriate cognitive assessment tools and awareness campaigns in order to improve diagnosis rates and to improve access to treatment and trials. In particular, there is an urgent need for cognitive assessment scales to be better translated and validated.
- Low- and middle-income countries face a greater challenge making the diagnosis of dementia in a timely fashion due to specialist HCP and technological restrictions.
- Commitment to the development of national dementia plans, supported by robust health and care system policies is needed to improve the diagnostic pathway, leading to more comprehensive post diagnosis support.
- A modified, patient-centric approach is needed in the assessment of dementia for low-educated individuals.
- Women living with Alzheimer's disease face a 'triple jeopardy' of barriers from stigma related to age, cognitive decline, and gender stereotypes and bias.
- People with young-onset dementia, including people with Down syndrome, require careful evaluation to rule out treatable conditions that may be mistaken for dementia.

The future of the diagnosis of dementia

- ADI calls on governments to deliver national awareness raising campaigns around the warning signs of dementia and timely diagnosis, in line with action area 2 of the WHO Global action plan on the public health response to dementia.
- The first point of contact for people experiencing symptoms that make them question whether they have an emerging dementia disorder is, in most cases, a primary care physician. (GP, family practitioner/physician). As global populations age and as new diagnostic and treatment breakthrough emerge, there is an urgent need to prepare healthcare systems globally to cope with an increase of demand at primary care level.

- The diagnostic infrastructure, particularly in a primary care setting, is not prepared for a large increase in the demand for pre-dementia (and early-onset dementia) Alzheimer's disease diagnostics.
- The emerging risk from COVID-19 must be recognised. This means paying close attention to symptomatic warning signs following a diagnosis of COVID-19.
- The development of plasma Alzheimer's disease biomarkers has ushered in a new age in which a biologically-based diagnosis of Alzheimer's disease may be generally available non-invasively and inexpensively and may be implemented for both research and clinical diagnostic purposes.
- With the approval by the United States Federal Drug Administration (FDA) of the first disease-modifying treatment for Alzheimer's disease, Aduhelm (aducanumab), it may soon be possible to treat earlier stages of the disease. However, further studies are warranted to prove clinical benefit.
- As disease-modifying treatments emerge, healthcare practitioner stigma should decrease.
- The new technologies, medications, and tools that are currently being researched and introduced into the clinical landscape, as well as the perspectives of people living with dementia themselves, shine a light on the existing socio-economic imbalances and act as important catalysts to propel progress forward.

Recommendations

- Healthcare systems globally should introduce annual brain health check-ups for people over 50, facilitated by evolution in biomarkers science, along with the opportunity to promote risk reduction strategies.
- Governments globally must urgently start to measure and record diagnosis more accurately. Accurate measurement of diagnosis rates is the key to treatment, care and support, to healthcare system preparedness, and to challenging stigma.
- Governments must prepare for a tsunami of demand for healthcare services as a result of global ageing populations, improved diagnostics, including biomarkers, and emerging pharmacological treatments.
- Improve dementia training and education, plus increase time allocation for diagnosis in primary healthcare. This is with the intention of combatting a lack of skills and confidence and to remove the counter-productive time pressure on primary care doctors when dealing with a complex and sensitive diagnosis and disclosure.
- Healthcare systems must invest in, and improve, diagnostic capabilities, moving towards precision diagnosis, to eradicate high levels of misdiagnosis.
- Improved disclosure training is required for clinicians to communicate a diagnosis transparently and sensitively, providing information on next steps, clinical follow up, condition evolution, treatment options and importantly direction to post diagnosis support options.
- Governments globally must recognise the right to a timely clinical diagnosis and put in place the capacity to deliver this, to enable better planning, treatment, care and support, in line with action area four of the World Health Organization (WHO) Global action plan on the public health response to dementia.
- Healthcare systems must make culturally appropriate, translated and validated cognitive assessment tools available to increase diagnosis rates. This is with the aim of providing better information provision and planning, plus increased access to treatments, trials and support.
- A call for standardised, online, ethical, government adopted, cognitive assessment tools, to enable people to take initial and informed steps and to mitigate against dangerous misinformation.
- National awareness raising campaigns must address the stigma surrounding dementia, especially in some low-income countries where up to 90% of cases go undiagnosed as well as actively promote awareness of the warning signs, in line with action area two of the WHO Global action plan on dementia.
- Best practice in assessment must be recognised as a combination of cognitive testing, backed up by scan and/or cerebrospinal fluid (CSF) testing, plus preparedness and readiness to embrace emerging biomarkers.
- Improved access to scanner technology required for confirmatory diagnosis, for access to emerging treatments and ongoing monitoring, with equivalent specialist training.
- Long-term clinical follow-up for people living with dementia, as part of a holistic, post diagnosis support package, to encompass disease progression and changes in diagnosis. This includes treatment monitoring and evaluation in an era where new disease-modifying treatments are becoming available.
- As two-thirds of people with Alzheimer's disease are women, more research must be funded into precision medicine focusing on evidence-based, sex-specific measures for cognitive, clinical and biomarker testing.
- A call to educate healthcare professionals and the general public about the role of cerebrospinal fluid testing and a repositioning of this misunderstood diagnostic tool, in line with similar perspectives on epidurals.

