Concerns about Cognitive Functioning, Dementia Worries, and Psychological Well-Being

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Trends

• Growing prevalence of Alzheimer’s disease (AD) and dementia

• Example -- Maltatoday (15 July, 2013): “The number of dementia sufferers in Malta is estimated to rise from the current 5,200 to 14,000 over the next 25 years.”

• Growing visibility of AD

• Growing public recognition of AD symptoms

• Growing fear
Worried about your MEMORY?

"I remember that holiday as clear as can be... but it's a struggle to recall what I did this morning."
From “Peanuts”

I dread getting old...

Don’t worry about it... you have a long way to go...

I don’t want to have to wear bifocal teeth!

You mean false teeth?

See? I’m getting old already. I’m losing my memory!
Limits of Knowledge

Scientific acknowledgment that AD is inevitably fatal and there are no behavioral or pharmaceutical agents that can slow down, stop, or reverse the course of the disease’s progression.
Has led to:

• What we refer to as “anticipatory dementia”
• What others have labeled as “dementia worries”*

Anticipatory Dementia

• The fear that “normal,” age-associated memory change is an early warning signal of dementia.

• The concern that “normal,” age-associated cognitive changes are indicators of the onset or the appearance of Alzheimer’s disease.
Anticipatory Dementia

The concept focuses on fears that people have about developing Alzheimer’s and how those fears are affected by subjective perceptions of memory functioning.
Some Examples
• To the Editor (*New York Times*):
• Thanks but no thanks for “Dementia’s Signs May Come Early.” Everyone I know over 65 is terrified of Alzheimer’s. Even a friend who just turned 50!
• Seems that the more information ... we get, the more we worry ourselves into “Alzheimer’s anxiety” ....
• As the teenagers like to say: T.M.I. (too much information).
• A. C. S.
  Hamden, Conn., July 18, 2013
“[A]ny time I misuse a word, forget a name I have [known] and should have known, momentarily lose the car in a parking lot, I scare the bergeebers out of me! I fear becoming a victim of AD.... I come to dripping tears thinking of this possibility.”

_Alzheimer’s Digest, July 29, 1999_
Anticipatory Dementia Process

Memory Changes → Memory Worries → Concerns about AD → Outcomes
Questions Posed by This Study

• Does being concerned make a difference in the daily lives of persons?
• More particularly, is psychological well-being affected by concerns about cognitive functioning and worries about developing dementia?
Methods: Sample

• Three waves of data
• Collected in 2000, 2005, and 2011
• From two samples ages 40-60 at T₁:
  ➢ (1) adult children with a parent diagnosed with probable AD.
  ➢ (2) a matched control group with no parental history of AD.
Data Collection

- $T_1$ data collected by telephone interviews with respondents residing in the New England states of the United States
- $T_2$ and $T_3$ data came from mailed questionnaires sent to the same Rs
Sample Ns

- 2000:  \( N=258 \)
- 2005:  \( N=206 \) (79.8%)
- 2011:  \( N=177 \) (85.9%/68.6%)
Measures: Predictors

The principal predictor is a summative measure of the number of waves Rs scored “higher” on five indicators of concerns about cognitive functioning and worries about dementia.
Measures: Predictors

- Self-assessed “poorer” memory functioning
- Number of types of memory changes
- Worried about ability to remember
- “Poorer” memory on Short Inventory of Memory Experiences (SIME)
- “Greater” concerns on Alzheimer’s Likelihood Scale
Predictors: Psychometrics

- Factor analysis: all load on a single dimension
- Chronbach’s alpha = .77
Predictors: Other Variables

- Subsample
- Subsample/concerns interaction term
- R’s educational attainment
- R’s age
- R’s sex
Psychological Well-Being: Four Outcome Measures

- Number of waves Rs were “higher” on
  - Depression (11 items, CESD, $T_3 \alpha = .870$)
  - Stress (10 items, Cohen, $T_3 \alpha = .913$)

- Number of waves Rs were “lower” on
  - Life Satisfaction (single item)
  - Mastery (7 items, Pearlin, $T_3 \alpha = .863$)
Results: Multivariate Betas
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Conclusions: Limited evidence*

Cognitive Decline  ➔  Well-being

Conclusions

“[But]...there has been almost no research about the potential consequences of [dementia worries] ... and this area especially represents terra incognita.”

Kessler et al. (2012), p. 280
Summary

First, our composite measure of cognitive and dementia concerns proved to be a strong and consistent predictor of all of our indicators of psychological well-being, explaining between 11 and 20 percent of the variance in the individual outcomes.
Summary

Second, the more one worries about cognitive functioning and changes and the more one is concerned about the possibility of having AD, the greater the detrimental effect on psychological well-being – regardless of whether one comes from a family in which a parent had AD.
Summary

The evidence found in this research points to a clear link between psychological well-being and the concerns and worries people have about their cognitive functioning and dementia.
Next Steps

Other outcomes, for example:

• Physical health?
• Take “preventive” measures?
• Information seeking?
• Talk to significant others and professionals?
Next Steps

• Replication on other samples
• Larger and more representative samples
Take Aways (1)

With population aging and with the growing visibility of dementia in general and AD in particular, concerns and worries about one’s cognitive status and functioning are likely to be brought with increasing frequency to the attention of health and human service providers.
Take Aways (2)

Those in the helping professions must recognize that these concerns and worries may be deep-seated and consequential.
Health care and human service practitioners would do well to recognize the potentially detrimental consequences of cognitive concerns and dementia worries for the psychological welfare and sense of well-being of their patients and their clients.
For Further Information


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