LETTER

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"Dementia worry" in memory clinic patients not diagnosed with organic mental disorder

In order to best meet the needs of their clientele, practitioners in memory clinics need information about the characteristics of patients who do not meet the criteria for diagnosis of an organic mental disorder such as vascular dementia, Alzheimer's disease (AD), or mild cognitive impairment (MCI). In particular, concern about having or developing dementia may prompt ``cognitively healthy'' people to visit memory clinics. In a pilot study, we investigated ``dementia worry'' (DW) in addition to the socio-demographic characteristics, physical health risk-factors and psychological symptoms of memory clinic patients for whom dementia and MCI diagnoses were excluded after a comprehensive diagnostic work-up. *Dementia worry* has recently been defined as an "emotional reaction to the perceived threat of developing dementia" (Kessler *et al.*, 2012). Accordingly, DW consists of both emotions (e.g. fear) and cognitions (e.g. thoughts, ruminations) regarding the perceived threat of developing dementia. Our study was evaluated by the Ethical Committee of the Medical Faculty Mannheim, University of Heidelberg.

From the full sample of $N = 266$ visitors to the academic memory clinic of the Central Institute of Mental Health Mannheim in Germany between April and August 2012, we identified $n = 34$ memory clinic visitors (12.8%) who received an exclusion of an organic mental disorder according to the ICD-10 criteria (F00–F09). Diagnoses of organic mental disorder were based on neuropsychiatric examination, neuropsychological testing (CERAD battery, Trailmaking Test, Wechsler Memory Scale WMS-R, Clock-drawing task), relatives' ratings of patient functioning, general laboratory investigations, EEG, structural neuroimaging with MRI and clinical ratings of depressive and other psychiatric symptoms. From this subsample, $n = 22$ patients ('exclusion sample') participated in the current study (i.e. participation rate: 65%; from the $n = 12$ non-participants, $n = 6$ could not participate due to logistical reasons, $n = 6$ did not indicate consent; participants did not differ from non-participants in terms of age, $t(32) = 0.55$, n.s.; or gender, $\chi^2(1, N = 32) = 0.35$, n.s.). A priori power analysis indicated that sample size was sufficient for detecting large effects ($r = 0.5$; $d = 0.8$) with 80% power and alpha at 0.05 using *t*-tests for two independent samples and correlation analyses, with DW as outcome measure (see below). Exclusion sample participants were on average $M = 62.0$ years old (SD = 9.0; range: 51–80 years); an analysis of their health records showed that their physical health was comparable to their age peers in the general population.

Exclusion sample participants completed a set of questionnaires including a measure of DW. The few empirical studies on DW have mostly operationalized DW as responses to the single-item question, "How concerned are you about developing dementia". To provide a more robust and more complete measure of DW, we constructed a ten-item scale by extracting items from existing measures of DW and adapted items from measures of other health worries (see Appendix A1 published as supplementary material online attached to the electronic version of this paper at http://www.journals.cambridge.org/ipg). In the current study, participants were instructed to indicate the extent to which each statement applied during the last six months before they came to the memory clinic in order to minimize response biases related to the acute situation (i.e. clinical assessment). Internal consistency of the measure was high ($\alpha = 0.89$). Furthermore, participants completed well-validated self-report psychological symptom scales for general distress (Brief Symptom Inventory – Global Severity Index), depression and anxiety (Hospital Anxiety and Depression Scale), and hypochondriasis (Short Health Anxiety Inventory) before they had received a diagnosis. The majority of the exclusion sample participants (81.8%, $n = 18$) had at least one clinically relevant score across the four scales of psychological distress. Namely, nearly two-thirds (63.6%, $n = 13$) indicated clinically relevant general psychological distress. About one-third indicated clinically relevant anxiety (36.4%; $n = 8$), depression (31.8%; $n = 7$) and/or health anxiety (36.4%; $n = 8$). In addition, more than half (59.0%; $n = 13$) had previously received psychological treatment and about half (45.5%; $n = 12$) had a history of psychotropic drug consumption. Together, the results suggest that memory clinic patients without organic mental

disorder are characterized by high levels of psychological distress, in line with previous research (Elfgren *et al.*, 2010).

