Public perception of dementia risk in the UK: A mental models approach

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Abstract

Dementia is a leading cause of death in the developed world. A number of modifiable risk factors for dementia have been identified, yet lay knowledge on dementia risk is limited. A mental models approach was used to compare lay and expert knowledge of risk in order to identify target areas for lay education. This method assumes experts and laypeople use different cognitive representations to make sense of phenomena. Semi-structured interviews were conducted with 8 experts and 15 laypeople to construct mental models of dementia risk. Interviews were transcribed verbatim and entered into NVivo qualitative data analysis software for coding. Findings indicated that laypeople had some knowledge of modifiable risk factors but in contrast to the expert mental model, laypeople poorly understood the causal links between these factors and dementia risk. Lay participants were unsure of the interaction between modifiable and non-modifiable risk factors and primarily attributed dementia risk to "bad luck". It is suggested that future dementia education could benefit by building upon a general appreciation of healthy behaviour with particular focus on explaining the causal pathways to dementia risk. Additionally, it may be productive to inform laypeople it is possible to "change one's luck" by engaging in protective behaviours.

Introduction

Dementia is a collective name for progressive degenerative brain syndromes which affect memory, thinking, behaviour and emotion (ADI n.d.). The World Alzheimer Report (ADI 2016) states there are currently 47 million people living with dementia worldwide and as world populations age, the number of people diagnosed with dementia is projected to increase to more than 131 million by 2050. Research into public perception of dementia, Alzheimer's disease and cognitive impairment has highlighted a gap in lay knowledge of dementia risk and modifiable risk factors (Chung et al. 2009; Friedman et al. 2015; Hudson et al. 2012; Yeo et al. 2007)

In their 2015 review of public perceptions about cognitive health risk and protective factors, Friedman et al. note that genetics and old age are perceived as key perceived risk factors for cognitive health and impairment, rather than modifiable behaviours such as poor diet, alcohol and smoking. Although age and genetics are important risk factors, there is growing evidence to suggest that modifiable lifestyle and health factors may substantially reduce the risk of developing dementia (ADI n.d.). Seven potentially modifiable risk factors for Alzheimer's disease have been identified (diabetes, midlife hypertension, midlife obesity, physical inactivity, smoking, depression and low educational attainment) (Barnes and Yaffe 2011; Kim, Sargent-Cox and Anstey 2015) and it has been suggested that approximately one third of Alzheimer's disease cases in Europe and the UK may be attributable to these factors (Norton et al. 2014). The recent *Lancet* Commission on Dementia Prevention, Intervention, and Care (Livingston et al., 2017) has placed a high premium on modifying risk factors and reducing the incidence of related cardiovascular illnesses earlier in life, noting that even with the possible development of future disease-modifying treatments, preventative measures will be critical to reducing dementia incidence and improving quality of life among those living with the condition.

In 2015, dementia was recorded as the leading cause of death in England and Wales, accounting for 11.6% of all deaths (ONS 2016). Contrary to the established view that dementia prevalence will continue to increase (ADI 2016), a recent review of 14 population-based studies (Wu et al. 2017) found that the prevalence and incidence of age-specific dementia in Western countries may be proportionally stable or in decline. Although the reasons for this pattern are unclear, Wu et al. (2017) speculate that factors such as education level, cessation of smoking and reduced prevalence of chronic disease may have played a role. Hence, from a public health perspective, improving public knowledge of modifiable risks could yield further improvements.

In order for people to make informed health decisions, an understanding of risk and practical preventive measures is needed. Effective risk communication must therefore focus on the things that people need to know but do not already (Morgan et al. 2001;2002; Bruine de Bruin and Bostrom 2013). Raising awareness of risk can however provoke fear and potentially result in an increase of self-diagnosis and self-referral of the 'worried well' (Draper et al. 2010). Successful integration of new risk information requires a thorough understanding of the beliefs lay people already hold (Downs et al. 2010) and an understanding of any difference that may be identified by age group (Haapala, Carr & Biggs, 2018). In the context of dementia, the complexity of risk communication is further compounded by the heterogeneity of dementia definitions, and the debates concerning the relationships between neurological and social factors (Kitwood, 1990; Iliffe & Manthorpe, 2017). The aim of this study was to examine the mental models on dementia risk held by experts and laypeople of all age groups, in order to identify any gaps and misconceptions in the latter that may be targeted in future public health communication.