- Clinicians must become aware and better informed about information, support and planning available via national Alzheimer and dementia associations, and the vital role they play in pre and post diagnosis support.
- Build on the innovative, often technology-based, approaches including telemedicine, which evolved rapidly during the COVID-19 pandemic. Research how these might best supplement, but not replace, future cognitive assessment, while acknowledging the benefits for remote or rural communities or for those unable to travel safely.
- Governments must prepare now for future pandemics to ensure that the diagnostic and treatment pathways are not disrupted at the levels experienced during COVID-19.

Why make a diagnosis and what are the current roadblocks?

Journey through a diagnosis

The journey through a diagnosis of dementia is a complex one. It is a multiple step process that begins by understanding the early signs and symptoms of an illness that is still plagued by an overall lack of social awareness. A shift in focus is needed, one that makes research, education, advocacy, and most importantly, universal access to an informed and knowledgeable healthcare system a priority. From there, it is a matter of creating a support system that prioritises the needs of the person living with dementia alongside the needs of their carer.

There is still much to learn and do about dementia and a united front is needed – one that reduces stigma, that increases awareness and that heralds change and scientific advances. ADI calls for governments to lead the way in providing a standardised and ethical online assessment option. Aligning a dementia-centric approach on all fronts is paramount.

Key points

- The term dementia is used to describe a group of symptoms affecting thinking, mood and behaviour severe enough to interfere with daily life.
- Most countries encourage individuals to visit their primary care physician (family doctor) as a first step towards a diagnosis of dementia.
- A significant roadblock to obtaining a diagnosis is a lack of knowledge and awareness about the disease by the general public.

Clinical assessment

The Internet has become a wide-ranging source of information for people who have access to it. When first faced with concerns regarding their cognitive decline, most individuals, or their family and friends, will naturally search the Internet for information as it offers a wide range of material about the condition. While there are many credible sites, especially those affiliated with universities or national dementia organisations, caution must be exercised as other websites may spread misinformation, fail to respect privacy policies, or have fraudulent intentions.

This online exploration does not, nor should it, replace an in-person assessment by a healthcare professional. The family physician is overwhelmingly the first point of contact for someone, or their family and friends, questioning changes to their cognitive condition, though consultation may also involve nurses and specialists.

Key points

- Primary care provides a more familiar, person-centred environment for the initial assessment.
- Referral to a specialist such as a geriatrician, neurologist, psychiatrist or neuropsychologist may be required for more complex cases of dementia.
- The online environment offers a wide range of resources for people seeking information about dementia although the quality of online resources varies greatly.
- To promote the benefits of the online environment while minimising harm, resources for dementia should be developed following established ethical guidelines.

Medical history and physical examination

Cognitive decline has the potential to greatly impact a person's activities of daily living. That is why gathering as much information as possible is crucial to the diagnostic process. The health-care professional may use a two-pronged approach, combining interviews and task checklists to obtain a complete medical history, along with a comprehensive physical examination to assess which major neurocognitive domains are affected.

A complete diagnostic picture also includes details about when symptoms began or became noticeable, their frequency and duration. This may be provided by the person concerned or a partner, friend or family member who has witnessed the behaviour. All these are key elements to the diagnosis of dementia and its underlying causes.

Key points

- The healthcare professional performing the diagnostic assessment needs information about the earliest symptoms and their progression over time.
- A complete physical examination is conducted with emphasis on signs of cardiovascular health and a neurologic examination including balance and gait.

Functional assessment

A comprehensive functional assessment has a dual purpose: to determine a person's ability to manage their everyday needs and validate concerns about their safety and independence. Major areas of concern are the risks associated with falls or injuries, driving and financial vulnerability. Cognitive decline can certainly impact a person's activities of daily living and people with these complaints will be asked about the symptoms they are experiencing. However, clinicians are also encouraged to use a semi-structured questionnaire as a diagnostic tool to discuss with a person's partner, family member or friend. In this way, clinicians will gain reliable insight into the changes observed over time and compare previous and current abilities. These daily living activities can range from basic, leisure or instrumental tasks. Should another person be unavailable, a visit to the person's home may be warranted to obtain additional information. An important motivating factor is to assess whether a person can safely continue to live independently at home.

There are several informant-based questionnaires available and criteria for use should include the population being measured, the severity of the disease and the living environment. Additionally, one must consider which daily activity topics from basic to complex are included, psychometric properties of validity and reliability of the measurement tool, areas of deficit that may impair functional performance, practicality and cultural relevance.

Key points

- The functional assessment plays a key role in the diagnosis of dementia.
- Cognitive decline may have a direct impact on activities of daily living.
- Questions about changes in daily life are usually more reliably answered by a family member, close friend or co-worker.
- If information about daily activities is not available or cannot be reliably addressed, a visit to the person's home may be required.

