

ELSA - Episode 7

Dementia - who's at risk and why?

SUMMARY KEYWORDS

Dementia, ELSA, alzheimer, cognitive impairment, affected, research, participants, important, study, ageing, years, population, risk factor, Alzheimer Society, identifying, protocol, real, support, people

SPEAKERS

Hannah Churchill, Christine Garrington, Dorina Cadar

Christine Garrington 00:00

Welcome to the ELSA podcast from the English Longitudinal Study of Ageing. I'm Chris Garrington. In this series, we're talking about how ELSA is helping us better understand what happens to us as we get older and to live longer, happier, healthier lives. In this episode, we're discussing dementia with UCL researcher Dorina Cadar, who's been using a special sub-study of ELSA to see who is at most risk of becoming a dementia sufferer, and with Hannah Churchill from the Alzheimers Society, about how the research can help people whose lives are affected by dementia. I started by asking Dorina how widespread a problem dementia is.

Dorina Cadar 00:34

Yes, dementia is indeed a significant concern since it represents a major cause of disability and dependency among the elderly. But we should also realise it affects really everyone who knows the individual. The World Health Organisation recognises dementia as a global public health priority. And in the UK, for example, we should know that our estimated 850,000 people with dementia. So let's consider if each person is supported by three other individuals, such as family members or friends, then that would be 2.5 million people who are directly affected by the disease. This is roughly a quarter of the people living in London, there is often a lack of awareness and understanding of dementia and what dementia is, resulting in stigmatisation and barriers to diagnosis and care. Although dementia may affect older people, it is not a normal part of ageing. The prevalence of dementia is increasing indeed after the age of 65, and it seems to double with every five years after that. So age is an important contributor but not the only one. Genetics, family history, cardiovascular risk factor and lifestyle have all role to play.

Christine Garrington 01:46

ELSA is a really important resource for researchers like you who want to better understand the broader sort of social and health impacts of dementia. Can you tell us a bit about why it is such an important resource?

Dorina Cadar 01:58

ELSA is indeed an important resource for information, firstly because this is a large ongoing study representative of the English population aged 50 and older living in a community in various parts of the country. Second, as we all know, there is enormous variation in the English population in terms of health, psychological well being, wealth and income, which make the study an incredible resource for investigating not only socio-economic differentials, but also psychological and psychosocial impact, medical risk factor for various chronic condition including dementia. So benefiting of this rich cross disciplinary nature of ELSA data, we have the opportunity to investigate various biopsychosocial determinants of health. What is extremely important is that ELSA can also bring a relatively fresh perspective on the current global challenges such as the impact of COVID 19 pandemic, on individuals living with dementia, and also their families and carers.

Christine Garrington 02:54

Now the team at ELSA have developed a tool called the harmonised cognitive assessment protocol. And now that's trying to help look at dementia more closely. So talk us through what that is and how that works.

Dorina Cadar 03:07

Yes, most of my work on ELSA is focused on these harmonised cognitive assessment protocol, also short HCAP, which is an international study with sister study in the US, China, India, Mexico, South Africa to mention just a few. In England, in ELSA, we selected more than 1000 participants aged 65 and older to take part in this HCAP study. And this harmonised protocol used about 17-18 different cognitive tests making the most detailed neuropsychological battery in a British longitudinal study. So we had about 90 interviewers who went to participants' home to assess them on this battery of tests. We also had informants interview with a family member or a knowledgeable friend. Some of the measures which were included in the respondent interview were related to memory, reasoning, numeracy and psychomotor speed. By being linked with the ongoing longitudinal framework of ELSA, HCAP study provides the potential to improve our understanding of the evolution of cognition from day to day, as people leave an age in various geographical regions and settings. Another major advancement of this study is that this is conducted in many different countries simultaneously. And this will facilitate cross country comparison of dementia prevalence worldwide.

Christine Garrington 04:31

It's a phenomenal resource Dorina, what have been the key things to emerge so far? What can you tell us about what's been found so far?

Dorina Cadar 04:31

We are still in the process of analysing and comparing the data across various countries, but this analysis will generate the basis for creating the diagnostic tool. However, we already observe a number of interesting findings within our ELSA HCAP sample. So for example, the performance of men was on average better than a women on mini mental status examination, verbal fluency, backwards counting, constructional proxies, logical reasoning and solving intelligence test. One or another women outperform men in memory and visualisation scanning abilities. We also observed the levels of

education were higher among men than women, there was an increased prevalence of this cognitive impairment and dementia prevalence is with age and lower socio-economic position.

Christine Garrington 05:25

I know that getting a better understanding of the prevalence of dementia in a population is something that's really important, were you able to achieve that?

Dorina Cadar 05:32

We estimated that around 23% of ELSA population sample age 60 and older at wave nine have cognitive impairment, and around 5% have dementia. These estimates are similar to what is expected in a population of this age. So we are confident in our prediction algorithm. A large proportion of those whose dementia had no formal education, and only a few of them had completed a higher degree. Not surprising participants classify with dementia or cognitive impairment or were older.