We compared the exclusion sample with a similarly aged convenience sample from the general population with regards to socio-demographic characteristics, having a first-degree genetic relative with dementia, physical health risk factors, and DW. To do so, we initially recruited a convenience sample including $N = 219$ from the larger social network of the research team of this project, including a wide variety of occupational and social groups. From this pool of participants, we included $n = 204$ participants who reported never having been tested for dementia in the ``non-clinical comparison sample.'' As expected, DW was higher among exclusion sample participants ($M = 0.83$, SD $= 0.66$) relative to non-clinical comparison sample participants ($M = -0.76$, SD $=$ 0.74), $t(224) = 5.50$, $p < 0.001$, $d = 0.73$ (one-tailed). These results suggest that memory clinic visitors without organic mental disorder may be referred to or individually seek out memory clinics specifically due to their high levels of DW. Furthermore, the proportion of participants with a first-degree genetic relative with dementia was significantly higher in the exclusion sample (45.5%) than in the non-clinical comparison sample (21.6%), $\chi^2(1, N = 226) = 6.23$, $\Phi = 0.28$, $p =$ 0.01. This result concurs with earlier findings that the majority of first-degree relatives of AD patients have high interest in predictive genetic testing (Roberts, 2000). (There were no significant differences between the exclusion and the non-clinical comparison samples with regards to age, $t(224) = 1.19$, n.s.; gender, $\chi^2(1, N = 222) =$ 1.40, n.s ; education, $\chi^2(3, N = 224) = 3.41$, n.s.; retirement status, $\chi^2(1, N = 225) = 0.21$, n.s ; children (yes/no), $\chi^2(1, N = 222) = 1.78$, n.s.; number of children, $t(220) = 0.80$, n.s ; or number of physical health-related risk factors for dementia, $t(224) = -1.56$, n.s.)

Within the exclusion sample, DW was substantially ($r > 0.4$; one-tailed) related to psychological symptoms, i.e. general distress, $r = 0.53$, $p =$ 0.005; anxiety, $r = 0.46$, $p = 0.02$; depression, $r =$ 0.40, $p = 0.03$; and hypochondriasis, $r = 0.50$, $p = 0.01$. DW was also marginally associated with having a first-degree relative with dementia ($r =$ 0.32, $p = 0.07$), in line with previous studies with non-clinical samples (e.g. Cutler and Hodgson, 2001). These results remained stable after the α levels were adjusted for multiple comparisons using Bonferoni–Holm adjustment. We suggest that people with high levels of psychological distress might react to "dementia encounters" such as personal contact with a person with dementia and/or cognitive lapses by ruminating (under the condition of depression), self-monitoring (under the condition of anxiety), and/or catastrophizing (under the condition of hypochondriasis), leading to high levels of DW. Alternatively, worrying that one may develop dementia due to perceived genetic risk may also negatively affect mental health. There was no indication that DW was related to socio-demographic characteristics, in line with previous research with non-clinical samples (Kessler *et al.*, 2012). DW was not significantly related to physical health-related risk factors for dementia. Similarly, previous research has shown that individuals' appraisal of their own risk for developing dementia is unrelated to the number of objective risk factors they have (Chung *et al.*, 2009).

The DW scale used in the current study demonstrated high internal reliability, discriminant validity, and factorial validity (see Appendix A1). Still, we caution that more information on the validity of the DW scale (e.g., test–retest reliability, external validity) is needed. We also caution that the size of the exclusion sample was insufficient for detecting small but meaningful inter-variable correlations or small differences between the exclusion and non-clinical samples. Overall, our preliminary results suggest that memory clinic practitioners should routinely assess not only patients' subjective cognitive complaints, but also potential ruminations, fear and anxiety related to dementia as DW can be indicative of a wider range of psychological symptoms.

Conflict of interest

None.

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E.-M. KESSLER,[1,2] J. K. SÜDHOF[3] AND L. FRÖLICH[4]

[1]Network Aging Research, Heidelberg University, Germany

[2]Department of Psychological Ageing Research, Institute of Psychology, Heidelberg University, Heidelberg, Germany

[3]Department of Clinical Psychology and Psychotherapy, Institute of Psychology, Heidelberg University, Heidelberg, Germany

[4]Department of Geriatric Psychiatry, Central Institute of Mental Health, Mannheim, Germany Email: kessler@nar.uni-heidelberg.de