Mood and behaviour assessment

Given the significant impact of dementia on an individual's quality of life, an increase in mood and behavioural symptoms such as depressive feelings, paranoia, anxiety, apathy and irritability may become present. These neuropsychiatric symptoms, whether associated with changes to the brain or an emotional reaction to current circumstances, need to be assessed in a comprehensive manner. In fact, these symptoms may precede dementia but are often overlooked when the focus is on cognitive testing.

Also frequently overlooked is the role of an informed carer who is understandably well-placed to observe these symptoms. When anosognosia is factored in, the impaired awareness of cognitive and emotional changes, this makes a carer's feedback even more relevant. Thus, a combined approach of self-reporting and informant interview and/or questionnaire will yield a more complete picture.

Key points

- Psychological symptoms associated with cognitive decline can be part of the disease process but may be reactions to what is happening.
- Depression is a common symptom in early dementia.
- Behaviours such as agitation, paranoia, aggressivity, sleep disturbances usually occur well after the diagnosis of dementia is made but can be present in earlier stages.
- The term anosognosia refers to limited awareness of cognitive and functional deficits, but also to impaired awareness of emotional changes.

Cognitive assessments

Cognitive assessment has long relied on the enduring tests that most clinicians are accustomed to using as measurement tools. These include the Mini Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MoCA). However, in this changing world, one that is experiencing both a growth in the ageing population and the wrath of a global pandemic, clinicians have had to adapt to these circumstances.

These well-established tests were developed in Western countries and employ in-person assessment with English as the primary language. These parameters limit their use in other countries as well as hinder vulnerable older adults living with dementia from visiting their healthcare professional because of imposed pandemic restrictions. Hence, the rapid introduction of telemedicine to remotely administer these assessments is an alternative that most clinicians favour.

While telemedicine has facilitated the implementation of remote cognitive evaluation, there exist certain constraints such as ensuring the collected information is based on informed verbal consent, safe digital environments, and respects the individual's confidentiality. Other barriers such as educational, cultural, sociodemographic considerations should factor into the decision to administer a test remotely.

While videoconferencing does allow for the presentation of visual stimuli or behavioural observations, unlike a consultation over the telephone, it is critical that any remote approach be unbiased across race, ethnicity, educational attainment, language and sensorimotor abilities. Equitable access to remote cognitive assessment irrespective of disease stage and level of carer support is critical. Therefore, there is a concerted effort underway to overcome language and cultural barriers with the development of new tests such as the Cross-Cultural Dementia Screening (CCD) test and the Visual Cognitive Assessment Test (VCAT). This brings to the forefront the idea that an international effort to form large multi-centre cohorts by pooling cognitive and biomarker data from institutions across the world to study the pathophysiology of neurocognitive diseases is needed.

Key points

- Cognitive assessments are required for the diagnosis of dementia and to track changes over time.
- The cognitive screening tests most used by clinicians are the Mini Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MoCA).
- Complementary cognitive tests may be required based on symptoms.
- Tests that overcome the influence of language differences are needed, such as the Visual Cognitive Assessment Test (VCAT).
- As a result of the COVID-19 pandemic, many clinicians have incorporated telemedicine into their practice.
- As with in-person assessment, telemedicine encounters require the protection of patient privacy and confidentiality.
- The clinician must be aware of telemedicine limitations and decide whether an in-person encounter is necessary.
- For telemedicine assessments, carers are often required to facilitate the visit.

Preliminary diagnosis of cognitive decline

The clinical diagnosis of dementia is reached at the primary healthcare setting. It starts with medical history, questioning the person with dementia about symptoms, and the person accompanying them to the appointment about observed cognitive changes and conducting a physical examination. From there, the assessment may include screening for cognitive deficits, psychiatric symptoms and a function-focused approach regarding the extent of the individual's abilities to perform activities of daily living. A primary care clinician may request blood screening and neuroimaging to rule out treatable causes of cognitive decline.

While the vast majority of individuals will remain, and receive treatment, in the primary care setting, those who present with atypical dementia symptoms, early-onset or rapidly progressive dementias benefit from additional assessments in specialised centres. At the end of the preliminary assessment, healthcare professionals should indicate whether the person has a normal cognition, mild cognitive impairment, a typical or an atypical dementia.

In the prospects for upcoming disease-modifying interventions for dementia, biomarkers may become an important tool for primary care. Biomarker testing including PET, SPECT and even blood tests are significant indicators of the degenerative process occurring in the brain and clinical use of these tests at the primary care level for dementia diagnosis are promising for forthcoming therapies.

Key points

- The clinical diagnosis of dementia is usually determined in the primary healthcare setting.
- An investigation is subsequently conducted to determine the cause of dementia.
- At the primary level, treatable causes of cognitive decline should be identified.
- Specialised assessment and advanced biomarker studies should be conducted in individuals with atypical, early-onset and rapidly progressive dementias.

Laboratory tests

General laboratory tests

There is a consensus that using laboratory tests as complementary tools to a standard cognitive evaluation is necessary to determine whether there are any treatable medical conditions that may affect cognition.

Basic laboratory tests are most often performed immediately after the initial clinical assessment, and clinically significant findings such as low B12 bring about replacement therapy that may help one component of the dementia pathophysiology.