Methods

Design

The mental models approach to communication aims to supply laypeople with the necessary understanding of risks to make informed decisions. The approach assumes that laypeople and experts utilise different mental models – cognitive representations of a given phenomenon – to make sense of it. The term expert denotes a person with scientific or professional knowledge of a risk phenomenon and does not imply someone whose beliefs are perfect or even superior to lay beliefs in all respects (Morgan et al. 2001;2002). The mental models approach seeks to bridge the gap between lay and expert perspectives, such that the public are well informed about risk.

Participants

Expert participants were required to be at least 18 years of age, English language speakers with at least 3 years' experience working in a professional clinical or research role associated with dementia. Lay participants were required to be at least 18 years old, English language speakers and with no professional experience or expertise in dementia. Purposive sampling was undertaken to gather a broad range of perspectives: experts in a variety of clinical and research roles were recruited, while lay participants were sampled to gain a broad range of ages, educational qualifications, and to achieve a balance between men and women.

Ethics

This research was reviewed by the University of [BLANK][1] ethics committee and adhered to the British Psychological Society Code of Ethics. All participants were provided with detailed information about the study and consent was obtained prior to interview.

[1] Omitted for the purposes of peer review

Procedure

Open ended, semi-structured face-to-face interviews were conducted with all participants. Whilst the content and structure of the interviews were similar for all participants, lay interviews were modified slightly to allow for additional questions that served as a prompt for further elaboration of answers. Lay participants were reminded that the intention of the research was to construct a model of public perception about dementia and there were no right or wrong answers to the questions. Questions were designed to be non-leading so participants could explain their knowledge in their own words. The interview schedule for expert and lay participants can be viewed in Appendix A/B.

Each interview lasted 30-45 minutes and began by asking participants to describe their understanding of dementia. This allowed interviewees to express their mental models before they were altered by further, more directive questions (Bruine de Bruin and Bostrom 2013). The expert participants instinctively expanded their answers and required few prompts. Lay participants required additional prompt questions (e.g. 'Do you know about any different types of dementia?' and 'Can you tell me what you think it means to be diagnosed with dementia?'), in order to elicit the full extent of their knowledge. The second stage in constructing the mental model was more directive: all participants were asked their awareness of different risk factors associated with dementia and what they believed a person could do to reduce their risk. Lay participants were again given prompts to elaborate on the topic (e.g. 'What characteristics do these people have?') until their response was complete. Lay participants were also asked where they would seek information about dementia. Both groups were questioned about the most effective method of communicating a health campaign that focussed on engaging the general public. Lay interviews were conducted until it became apparent that no further new beliefs would emerge and the data had reached

theoretical saturation (Bruine de Bruin and Bostrom 2013). Interviews were recorded using a Roland R05 digital MP3 recorder.

Analysis

Audio recordings of each interview were transcribed verbatim and QSR NVivo 11 software was used to code the transcriptions. The expert interview transcripts were read and coded concurrently by identifying broad themes and concepts. Further detailed analysis allowed for more precise coding and established thematic key concepts with sub-categories providing a more accurate model of the expert's view.

Using the expert mental model key concepts, the lay interview transcriptions were compared with the existing model to identify any gaps and differences. The codes were then analysed within and between each model. The risk factors within the mental models are classified according to the regularity with which they were mentioned. A comparison of the expert and lay models revealed similarities and differences in the data and identified the knowledge missing from the lay mental models.

Results

Expert Mental Model of Risk

Eight experts with professional experience of dementia research, treatment and care were recruited. Five interviews were conducted on a one-to-one basis, and one panel interview was conducted with a further three participants. Table 1 shows the key demographics of the expert interviewees.

Table 1 near here

There was consensus amongst the experts that a healthy lifestyle in general was protective against the risk of developing dementia. The experts identified seven potentially modifiable risk behaviours for dementia: diet, other health conditions, alcohol, social stimulation, exercise, education and smoking. Age and genetics were identified as non-modifiable risk factors. The expert participants identified a number of relationships between the risk factors and their corresponding causal elements, which is reflected in the model pictured in Figure 1.

Figure 1 near here

The foremost modifiable lifestyle risk identified in the expert mental model and cited by all participants was 'diet', with fat, sugar and salt referenced as specific health risks. Good nutrition in early formative years was declared to be a protective factor against developing dementia in later life.