Christine Garrington 06:06

Because ELSA is a longitudinal study that follows the same people over time, you're able to look back at people's histories and see whether there are any links, and see there any other factors in people's backgrounds that might be a factor is that right?

Dorina Cadar 06:19

So what we found was that a higher proportion of participants classified with cognitive impairment in dementia at week nine, had worse health almost a decade earlier with higher prevalence of high blood pressure and diabetes, but also higher levels of depressive symptoms and loneliness. We also found the participants who were physically inactive, by the Wave 4 in 2008, had an increased dementia risk a decade later. So it's important to consider that many of these modifiable risk factor coexist and are part of the pathways in case of stroke, microvascular infarct, for both vascular dementia and Alzheimer type of disease. And notable strength is that the longitudinal structure of ELSA allows medical and psychosocial risk factor to be assessed many years before this condition develop, which demonstrated this factor precede the occurrence of cognitive impairment and dementia and later life.

Christine Garrington 07:13

Thanks to Dorina. So I'll come back to you in a moment to ask you a bit about what that all really means for people with dementia. But I want to turn now to Hannah from the Alzheimer's Society, for people who have little experience or understanding of dementia. Let's take a step back here, Hannah. And I wonder if you can just take a bit of time here to describe just how it affects people's lives?

Hannah Churchill 07:38

Dementia itself is an overarching term that we use to talk about a group of symptoms, which includes things like memory loss and changes to personality. And below this umbrella term set a number of different diseases which cause these symptoms. So Alzheimer's disease is the most common type of dementia. And it's characterised by memory loss. We also have other types of dementia, such as vascular dementia, where we know the vasculature in the brain has been affected. And these two cognitive decline. There's countless numbers of dementia, that the most common alongside Alzheimer's disease and vascular dementia, Frontotemporal dementia, which tends to affect a younger

group of people. And as the Dorina said, your risk of dementia does increase with age, but it does affect younger people as well. And there are a significant number of people, around 45,000 people under the age of 65, who were living with young onset dementia, it's a condition which affects individuals, and 850,000 people in the UK, but those around them as well. And this really is a major public health concern. This absolutely chimes with what we're seeing in the field of dementia research at the moment. The real challenge that we have in dementia, or one of the key challenges is that people's symptoms seem to appear 15 to 20 years after they've begun to develop the conditions. So that means that we're bringing treatments and care to people when they're further down the line than we would want them to be, so the the ideal situation is we identify people long before they develop any symptoms, as the condition is beginning to develop in the brain at a point where we think treatments might be more effective. And we're starting to see improvements in diagnostics in through techniques like this. Also through new research using blood tests, smart technology, so people using smartphones to identify the really early cognitive changes that we see in the brain and improves scanning techniques as well. But it's really the in depth work that Dorina and her team are doing and the ELSA project, that gives us the real fine details of this area of work.

Christine Garrington 09:41

Yeah, that moves me on very nicely to my next question, which was really going to be about just how important research like this and findings like these are for people whose lives are affected by dementia?

Hannah Churchill 09:53

This is hugely important for for people living with dementia today and those who may go on to get dementia in the future. We hope this will allow us to introduce people as trials earlier when treatments might be more effective, it also allows people to plan emotionally, financially, for what might be coming in the future and for the families as well to prepare themselves. We know that the number of people with dementia in this country is growing and we're likely to hit 1 million people living with dementia in the UK by 2025. And the only way we will be able to buck that trend is through understanding the best ways to prevent dementia and the best ways to treat dementia. And research like this is essential for doing that.

Christine Garrington 10:27

Dorina coming back to you, I wonder if you can tell us a bit then about what the protocol has told us and how it's helped us understand what we didn't know before? Yeah that again, that moves me on very nicely to my next question, because there's obviously a lot more to come, but I wonder how that information is being fed through and how it can help improve the lives of those affected Do you have a feel for that arena?

Dorina Cadar 10:37

Yeah, the million dollar question. First of all, we are now able to ascertain more precisely people whose cognitive impairment as this is more challenging to do based on simple cognitive measure that we had before in ELSA. Now it's also important to note that identifying individuals with cognitive impairment and dementia is crucial for early intervention, for care planning and also for treatment. So a significant challenge however, remains to define what constitutes normal spectrum of cognitive ageing, in contrast