- The performance of general blood tests is an important step in the diagnostic process to rule out causes of cognitive changes.
- The list of blood tests is comparable to an annual general assessment for health status in mid or late life.
- Specific tests may be added based on findings from the general physical examination.

Brain imaging using CT and MRI

As people near the age of 65, instances of memory and thinking problems are often associated with the onset of dementia. Hence the reason doctors order brain scans to confirm such a diagnosis, as well as to rule out other potential causes of the memory or thinking problems experienced by an individual.

Many medical guidelines suggest the superiority of magnetic resonance imaging (MRI) in assessing individuals with dementia. However, neuroimaging with computed tomography or magnetic resonance unequivocally benefits dementia patients with acute onset of cognitive impairment, rapid neurologic deterioration, seizures, or findings on physical examination suggestive of vascular disease, tumour, or other brain focal abnormalities. It should be noted that these tests are costly, and accessibility is not universal.

Key points

- Head magnetic resonance imaging (MRI) or computed tomography (CT) should be considered as part of the initial laboratory evaluation of dementia.
- Structural imaging serves primarily to rule out treatable causes of dementia.
- Structural imaging MRI provide insights regarding the underlying causes of dementia.

Brain imaging using PET and SPECT

When an individual presents with suspected signs or symptoms of cognitive decline, clinicians will perform the basic dementia assessments such as medical history, neurological examination, basic laboratory screening tests, and cognitive assessment. Other tools, such as PET and SPECT techniques, that visualise and quantify an extensive list of biochemical processes have undergone much progress in the last fifteen years. However, the availability of PET and SPECT screening methods to diagnose the underlying causes of dementia remains limited worldwide due to cost and accessibility, even in high-income countries.

Key points

- Neuroimaging using positron emission tomography (PET) or single-photon emission computed tomography (SPECT) increases the diagnostic accuracy of Alzheimer's disease and dementia with Lewy bodies.
- Applying appropriate use criteria, PET or SPECT neuroimaging may improve the management of patients by revealing specific brain diseases underlying their dementia.
- There is a high demand for diagnostic imaging tests that can identify other brain diseases causative of dementia.

Spinal fluid

Cerebrospinal fluid biomarkers provide reliable and clinically relevant diagnostic information in dementia cases of diagnostic uncertainty. Due to its lower cost, cerebrospinal fluid biomarker might constitute a viable diagnostic method in low- and middle-income countries. Importantly, the scalability of cerebrospinal fluid biomarkers seems a sustainable option for assessing patient eligibility for the upcoming disease-modifying interventions.

Cerebrospinal fluid biomarker research developments bring hope for the diagnosis of non-Alzheimer's disease neurodegenerative processes underlying dementia.

Key points

- Lumbar puncture (cerebrospinal fluid or CSF) is a safe and acceptable procedure towards a specific diagnosis in people with dementia of uncertain aetiology.
- Cerebrospinal fluid analysis biomarkers constitute an affordable alternative to imaging biomarkers, with excellent diagnostic properties.
- There is a need for cerebrospinal fluid biomarkers specific for dementias of causes other than Alzheimer's disease.
- Accessibility to cerebrospinal fluid analytical infrastructure remains unavailable in the vast majority of low- and middle-income countries.

Genetic testing

There are a small percentage of individuals who carry gene defects that contribute to the development of dementia. These genes can either cause, protect or increase the risk of developing dementia. Therefore, having extensive knowledge of their family's medical history becomes a crucial component to an individual seeking answers. This is especially true when they present with atypical, young-onset or rapidly progressive symptoms.

If a potential link is established, a physician will order tests to look for brain accumulation of amyloid, tangles, alpha-synuclein, transactive response DNA binding protein 43 kD (TDP-43) and other pathogenic proteins to indicate the presence of dementia. By delving deeper into potential causes, genetic testing offers a precise molecular diagnosis. If confirmed, healthcare professionals can provide information, guidance, and support in order to help make choices in their personal lives, related to their own personal risks, having children, and planning for the future.

Autosomal dominant Alzheimer's disease can be a particularly burdensome form of the condition as it tends to affect people between the ages of 30 and 50. The hereditary component of this form of the disease merits further study across different ethnic cultures to assess the heterogeneity in the pathogenesis of Alzheimer's disease. Frontotemporal degeneration (FTD) is yet another classification of dementia that affects individuals at a younger age, usually under 65, with genetic factors. Though recent studies have advanced the understanding of frontotemporal dementia, these have primarily focused on individuals of European lineage. This means there is still a long way to go in order to enhance the knowledge of genetic profile associated with frontotemporal degeneration in China.

Key points

- A structured genetic assessment is required if there is a suspicion of familial type of dementia.
- Genetic assessments should be conducted by a specialised team able to manage all the medical, ethical and social complexities associated with genetic testing.
- Although APOE4 is the major genetic risk factor for Alzheimer's disease, APOE4 genotyping is not currently recommended in routine clinical practice.
- Access to genetic assessment constitutes a major challenge in low- and middle-income countries.