> "If you've got a healthy brain, by definition you are less likely to get dementia…we think there may be things to do with early nutrition that contribute to the way the brain grows which then would make it more resistant to dementia later."[5]

Poor diet was also acknowledged as contributing to a person becoming overweight which was subsequently associated with instances of diabetes and stroke (other health conditions) - cited as a direct cause of vascular dementia.

> "If you are overweight and smoke too much that is going to give you risks of having strokes, that's going to increase your risk of things like vascular dementia there's no doubt that cause and effect."[8]

The model illustrates the direct link between poor diet with the corollary condition of being overweight and the causal relationship of other health conditions on dementia risk. The experts declared that diabetes, stroke, high blood pressure and heart disease were a significant

contributory risk factor in developing dementia and acknowledged good physical health as being directly associated with good mental health.

> "[Health risk factors are] any other chronic illness because anything else that drags you down physically, is likely to drag you down mentally as well."[7]

> "Parkinson's disease and stroke are causes of [dementia], so they don't increase the risk they are actual causes of dementia."[3]

'Exercise' was frequently mentioned alongside other 'healthy lifestyle' factors (e.g. diet, alcohol misuse, smoking) and consistently identified as a significant influence on risk.

> "Some of those things that are associated with dementia, to keep your cardio vascular system healthy, you probably need good physical exercise, you need exercise that keeps your circulation up and pushes the blood around your system well and that helps to keep you healthy."[5]

A lack of exercise combined with a poor diet was identified as contributing to dementia risk both directly, and indirectly via other health conditions. 'Social stimulation' was identified as beneficial for inducing mental stimulation along with a regular routine of activity. Social activity was also considered to be essential for emotional fulfilment and protection against depression. The importance of brain training was disregarded, however 'education' was identified as a potential protector to cognitive damage.

> "There was a thing if you do brain training you'll prevent dementia but that's a complete fallacy actually, it's not true. The studies don't show that."[4]

> "Education protects you from dementia, possibly because you build up rich networks, which are then more resistant to damage if you start to develop some of the pathology that goes with dementia."[5]

‘Genetics’ and ‘alcohol’ were acknowledged as risk factors by half the expert participants. Both factors were associated with younger onset dementia in people aged under 65, however this was acknowledged as quite rare and possibly also dependent upon other manageable health behaviours.

> “Certainly with Alzheimer’s, you may be predisposed to develop it but whether you get it or not probably depends on the other factors as well and how soon you get it”[1]

There was disagreement amongst the experts regarding the importance of smoking as a risk factor. 50% of interviewees claimed smoking was a significant risk and one expert categorically denied this to be the case.

> “Certainly some epidemiological studies have shown it [smoking] to be protective. Probably because of its stimulation of nicotinic receptors in the brain.”[3]

Participants in the expert group who asserted that ‘smoking’ was a risk factor did so in association with other healthy lifestyle factors that were recommended for the promotion of good general physical health and the prevention of other chronic health problems rather than exclusively to prevent the risk of dementia. Both opposing views are reflected in existing research that acknowledge smoking is a risk factor for several chronic diseases [Zhong et al. 2015; Beydoun et al. 2014). However, it cannot be assessed as a significant risk factor independent of other health behaviours, and the risk that does exist may only apply to those who currently smoke. As there was strong support for both viewpoints, the risk factor of ‘smoking’ is included in the expert model as a disputed risk.

Old age was consistently identified as a non-modifiable risk factor which increases exponentially over time regardless of other modifiable health behaviours.

> “Certainly from the research evidence, by far the biggest factor is age, in that the incidence and the prevalence of dementia doubles every 5 years people age, which doesn’t make much

> difference between the age of 40-45, but by the time you get to 80, then living another 5 years is going to really significantly increase your risk and it is a much greater risk than anything else that we know about."[3]

Lay Mental Model of Risk

The sample of 15 lay participants included people of a variety of ages, ethnicities, and educational attainment. The majority were white and educated to degree level and above. Table 2 shows the demographic profile of the lay participants.