to cognitive impairment and to take into consideration also the specific population norms on which clinician agreed. Secondly, the cognitive performance data collected every two years in a previous waves of ELSA coupled with this new study have allows us to develop a better understanding and algorithms for identifying how cognition progress at population level, let's say from day to day basis, and progression over time. This assessment can confirm that many cases in the community are not identifying through current clinical channels. The under detection of dementia cases could be related to the availability of services, let's say in various geographical regions of England, the waiting times for clinical consultation or simply to the reluctance of older people to come forward to express this thinking and mental problems. We cannot also dismiss the lack of awareness for example, seeing that impairments are part of normal ageing, because participants ELSA HCAP will be follow up in the future every other two years, it will be possible for us to quantify the consequences of severe cognitive impairment for family income, expenditure, financial decision making, social activity, mental well being and physical health. This information has really the potential to strengthen the evidence base for health and social care provision to this vulnerable sector of the population. It's difficult, but our work suggests important avenues for developing some appropriate public health messages and develop policy implications in terms of early identification, and dementia prevention. Several actions seem to be supported by our work. These are maintaining physical activity, for example, preventing and treating cardiovascular risk factors, now remaining socially and intellectually engage in order to avoid loneliness, which we understood that it's important risk factor for dementia. It has been estimated that the potential for Alzheimer disease prevention through modification of seven risk factors which are diabetes, hypertension, in midlife, midlife, obesity, smoking, depression, low education and physical inactivity is around 30%. So by intervening on this modifiable risk factor, we hope to see a reduction in dementia in dementia cases. However, the reality is that it will take some time for these risk factors to be fully incorporated into public awareness and policy. And we know that in difficult climates like pandemics, this is even more harder to achieve. But we need to remain optimistic.

Christine Garrington 13:59

Yeah, that was going to be exactly my question for you, Hannah here, which is this whole, you know, question of how do these messages get through, especially in these incredibly challenging times when, you know, you're fighting to get the attention of, you know, of ministers and policymakers and public health people who are all absolutely 100% focused on COVID-19 at the moment, that must be a huge challenge for you, Hannah.

Hannah Churchill 14:26

It's a real scramble to get through to the people that we need to reach in these circumstances. Alzheimer's Societies implementing work. We have seen real progress over the last six months partly due to the horrific circumstances that people with dementia have found themselves in in the last six months during the pandemic. They really have been hardest hit around a quarter of coronavirus deaths have been people with dementia which is a staggering statistic. And alongside that we know isolation is causing real stress for carers, deterioration in mental health for themselves and also people living with dementia, as well as a deterioration in their symptoms, it's really been incredibly difficult for time for this vulnerable group. We work incredibly closely with Dementia Research Community as well as people affected by dementia. We are here to represent them and to ensure that their voices are heard in these circumstances.

Christine Garrington 15:15

Yeah, and notably, you know, we're talking as it is about to be world Alzheimer's Day and Alzheimer's Awareness Month, never a more important time to be talking about this topic, right?

Hannah Churchill 15:25

This World Alzheimer's Month is really focusing about, about talking about dementia and making people feel more comfortable talking about dementia. We know that across many different cultures, there's a real stigma around the condition and talking about it, around accepting it, around discussing your diagnosis. This is a global campaign that people are supporting on World Alzheimer's Day on the 21st of September. And we're really encouraging people to learn a bit about dementia and Alzheimer's disease, and to encourage people to feel more comfortable talking about it. We're running dementia friends sessions, so people can find out more about dementia and how to talk to people with dementia. We're running memory walk, which is our flagship fundraising event, we normally would bring people together in big groups to go for amazing walks and amazing places. But we're encouraging people to sign up to memory walk and get involved on their own personal walks with their families and support Alzheimer Society through that.

Christine Garrington 16:15

Thanks, Hannah. And I just like to wrap up if I may, by asking you both. Really what comes next?

Dorina Cadar 16:19

Indeed, we hope to be able to repeat the ELSA harmonised cognitive assessment protocol in the near future, perhaps every four years, it would be wonderful to be able to add an imaging study and enhance the research possibility of identifying structural brain changes over time related to healthy ageing. From the level of normal to abnormal changes, atrophy and neuronal loss. Repeated measure of cognition combined with detailed functional imaging, highlighting specific let's say biochemical and molecular processes could inform and refine our diagnostic accuracy and precision. However, these types of investigation, as you can imagine, require specialised clinical assessment, which are expensive in this country and elsewhere. And for this, we will need larger research grants and governmental funding which are difficult to get in the current climate. But we are hopeful.

Hannah Churchill 16:22

Alzheimer Society and Alzheimer's Research UK or two of the leading medical research charities are in dementia. And our role over the last decade or so has been supporting a lot of early career researchers who are trying to build capacity within the dementia research community. Unfortunately, during the pandemic, as with many other charities, we've been hit very hard financially, as we've been unable to run a lot of fundraising events. So, a lot of our work across the board by including our research has been put on hold for now. So we aren't able to support new research this financial year. So we led a campaign in the last month or so supported by nearly 300 dementia researchers and wrote to science minister, Amanda Solloway to underline this huge issue that we're facing. It's a challenge for the charities but in reality, it's a challenge for the people affected by dementia. We can't afford to lose a generation of dementia researchers over the next couple of years, and we think that across dementia research charities is likely to be a 40% fall investment in research and that could take 4-4.5 years to

recover to the level we're at pre the pandemic. It is a big issue and something that we will need to prioritise for people affected by dementia who've been hit so hard by COVID, but also by lack of support through the social care system.

Christine Garrington 18:27

Thanks to Hannah Churchill and Dorina Cadar for talking to me for this episode of The ELSA Podcast. You can find out more about ELSA on the studies website at www.ELSA-project.ac.uk. Don't forget to subscribe to our podcast to get forthcoming episodes when we'll be discussing further How else is used in important policies and practices that affect our everyday lives.