Diagnostic tests: novel biomarkers

The emergence of biomarkers into the diagnosis of dementia is being hailed by physicians around the world as an inexpensive and effective method to identify and monitor the accumulation of abnormal proteins in the brain. Physicians are anticipating the widespread adoption of these blood tests into their everyday practice, as high sensitivity techniques to quantify disease pathophysiology in peripheral blood samples will advance clinical care.

Specialised tests such as PET and SPECT allow for the visualisation of a host of biochemical processes, thus providing for increased diagnostic accuracy. A lumbar puncture is a safe and effective procedure that detects the presence of pathological processes in the brain and novel biomarkers will allow for precise identification of accumulated abnormal proteins in the brain in a widespread and affordable way. This is especially relevant as the population ages and more people will seek a dementia assessment in the coming years. Though still in its infancy when it comes to standardisation, transferability and reproducibility, plasma biomarkers promise to accelerate diagnosis and permit a level of yet unseen personalised care on a global scale given their ease of use, affordability and adaptability.

Key points

- Blood biomarkers for p-tau181, p-tau217 and p-tau231 reflecting brain tau and A β pathology have been developed and validated in research and are being assessed through the appropriate channels for commercialisation and general clinical use.
- Novel biomarkers of non-Alzheimer's disease pathology are needed for research and clinical care.

Formulation of diagnosis

Differential diagnosis

As a matter of course in today's primary care environment, most clinicians follow the prescribed protocols to formulate and render a diagnosis of dementia and its most likely aetiology. This is necessary to determine what kind of dementia an individual may have, be it a typical form like Alzheimer's disease to rarer, atypical types such as dementia with Lewy bodies, that would require specialised and collaborating assessment. This includes taking a family history and laboratory testing data.

However, there are new developments that will impact this routine in due course. Firstly, accelerated changes in the field of biomarkers coupled with people seeking answers to their cognitive complaints much sooner than before, will engender changes both in data collection and analysis. The majority of clinicians welcome these changes as they foresee quicker and more detailed analysis results as well as being able to render a diagnosis in the earliest stages of the syndrome.

The advent, but more importantly, the advancements of machine learning and artificial intelligence are inching the world of clinical decision-support tools towards more of a reality in dementia care. This even extends to mobile applications that can administer cognitive tests and provide individuals and their carers with digital diagnostic and therapeutic support. In the future, the prospect of identifying risk markers, forecasting disease to support differential diagnosis and modelling disease progression will likely revolutionise the management of dementia.

Key points

- The diagnosis is generally finalised at the second visit, usually within six months after the initial assessment.
- Over 80% of people over the age of 65 with a typical amnesic presentation of dementia will receive a diagnosis of Alzheimer's disease.
- If the structural MRI indicates the presence of significant vascular pathology, the diagnosis might be mixed Alzheimer and vascular dementia.
- Atypical dementias (non-amnesic presentations) usually require specialised assessments that may include neuropsychology, biomarkers and genetics testing since they may be caused by several possible conditions.
- As disease-specific blood biomarkers become available and machine learning is being developed to support clinical diagnosis, early identification of Alzheimer's disease will facilitate access to secondary prevention and disease-modifying therapies.

Disclosure of results

A visit to a healthcare professional to receive diagnostic results can be a nerve-wracking experience. It can elicit fear – fear of the unknown and perhaps also that suspicions may be confirmed. Some people with anosognosia, a lack of awareness about their condition, may appear indifferent or unconcerned while others may feel high levels of anxiety and may have depression or suicidal thoughts. A skilled clinician, while remaining truthful, should be able to discern which way an individual is leaning in their reaction and adapt their responses accordingly during the disclosure process.

When it comes to taking matters into your own hands, the proliferation of genotyping kits has given people the opportunity to explore their probability of developing dementia. Some individuals prefer to know their risk level so they can be prepared and plan for the future. There are, however, predictive limitations to these types of available kits, and most medical professionals discourage their use for this purpose.

The COVID-19 pandemic, and its restrictions, led to changes in the diagnostic process, and how disclosure is conducted. Telephones, and now video-calling, has made remote disclosure a reality. However, constraints are evident, especially as the uncontrolled environment may inhibit the ability of the clinician to pick up on an individual's non-verbal cues, not to mention any technical issues that may interfere with the consultation. Learning from both the clinicians' experience and people who have received a remote diagnosis should provide direction for an effective reciprocal exchange and development of best practice.

Key points

- A timely diagnosis of dementia has many benefits such as post diagnosis support and planning for the future.
- Disclosure of results is the moment most feared by people seeking a diagnosis as well as their family members or friends.
- Although most clinicians are at ease with disclosing a dementia diagnosis, they need to be aware that a risk of catastrophic reaction may exist.
- Clinicians should promote informed decision-making, employ proven health communication techniques and provide guidance on appropriate next steps.
- The COVID-19 pandemic has increased the need for remote clinical assessment and disclosure of the diagnosis of dementia.

Initial management following a diagnosis of dementia

Alzheimer's disease and other types of dementia have no cure yet. As the population ages and more people are diagnosed, we need to ensure that the general public becomes better educated about dementia. This starts with health and social care systems that must also be agents of change in their own right. This system is multi-layered and complex. Having a foundation built on informed, reliable and support-driven information and guidance is a priority that demands attention and action.