Table 2 near here

Lay participants identified five potentially modifiable risk factors for dementia: diet, exercise, active mind, alcohol and social stimulation, together with three non-modifiable factors: age, genetics and bad luck. Contrary to the expert mental model, the lay participants did not specify the direct and indirect causal pathways of a generally healthy lifestyle, nor its impact on dementia risk. The lay participants were largely sceptical about the potential influence of modifiable risk factors with the majority identifying 'age' as the most significant risk factor for developing dementia. Almost two thirds of participants suggested that 'genetics' were a contributory factor, and more than one third reflected that developing dementia was simply 'bad luck'. The lay participants identified few relationships between the risk factors which is reflected in the model design pictured in Figure 2.

Figure 2 near here

In common with the expert mental model, 'age' was consistently identified by almost all participants (93%) as a significant risk factor for developing dementia, however the definition of what constituted old age differed amongst the participants. A variety of ambiguous terms were used including 'old age', 'elderly' and 'older people' aged in their

60s, 70s and 80s. The vague notion of 'old age' being those older than themselves, was true of all participants regardless of their own age.

Whilst 'diet' and 'exercise' were consistently identified as significant risk factors, several lay participants expressed surprise to learn that being overweight was a risk factor for dementia. Failing to engage an 'active mind' was consistently identified as a risk factor yet in contrast with the expert model, this was attributed to brain training exercises rather than social stimulation and active routines.

Almost two thirds of lay participants considered the possibility that dementia may be hereditary, however their comments often lacked conviction.

> "I do wonder if it's a hereditary thing, I don't know. That's what I seem to think because people, families have longevity in their genes and they have all sorts of things in their genes, so possibly dementia might be something that is hereditary." (Female, age 65-74)

Whilst reflecting on the possibility that 'genetics' could be a risk factor, several participants attributed this risk to 'bad luck', with some using the two concepts interchangeably.

> "I think that if it's going to happen, it's going to happen. I don't think you can catch it or you can cause it, I think it's something that is possibly innate in your person, in your own physiological make-up." (Female, age 35-44)

> "I still think probably the biggest factor is just, it's not exactly luck but, just if your number's marked, you know if you're prone to it in your DNA. You probably can delay it through your behaviour, but I don't think you can stop it." (Male, age 45-54)

One third of interviewees considered 'alcohol' to be an important risk factor, however, this was disputed by some whilst others were uncertain. As a result, 'alcohol' features in the model as a disputed risk.

> "If I had to pick something that would be really bad for your brain I think probably things like alcoholism, like if you'd been an alcoholic all your life that maybe that would have a bad effect on your brain in the long term but I don't know". (Female, age 25-34)

> "I don't think for instance people that drink are predisposed to get Alzheimer's or dementia." (Female, age 35-44)

Examination of the lay participants' responses reveals that, while they knew about some important risk factors, they lacked understanding of how these were linked, and the causal pathways to dementia. On the contrary, the risks identified appear to be derived from a general appreciation of health behaviours that contribute towards overall health. Answers to the question, 'Can you tell me what you know about dementia?', typically highlighted some general awareness of the disease, but not its variants, symptoms and causes. All age groups confessed to ignorance and confusion about specific aspects of dementia.

> "I relate it to Alzheimer's a lot and I'm not quite sure how the two technically relates even though they seem similar". (Female, age 25-34)

> "It's a disease of the mind, I don't know if disease is the right word, where people lose their faculties of being able to recall long term, or possibly short term. They have problems with long or short-term memory. I don't know which one it is". (Male, age 35-44)

> "It's something to do with a build up of proteins in the brain. I don't really know much about it to be honest. A lack of memory, loss of memory, some logical faculties, loss of faculties basically. That's about all I know of it". (Male, age 55-64)

Most lay respondents expressed a desire for simple, clear information about the symptoms and causes of the illness. Although dementia risk was acknowledged as existing throughout the wider population, lay participants appeared not to attribute risk of dementia to themselves.

> "When I think about doing something healthy it's more about heart, weight that sort of thing. I don't think I'll walk to prevent having dementia, I don't put the two together, no" (Female, age 35-44)

Importantly, it became apparent that many lay participants believed that the diagnosis stage presented the best opportunity to modify health behaviour.

> "I think the earlier it's diagnosed, maybe you can start doing something about it, you can start making lifestyle changes." (Male, aged 35-44)

> "If you're aware that you're developing symptoms early on you can take steps to maybe reduce it." (Male, aged 55-64)

Perceived barriers to lifestyle change

Almost all lay participants identified a lack of information about dementia as a barrier to lifestyle change. Lay participants emphasised their desire for "scientific proof" of risk factors.

