



Risk disclosure and its consequences Perspectives of asymptomatic research participants in the UK and Spain

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Thursday, August 21, 1986

Medicine

Alzheimer's breakthrough seen

Simple eye exam may said Dr. Carol A. Miller, chief of neuropathology lt's nicking on a trute University of Southern California. The study was directed by Dr. David R. li's nicking on children said. Human, a researcher in Miller's lab., and was Miller said.

BOSTON (AP) — The discovery of an apparently unique form of optic nerve damage in brain. Symptoms include memory victims of Alzheimer's disease may make it discontinuous and changes in personality to the study dectors examined the

cause of senanty in the energy, who are samulated. 2.5 million victims in this country, it is not the only cause. Its symptoms are confusing, and doctors often cannot be entirely sure they have

degeneration of the optic nerves in people with Alzheimer's disease. The next step will be to see if this causes specific, unique vision abnormalities

optic nerves of 10 Alzheimer's victims and found

However, they did not check people with other

It's picking out Alzheimer's from any one of 40

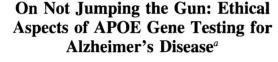
Thursday, August 21, 1986

50% TO 75% OF

Callection stock when you buy your lenses at

Dr. Alfredo A. Sadun of the Estelle Doheny Eye Foundation in Los Angeles, is testing Alzheimer' to serve as a signpost of the disease.

"I don't know how much it will help the patient, because who wants to know they will become demented?' said Miller.



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Sunday Review

What if You Knew Alzheimer's Was **Coming for You?**

Simple blood tests may soon be able to deliver alarming news about your cognitive health.

By PAGAN KENNEDY NOV. 17, 2017

"when it comes down to what we want to use data and AI for, it is early detection and diagnosis. That's, that's one of the big ones

for us. And [that raises] questions around, why would you want to know early?"

(digital health tech researcher, interview with RM, SPACE study 2020)

"I don't know how much it will help the patient, because who wants to know they will become demented?" said Miller.

Consequences of risk communication to asymptomatic individuals



- ApoE result communication does not cause distress among the majority of people who do not have major anxiety or depressive disorders, and who display an interest in genetic testing
- REVEAL (11/14 studies)
 - Selected/non-representative populations
 - US based
- Some evidence of change in LTC uptake, behaviour change
- A small % of people did experience psychological effects
- Possible 'nocebo' effect
- Increased fears of employment discrimination
- Focus on short-term psychological effects (anxiety, depression)
- Over time, seen as valuable but with lasting effects for some (Zallen 2018)

Approaches to the Communication of Alzheimer's dementia Risk (ACAR)

- 1. What do older adults involved in dementia research expect would be the implications of learning Alzheimer's dementia risk?
- 2. What expectations would they have of any disclosure process?



Approaches to the Communication of Alzheimer's dementia Risk (ACAR)

Focus group based research in the UK (Milne) and Spain (Diaz) and with EWGPWD

N=61 (32 (20F/12M) in four groups in Spain, 19 (10F/9M) in four groups in the UK), 1 group of EWGPWD.

Information provided on changing approach to Alzheimer's research

Thematic analysis around shared structured protocol







Background

Discussion influenced by family experiences

Some already felt that they were 'at risk' because of family history

Most people expressed interest in learning their risk status – but didn't feel their desire to know was typical



Risk and time

"you're not going to have an attack of Alzheimer's, it's more of a, it's a 'living with' situation, which sometimes heart disease can be, obviously, but sometimes you don't get the option of living with it!" (UK2)

The risk experience

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At, with and beyond risk: expectations of living with the possibility of future dementia

Richard Milne¹, Ana Diaz², Shirlene Badger¹, Eline Bunnik³, Karine Fauria⁴ and Katie Wells⁵



Living at risk

Reducing risk

"I think it's important to know to act. Although there is no medication, if factors such as diet, environment influence it, you can act somehow" (SP3)

Reducing risk

"What are we going to change? Do we eat better? But we already do that, or we should. Do we exercise more? We should do it. What are we going to change? . . . You will not change anything; I think, honestly."

(SP4)

Pre-emptive suicide

"I want to know immediately, that is, even a risk of 80%, not 99%, to make my own decisions ... Bump me off before I get to be like my mother." (SP2)

Living with risk

Informal vigilance

"It would have an impact on how I then lived my life, and how I conducted my relationships with others, and my work. I would be looking for the signs of it . . . I'm bad enough as it is." (UK1)

Formal monitoring

"For me what is important about knowing the risk is early detection, a serious advantage is that you can monitor to diagnosis." (SP2)

Living beyond risk

Planning for self and others

I would do many things if I knew that this was going to happen to me. I would spend more time with my family, I have a grandson of a year and a half and one of eight months. I would try to be with them as much as possible and all those things.'

(SP1)

Summary

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Similar conversations in UK and Spain

Learning one's Alzheimer's risk may have medium and long-term effects

These are neither clearly benefits nor harms, but disruptions that need understanding and supporting

Future relationships with families and healthcare need to be accounted for in preventative programmes

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Ethics Review

Ethical Arguments Concerning the Use of Alzheimer's Disease Biomarkers in Individuals with No or Mild Cognitive Impairment: A Systematic Review and Framework for Discussion

Marthe Smedingaa,b,*, Krista Trompb, Maartje H.N. Schermerb and Edo Richard

Ethics Review

Perspectives on Communicating Biomarker-Based Assessments of Alzheimer's Disease to Cognitively Healthy Individuals

On the personal utility of Alzheimer's disease-related biomarker testing in the research context

Eline M Bunnik, 1 Edo Richard, 2 Richard Milne, 3 Maartje H N Schermer 1