Key points

- Increased education about dementia will have a significant positive impact on the quality of life of people who have been diagnosed with dementia as well as their carers.
- The World Alzheimer Report survey suggests that the greatest difficulties encountered upon receiving the diagnosis of dementia were lack of adequate information (54%), access to specialised tests (28%), financial constraints (25%) and access to healthcare services (21%).
- People with dementia and carers should be provided with information about the type of dementia they face and potential changes in decision-making capacity.

Re-evaluation of diagnosis over time

There is a need for longitudinal follow-up of people with a dementia diagnosis not only for the comprehensive management of their condition, but also to reassess the diagnosis which may change over time. Clinicians are advised to be on the lookout for new symptoms and physical signs that may indicate a co-morbid event such as a stroke, but also a change of perspective on the cause of the dementia.

There may be rare circumstances where the initial diagnosis of dementia is no longer appropriate, since the person's symptoms have resolved. The term 'pseudo-dementia' can be found in the older medical literature. This should not be considered a misdiagnosis but rather a natural evolution of symptoms, explained by reversible causes such as depression, substance abuse, or a systemic disorder.

As more and more biological characterisations of the probable cause of dementia takes place using biomarkers, people who appear to have Alzheimer's disease but are amyloid negative will need closer follow-up to clarify the underlying cause of their condition, which may alter prediction for progression and treatments.

Key points

- Long-term follow-up of people with dementia is needed as new symptoms and physical signs may appear and lead to a change in the original diagnosis and prognosis.
- Some causes of dementia may be partially reversible.
- Dementia due to conditions other than Alzheimer's disease may require additional clinical and laboratory assessments.
- As research is progressing on the biological definition of Alzheimer's disease, similar efforts are needed for non-Alzheimer dementias.

Particular circumstances

Limited access to healthcare resources

There are some great equalisers in life that make us realise that no matter who or where we are, we are more alike than we are different. Dementia is one of those equalisers. An estimated 55 million people worldwide have dementia, and that number continues to grow every day. It is a condition that does not care about gender, culture, ethnicity, religion, citizenship or sexual orientation. It pays no heed to education, achievements, contributions or how much money a person has. In essence, it is impervious to anything that makes you... you.

However, when delving a little deeper, it is apparent that things are not created equal after all. For people in low- and middle-income countries, and in rural areas, dementia falls prey to an often understaffed or underfunded healthcare system that does not provide enough access, nor adequate dementia training or dementia-centric care management and support. When coupled with people's lack of awareness of the signs; language barriers that impede critical testing; cultural biases that make one want to hide symptoms; reluctance to travel long distances for medical appointments; and a lack of facilitating modern technology, a person may be far advanced in their condition and consequently have a significantly diminished quality of life.

In Africa, in addition to the constraints listed above, cultural beliefs about dementia, stigmatisation, a reluctance by healthcare workers to diagnose dementia and a lack of tools to do so adequately remain key challenges. STRiDE – strengthening responses to dementia in developing countries – has developed a new pragmatic approach that does not rely on clinicians. Rather, trained researchers will use a standardised set of cognitive and functional measures to estimate dementia prevalence. It is a step in the right direction as countries need to invest in the development of resources to support dementia diagnosis and care.

Key points

- Low- and middle-income countries face a greater challenge making the diagnosis of dementia in a timely fashion due to human and technological restrictions.
- Well-structured virtual educational programmes may facilitate quick dissemination to the public about dementia risk factors and warning signs.
- Data gathering on the prevalence of dementia is a crucial step to inform stakeholders.
- Formulation of policies and national dementia strategies are needed to improve diagnostics and the living condition of people with dementia in all countries.

Low education

Individuals of any age bring with them their own personalised conditions. Consequently, the diagnosis of cognitive impairment and dementia, especially at the earliest onset, may be challenging. These difficulties are compounded for low-educated or illiterate individuals. A modified, patient-centric approach in the assessment process is needed, as are sensitivity, understanding and expertise on behalf of the healthcare professionals when working with these populations.

Specific tests have been developed (Rowland Universal Dementia Assessment Scale, Cognitive Abilities Screening Instrument – Short version, Brief Cognitive Screening Battery with Figure Memory Test and the Functional Activity Questionnaire) and are available to assist clinicians in their diagnostic process. The Figure Memory Test component of the Brief Cognitive Screening Battery 1 was shown to be effective in diverse cultures, thus showing promise for its general use.

Key points

- The diagnosis of cognitive impairment and dementia can be challenging but the circumstances of low-educated individuals amplifies the difficulties.
- A modified, patient-centric approach to the assessment is needed among such populations.
- A variety of specific cognitive tests have been developed and are available to assist clinicians in the diagnosis of dementia.

Sex, gender and cultural factors

The scientific and medical communities are not immune to long-standing personal and cultural biases. Providing medical access to individuals with dementia and services for their families is essential as are solutions to develop targeted interventions to improve care provided and quality of life. As worldwide life expectancy increases, these are critical factors to consider today and for the future.