> "Is there anything, even as simple as say what we're eating and lifestyle that can delay it, because that's what people need to know. Because is this something that has always happened, or is it a 21st century disease, or is it just because we're living longer, or is it because life is more stressful. These are questions that all need to be looked at and answered." (Female, age 65-74)

However, although expert participants acknowledged that people increasingly require evidence to support heath risk claims, lay language pointed more to the provisional nature of scientific knowledge.

> "Would losing weight, drinking less alcohol and exercising more, lower the risk? No-one's come out and said it does. No-one's come out and said it doesn't have they? That's the thing." (Male, age 55-64)

Several lay participants expressed dissatisfaction with trite healthy lifestyle advice that caused people to 'switch off'. This concern was shared by several expert participants who also recognised the problem of presenting healthy lifestyle advice without the accompanying evidence to corroborate it.

> "It's the same things, sort of what you'd say about cancer really. Stop smoking, lose weight, drink less alcohol and exercise more. It's like the four things isn't it that you're always told to do." (Female, age 55-64)

> "There's nothing worse than health campaigns that are just banging on the same thing you've just heard constantly all your life, eventually you just stop listening I think." (Male, age 45-54)

> "I guess the challenge for NHS and other public health is how to make the message sufficient so that people don't stop reading it. It's a problem isn't it because it's the same message all the time."[4]

The expert interviewees agreed that lifestyle change promotion presents a challenge. It was acknowledged that many of the lifestyle risk behaviours associated with dementia were also identified with other previously well-known chronic illness (e.g. stroke and heart disease) and previous attempts to modify behaviour had met with mixed results.

Lay participants expressed concern regarding the credibility of sources of health guidance, with many in particular highlighting problems associated with information obtained from the internet. In addition, there was some scepticism expressed regarding the credibility of health advice that seemingly contradicted their own experience of dementia risk and diagnosis.

Discussion and Conclusion

Discussion

In this study, a number of important differences between lay and expert mental models of dementia risk were identified. First, although lay participants were aware of some relevant risk factors, these were not understood in an integrated manner. The lay mental model we constructed showed a lack of knowledge on the causal pathways by which modifiable lifestyle factors affect dementia risk. Second, whilst the general public express a desire for preventive health behaviour knowledge, they currently have a reactive attitude towards lifestyle health behaviours. During the course of our interviews, it became apparent that many lay participants believed that the diagnosis stage presented the best opportunity to modify health behaviour. Additionally, laypeople were unaware of the link between dementia and other cardiovascular illnesses, and experts and lay people had different perspectives on the role of cognitive stimulation as a protective factor: While experts specifically identified occupational and social stimulation as key components of this, laypeople spoke in more general terms about 'keeping the mind active'. This was consistent across all age groups.

The lay knowledge examined in this study also highlights gaps in understanding of dementia in general, with very few participants able to describe clinical features and dementia subtypes. For example, and consistent with previous research (Kim et al., 2015), our interviewees showed confusion about the connection between Alzheimer's disease and dementia. Most knowledge about dementia appeared to be limited to personal experience of family members, friends or celebrities affected by the disease. However, the question of whether public understanding of dementia subtypes is necessary for adequate dementia risk knowledge was beyond the scope of the present research and should be explored in future studies.

Perhaps the most important difference between the lay and expert mental models, from a risk communication point of view, concerned the role that old age and genetics play in

dementia risk. Although laypeople and experts both identified age and genetics as risk factors – a promising finding from the point of view of health educators – lay participants did not recognise that the influence of these factors is affected by engagement in modifiable, risk-reducing health behaviours. Instead, the lay participants believed that the significance of age and genetics as contributory factors in developing dementia was "bad luck" – something they had no control over. This chosen language of "bad luck" has potentially significant implications for communicating about dementia risk, to which we now turn.

Recommendations

The mental models approach to risk communication does not aim to provide the public with a perfect understanding of risk factors – rather, the important objectives are to correct any fundamental misunderstandings, to present the key risk information in a language that lay people can easily comprehend, and to empower the public to make informed decisions about their own risk-related behaviours (Morgan et al. 2001;2002; Bruine de Bruin and Bostrom 2013). In terms of this study, although the lay mental model showed notable gaps and simplifications, it also included many important risk factors (notably age, genetics, and alcohol consumption), and points to some productive possibilities for dementia education – both within the clinic and the wider public health realm.

First, although lay participants did identify some modifiable risk factors, the role of genetics was seen as deterministic – that is, with certain genes present, dementia would develop irrespective of health behaviours. This shows an important misconception about the relationship between genetics and dementia and suggests one possible gap in lay knowledge to address: the knowledge that behavioural changes can significantly alter the expression of genes. If people are to be motivated to adopt dementia-protective behaviours, it is important that people feel they have control over their risk, as the body of literature on self-efficacy

suggests (Olander et al. 2013). Future research using large-scale surveys should examine how widespread this deterministic view of genetics is. If the view is widespread, correcting this could be an important target for future interventions.

Although lay participants' talk about dementia being down to "bad luck" points to a key problem in the lay mental model of dementia risk, it may also point to a solution. "Luck" is a commonly used and easily understood term in lay discourse, and future communications about dementia risk may be able to deploy the term to improve public understandings. For example, information about dementia risk might inform the public that it is "possible to change one's luck" by engaging in the right behaviours. Such educational strategies would need developing and testing in subsequent mental models studies of dementia risk, but our preliminary study shows some intriguing initial starting points.

Another interesting difference between the lay and expert mental models was the extent to which causality was understood by laypeople and experts. While experts could describe the causal pathways from health behaviours to dementia – directly through the impact of these behaviours on the brain, and indirectly through other illnesses – this knowledge was not evident within the sample of lay participants. Although this difference is to be expected, it is worth considering whether such knowledge is important for an informed lay public. For example, if the causal links between behaviour and dementia risk are made clear, the trustworthiness of communications could be increased – and trust is correlated with receptiveness to learning (Levin and Cross 2004). Indeed, our lay participants expressed frustration with the perceived tendency for behaviour change communications to be pitched in nonspecific ways aimed at promoting a generalised "healthy lifestyle".

Public health campaigns should focus on presenting a positive message that promotes the enjoyment and benefit that everyone can gain from adopting a healthy lifestyle at any age

to motivate behaviour change (Livingston et al., 2017). This will address the need, identified in this study, to introduce consideration of dementia risk not just to those in mid-life, but to the younger generation. Earlier introduction of health education places people in a better position to make positive changes that will benefit their future health. Lay people may find that their luck improves, if public health campaign messages can convince them that engaging in a healthy lifestyle today will provide benefits which accrue in the present together with the additional advantage of delivering preventative health benefits for the future.

Strengths and limitations

Our study identified some interesting differences in lay and expert interviewees' perspectives on dementia risk however this article is only a first step in mental models research to establish what aspects of lay knowledge to address in future risk communications. The current study is limited by a small sample size and as the majority of lay participants were educated to degree level and above there is a risk of socio-economic bias. Future research will need to establish the overall patterns in lay and expert perspectives in large-scale surveys, and subsequently explore ways of changing knowledge with different communication techniques. The findings presented here can be developed into survey questions that reflect relevant beliefs, presented in a manner that the target lay audience can understand (Bruine de Bruin and Bostrom 2013).

This study was notable in terms of including younger participants' perspectives on dementia risk, while most of the available dementia risk research concerns older people. This knowledge of the risk beliefs of people in their 20s is crucial to facilitate effective delivery of public health information to the next generation (Haapala et al., 2018), and it is recommended that future public health information about dementia is not restricted to those in later life.

Early adoption of positive health behaviour could reduce the risk of other chronic health conditions and consequently reduce the risk of developing dementia.

However, even having established effective ways to communicate dementia risk, and as is well known from behaviour change research (Chung et al. 2009) improved knowledge of risk factors does not necessarily lead to a perceived personal risk or a willingness to make necessary changes to reduce the risk of developing dementia. Additionally, improving knowledge of dementia risk factors among the general population carries the possibility of increasing the number of "worried well" visiting memory clinics (Draper et al. 2010). Future risk communication will have to balance the needs of an informed public against increased public worry about dementia.

Conclusion

The most significant difference between the lay and expert mental models assessed in this study is the expert understanding of the positive effect of modifiable health behaviours. The results of this study indicate that the expert model of risk was broadly based upon the need for a generally healthy lifestyle that would be protective of chronic health conditions and developing dementia. Whilst the lay mental model also demonstrated awareness of several factors of a healthy lifestyle, there was no clear understanding of the need for implementation on a personal level, nor its impact on dementia risk. Although healthy lifestyle behaviours were known, laypeople generally attributed their risk of developing dementia to genetics or bad luck.