That is why there is such a rallying cry for change and recommendations that include campaigns to increase public awareness about brain health and reduce its associated stigma as well as outreach to underserved groups, all to help overcome systemic barriers in place. This includes adapting standardised assessment tests to account for educational and cultural differences. Under- or late diagnosis adds a tremendous burden on individuals with dementia, their carers and the healthcare system in general. An improved understanding of dementia is needed to reform infrastructure in a meaningful and necessary way, as well as integrate consequential policy changes.

Key points

- Evidence suggests that minority groups and women are not diagnosed with dementia in as timely a manner as others.
- There is insufficient awareness of how sex and gender influence the diagnostic journey.
- Precision medicine with the inclusion of sex and gender factors will optimise not only the diagnostic pathway, but also patient experience.
- For effective and culturally optimal diagnosis and care, health and social care providers must comprehend, and be responsive to, the specific characteristics and needs of Indigenous Peoples with dementia.

Impact of a world pandemic on the diagnosis of dementia

The impact of the COVID-19 pandemic is far-reaching, and we have yet to cross the finish line. Most countries enforced lockdown measures to contain the spread of the virus which greatly restricted people's movements and cut off access to healthcare services for people with dementia symptoms, or follow-up appointments for those already diagnosed. Not only that, but it resulted in feelings of isolation, separation and loss with ensuing repercussions manifesting as depression, agitation, anxiety, troubled sleep, and cognitive decline. It also placed the onus of responsibility on informal carers who faced their own challenges with increased workloads, leading to carer fatigue and burnout as services that provided much needed respite were closed.

As an example, the impact of COVID-19 in Italy has been extensive with high death rates. Greatly affecting the older population in long-term care facilities, many experienced additional deteriorations of cognitive and functional ability. This too can be traced to the reduction or cessation of medical and support services. The full measure of COVID-19's effect is not fully known as data from death certificates and medical records varies substantially in reporting dementia as a contributing factor.

The fact is, older people with cognitive impairment or dementia who reside in long-term care facilities are more susceptible to infection, leading to higher rates of death in this age group and setting. The isolation imposed by lockdown measures exacerbated conditions in low- and middle-income countries where fragile healthcare systems already exist. In the interim, efforts to set up telemedicine and home-based care for geriatric individuals are aimed at providing reliable medical care.

Key points

- The COVID-19 pandemic has delayed access to diagnostic assessments and follow-up health and social care services.
- Social isolation has worsened dementia-related symptoms even in the absence of COVID-19.
- There is expected to be an underreporting of COVID-19-associated deaths in people with dementia.

Multiple co-morbidities

Identifying vascular risk factors that contribute to the development of cognitive impairment is instrumental in how the illness is managed. The distinctive perspectives converging on the same topic highlight the complexity of recognising symptoms and rendering an accurate diagnosis. These contributing risk factors are two-fold. They include non-modifiable ones, those out of your control, such as age, gender, ethnicity or genetics, as well as modifiable ones, signalling the lifestyle choices you make and control, including smoking, level of physical activity, alcohol consumption or hypertension. For example, modifiable risk factors greatly contribute to the onset of stroke, which engenders possible long-term cognitive degeneration.

Malnutrition, or even a decrease in caloric intake, is another prevalent risk factor, leading to a deficiency in essential nutrients associated with cognitive impairment and dementia in older adults. This condition can be enhanced by taking fortified nutritional supplements that complement food intake and provide vitamin supplementation.

Identifying idiopathic normal pressure hydrocephalus (iNPH) at the earliest opportunity, for example when gait disturbance appear, may ward off further complications before cognitive deficits occur. As many of these factors are present at middle age, a preventive approach should be adopted. For example, in community-dwelling individuals of a mean age of 53 years, walking more than 7,500 steps a day, which is considered light physical activity and accessible to most older adults, was associated with higher total brain volume, equivalent to approximately 1.4 to 2.2 years less brain ageing.

Key points

- Differentiating whether a dementia syndrome is due to Alzheimer's disease, cerebrovascular disease or mixed origin may be challenging as they present similar risk factors and cognitive profiles.
- More than 80% of the global burden for stroke is attributable to modifiable risk factors.
- Better understanding of the determinants of vascular contributions to cognitive disorders is required.
- Risk of malnutrition and subsequent vitamin deficiencies are strongly correlated with cognitive decline and nutritional status should be routinely explored.
- In the case of ventriculomegaly, it is important to evaluate the presence and severity of the key symptoms and signs of idiopathic normal pressure hydrocephalus (gait changes, cognitive decline and urine incontinence).

Young-onset dementias

Young-onset dementia can be seen as particularly cruel as it strikes individuals before the age of 65, young people in their prime with jobs, children and an active social and physical life. It contradicts what most people associate with this age group, namely, that it is an 'old person' condition that young people need not concern themselves with.

Although half of these cases are attributable to the onset of various dementias, other rarer underlying causes may be at play when young-onset is diagnosed. As some of these causes are treatable or reversible (for example, a person who has suffered repeated head trauma or abused alcohol and drugs) referring these individuals to specialised centres, such as memory clinics or a hospital's neurology department, is especially critical.