Lay participants' reluctance to accept that they personally were at risk presents a barrier to behaviour change. This view was consistent across all age groups underlining the requirement to target all ages with communication about health risk to protect against dementia. It is essential that known health risk behaviours for developing dementia are

successfully integrated with the existing lay conception of risk in general and healthy lifestyle. The results of this study highlight the need to effectively communicate in a positive manner the short and long-term benefit of engaging in known healthy behaviours and emphasise that benefit with regards to dementia on a personal level. Future dementia risk communication and education must confront the challenge to empower laypeople to make their own *luck* regarding their own heath with the ultimate aim of reducing their risk of developing dementia.

I confirm all personal identifiers have been removed or disguised so persons described are not identifiable and cannot be identified through the details of the story.

References

ADI (Alzheimer's Disease International) n.d. *About Dementia*. Retrieved from https://www.alz.co.uk/about-dementia. Accessed 6th August 2017

ADI (Alzheimer's Disease International) n.d. *Risk Factors*. Retrieved from https://www.alz.co.uk/info/risk-factors Accessed 6th August 2017

ADI (Alzheimer's Disease International). 2016. *World Alzheimer Report 2016*. Retrieved from https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf Accessed 1st August 2017

Barnes, D. E., & Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurology, 10*(9), 819-828. doi:10.1016/S1474-4422(11)70072-2

Beydoun, M. A., Beydoun, H. A., Gamaldo, A. A., Teel, A., Zonderman, A. B., & Wang, Y. (2014). Epidemiologic studies of modifiable factors associated with cognition and dementia: Systematic review and meta-analysis. *BMC Public Health, 14*(1), 643. 10.1186/1471-2458-14-643

Bruine de Bruin, W. & Bostrom, A. (2013). Assessing what to address in science communication. *Proceedings of the National Academy of Sciences of the United States of America, 110*(Supplement 3), 14062-14068. doi:10.1073/pnas.1212729110

Chung, S., Mehta, K., Shumway, M., Alvidrez, J., & Perez-Stable, E. J. (2009). Risk perception and preference for prevention of Alzheimer's disease. *Value in Health, 12(4),* 450-458. doi:10.1111/j.1524-4733.2008.00482.x

Downs, J. S., de Bruin, W. B., Fischhoff, B., Hesse, B., & Maibach, E. (2009). How people think about cancer: A mental models approach. *Handbook of risk and crisis communication*, 507-524.

Draper, B., Peisah, C., Snowdon, J., & Brodaty, H. (2010). Early dementia diagnosis and the risk of suicide and euthanasia. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 6*(1), 75-82. 10.1016/j.jalz.2009.04.1229

Friedman, D.B., Becofsky, K., Anderson, L.A., Bryant, L.L., Hunter, R.H., Ivey, S.L., Belza, B., Logsdon, R.G., Brannon, S., Vandenberg, A.E. & Lin, S., 2015. Public perceptions about risk and protective factors for cognitive health and impairment: A review of the literature. *International Psychogeriatrics 27(8):*1263-1275

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandandwalesseriesdr/2015 Accessed 6th August 2017

Haapala, I., Carr, A., & Biggs, S. (2018). Differences in priority by age group and perspective: Implications for public health education and campaigning in relation to dementia. *International Psychogeriatrics, ,* 1-9. doi:10.1017/S1041610218000935

Hudson, J. M., Pollux, P. M. J., Mistry, B., & Hobson, S. (2012). Beliefs about Alzheimer's disease in Britain. *Aging & Mental Health, 16*(7), 828-835. 10.1080/13607863.2012.660620

Iliffe, S., & Manthorpe, J. (2017). Dementia: is the biopsychosocial model vindicated? *British Journal of General Practice, 67*(661), 344-345. **doi:** 10.3399/bjgp17X691781

Kim, S., Sargent-Cox, K. A., & Anstey, K. J. (2015). A qualitative study of older and middle-aged adults' perception and attitudes towards dementia and dementia risk reduction. *Journal of Advanced Nursing, 71*(7), 1694-1703. 10.1111/jan.12641

Kitwood, T. (1990). The dialectics of dementia: with particular reference to Alzheimer's disease. *Ageing & Society, 10*(2), 177-196. doi: 10.1017/S0144686X00008060

Levin, D. Z., & Cross, R. (2004). The strength of weak ties you can trust: The mediating role of trust in effective knowledge transfer. *Management Science, 50*(11), 1477-1490. 10.1287/mnsc.1030.0136

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., . . . Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet, 390*(10113), 2673-2734. doi:10.1016/S0140-6736(17)31363-6

Morgan, M. G., Fischhoff, B., Bostrom, A., Atman, C. J., & Books24x7, I. (2001;2002;). *Risk communication: A mental models approach*. Cambridge: Cambridge University Press.

Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K., & Brayne, C. (2014). Potential for primary prevention of alzheimer's disease: An analysis of population-based data. *The Lancet. Neurology, 13*(8), 788-794. 10.1016/S1474-4422(14)70136-X

Olander, E. K., Fletcher, H., Williams, S., Atkinson, L., Turner, A., & French, D. P. (2013). What are the most effective techniques in changing obese individuals' physical activity self-efficacy and behaviour: A systematic review and meta-analysis. *The International Journal of Behavioral Nutrition and Physical Activity, 10*, 29. 10.1186/1479-5868-10-29

ONS (Office for National Statistics). 2016. *Deaths registered in England and Wales (Series DR): 2015*. Retrieved from:

Yeo, L. J., Horan, M. A., Jones, M., & Pendleton, N. (2007). Perceptions of risk and prevention of dementia in the healthy elderly. *Dementia and Geriatric Cognitive Disorders, 23(6),* 368-371.

Yu-Tzu Wu, Alexa S. Beiser, Monique M. B. Breteler, Laura Fratiglioni, Catherine Helmer, Hugh C. Hendrie, . . . Carol Brayne. (2017). The changing prevalence and incidence of dementia over time - current evidence. *Nature Reviews Neurology, 13*(6), 327-339.

Zhong, G., Wang, Y., Zhang, Y., Guo, J. J., & Zhao, Y. (2015). Smoking is associated with an increased risk of dementia: A meta-analysis of prospective cohort studies with investigation of potential effect modifiers. *PloS One, 10*(3), e0118333. 10.1371/journal.pone.0118333

APPENDIX A

Expert Interview Schedule

- Can you tell me your job title, the length of time in the role, and what your job entails?
- Suppose I'm a member of the public who wants to understand what dementia is – How would you explain the illness to me?

  (e.g. different kinds of dementia, how they differ, any commonalities in diagnosis/treatment)
- Can you tell me about the most important health risk factors associated with dementia?
- Do you consider any particular type of person at specific risk?
- What factors influence the increased risk for these types of people?
- What can people do to reduce the risk of dementia?

  (e.g. health behaviours)
- Do you have any personal experience of dementia risk reduction programmes?

  (e.g. publications)
- What do you believe is the most effective method of communicating with the general public regarding their health?

  (Public Health England/Dorset Memory Service info)
- Are there any risks in improving public knowledge of risk?

  (how much information is too much?)

Is there anything you would like to add about your views or opinions about dementia in general?

APPENDIX B

Lay Interview Schedule

- Can you tell me what you know about dementia?
  Do you know about any different types of dementia?
  Can you tell me what you think it means to be diagnosed with dementia?
- Can you tell me who you think is at risk of getting dementia?
  What characteristics do these people have?
- What do you think increases the risk of getting dementia?
- What do you think people can do to reduce the risk of getting dementia?
- Personally, how does dementia compare to other chronic health conditions, such as cancer, diabetes etc?
- Do you think there is any link between healthy behaviour and dementia?
- Can you tell me what you think would be positive lifestyle choices to reduce the risk of getting dementia?
- If you were looking for information about dementia, where would you go?
- Can you tell me about any health campaigns you may be aware of and where you saw them?
- What would be the best method of engaging your attention in a health campaign?
- What kind of information would you like to learn from a health campaign about dementia?
- Are you aware of the NHS One You Campaign?
- What is your view on the following posters?
  Which one do you think is presenting the most effective message?
  Where would you like to see posters like this?
- If you were designing a poster to increase awareness of dementia, what would be your main topic?
- How important do you think it is to increase awareness of dementia?
- Greater awareness may result in an increase in early diagnosis – what is your personal view about this?
- Is there anything you would like to add about your views or opinions about dementia in general?