This is part of the reason a young-onset diagnosis can be an especially long, complex and difficult journey. By ensuring they are not misdiagnosed, which further exacerbates the symptoms, pinpointing these other factors is necessary to orient the management of the case. This includes providing the appropriate and effective therapies or medication in a timely manner.

Key points

- People with young-onset dementia, including individuals with Down syndrome, require careful evaluation to rule out treatable causes of dementia.
- Biomarkers play a major role ruling out Alzheimer's disease in young-onset dementia.

Cost factors in diagnosing dementia

A timely and accurate diagnosis of dementia entails some costs, but they are offset by a delayed or inaccurate diagnosis that impedes a structured management of the condition.

Comparing global healthcare systems and developing optimal diagnostic pathways from a cost perspective is vital. That said, the approach must also account for a time-effective clinician approach that incorporates time to provide necessary information to people with cognitive decline and their families.

Key points

- Adequate training of medical students and family practitioners is the most cost-effective approach for a timely and accurate diagnosis of dementia.
- Costs associated with a timely and accurate diagnosis are preferable to a delayed or inaccurate diagnosis that impedes a structured management of the condition.
- In relation to the emergence of biomarkers leading to an earlier and more specific diagnosis of dementia, further work is required to find cost-effective ways to orient people towards the best diagnostic pathways.

The future of the diagnosis of dementia

New challenges and opportunities in the diagnosis of dementia

It is evident that receiving a diagnostic assessment for dementia should ideally begin at the primary care level. That said, this is precisely where the barriers to getting such a diagnosis exist. From a clinician perspective, a lack of competence and training regarding dementia coupled with a high patient load and remuneration systems that do not encourage lengthy consultations contribute to the complications. Alternatively, from an individual's viewpoint, lack of recognition of potential signs of dementia along with perceived stigma and fear, costs, difficulties with remote locations and scarce transportation also play their part in delaying a diagnosis.

Nonetheless, there is a movement towards change. Primary care physicians have expressed interest in the potential for biomarker screening tests while the proliferation of self-testing kits point to a heightened awareness by people questioning their symptoms.

However, the ageing population and the influx of people seeking a definitive diagnosis based on the genetic risks indicated by these kits will present major challenges for clinicians, including the shift towards diagnosing pre-dementia states. This is why the advent of validated blood tests to confirm aetiology is being so enthusiastically supported. Cost-efficient, non-invasive and easily implemented – it is hoped that this trifecta of benefits will make dementia diagnosis on a wide-scale a new reality.

Key points

- Clinicians recognise the need to make their practice more efficient in the diagnosis of dementia.
- New blood biomarkers may facilitate diagnosis of the causes of dementia.
- Medical and health science university faculties must integrate new insights and knowledge about diagnosis and management of dementia.

Conclusions

This World Alzheimer Report has addressed a range of topics and has looked through various clinician lenses into the world of dementia.

These different perspectives have one goal – to increase the efficacy of the diagnostic process. Ranging from validated blood tests towards an aetiologic diagnosis; cognitive scales that are better adapted to various cultures and languages; validated online algorithms; cognitive scales validated for telemedicine; and self-screening tests prior to clinical assessment, this is an impressive collection.

One of the common theme centres on the importance of clinical assessment initiated online and the potential use, and advantages, of available web-based algorithms. The interest in blood tests as a way to streamline the aetiologic work-up regarding the cause of dementia would be cost-effective, but the routine use of APOE genotyping would require training in the disclosure of genetic information. Although not yet an issue for most clinicians around the world, the diagnosis of a dementia with no evidence of amyloid build-up means a broader differential diagnosis for which we are still lacking longitudinal information.

The key role of primary care practitioners requires education about the diagnosis and management of dementia in medical schools and throughout practice.

Forward thinking

Alzheimer's disease and related disorders have no cure yet – and as the population ages and more people are diagnosed, we need to ensure that the public is better educated about the signs and symptoms of dementia. This would prompt individuals to consult healthcare professionals more, as well as gain a better understanding of how to manage their illness. The responsibilities entailed with this disease are considerable. It requires a rigorous commitment in an all-encompassing and dynamic world. That is why it is often referred to as a journey and it is precisely why governments also have an essential role to play. There is a pressing need to develop public awareness campaigns that educate, enact policies that bring about change, create programmes that expand accessibility and endorse support systems that assist all the many carers. The world needs to embrace health literacy about dementia – not only increasing an individual's opportunity to get their foot in the door, but while there, obtain a variety of dementia support and information they can understand and rely on. Empowering this concept will ensure the best quality of care, safety and dignity of the person who is diagnosed.

Medical schools across the globe have an equally important responsibility to better educate students today so that they may be better healthcare professionals tomorrow. This is not simply relegated to understanding the various diagnostic options, but most importantly, how to assist an individual and their carer on the best ways to navigate their post-care in a progressively complex medical environment. Dementia is now the 7th leading cause of death, and there exists an ethical imperative in the medical community to properly arm citizens around the world with all the necessary knowledge and skills they require, as well as actively engage them in their own healthcare needs. Only in this way can post-care become optimal care.

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