Dementia worry: a psychological examination of an unexplored phenomenon

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Abstract According to recent surveys, dementia worry (DW) is a widespread phenomenon in mid-life and old age, at least in Western populations. DW has been shown to be only loosely related to sociodemographic factors. Unfortunately, the concept of DW has found only very little conceptual and empirical attention in previous research. In this conceptual review, we take (mostly) a psychological approach to DW. First, we define DW as an emotional response to the perceived threat of developing dementia. We then conceptualise DW as a hybrid, combining elements of ageing anxiety and health anxiety. On the population level, we argue that the high prevalence of DW may be reflective of the increasing awareness of dementia in times of increasing ‘dementia encounters’, widespread misperceptions of risks and consequences of dementia and

a perceived lack of coping resources. Finally, we propose that DW may affect a range of important behaviours, such as how people interpret evidence of their own or others’ age-related cognitive changes, how they interact with people with dementia, how they anticipate and plan for their future, how they engage in screening and prevention behaviours and how they exploit healthcare resources. We conclude with suggestions for future research, including a further in-depth investigation of psychological and micro-/ macrosocial factors associated with DW.

Keywords Dementia · Alzheimer’s disease · Worries · Hypochondriasis · Health anxiety · Ageing anxiety

Introduction

Through the mass media and personal experiences, the average person’s ‘contact’ with dementia has readily increased over recent years. Over the last decade, there has been increasing public salience of prominent figures with dementia, such as Ronald Reagan, Iris Murdoch and Margaret Thatcher, as well as an increasing number of media reports depicting the life of individuals living with dementia (Kessler and Schwender 2012). Likewise, media dissemination of scientific progress in understanding dementia—as well as its treatment and prevention—seems to have escalated. In addition, due to the increasing incidence rates of dementia, more and more people personally know someone living with dementia. Currently, 44 % of the US population has a family member and/or a friend living with dementia (MetLife Foundation 2011).

As the number of ‘dementia encounters’ through media and personal exposure rises, it seems important to understand how individuals react to such encounters. In this

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article, we explore the concept of *dementia worry* (DW) as one phenomenon that may accompany increased ‘contact’ with dementia. It is well known that personal experience with and media exposure to physical conditions can alter one’s perceived susceptibility to a disease (e.g., ‘medical student disease’ and ‘AIDS phobia’). As dementia becomes a more salient part of daily life, individuals may be concerned that they themselves will develop dementia. Such concerns may not only affect older people who commonly perceive and complain about changing or declining memory abilities (e.g., Jonker et al. 2000; Lineweaver and Hertzog 1998) but also younger people and people with unimpaired memory functioning (objectively and subjectively). There is thus a need to understand DW within the general population. That said, it is interesting that the concept of DW has found only very little conceptual and empirical attention in previous research, particularly not in either behavioural and social gerontology or life-span research. This is unfortunate because DW may not only be a widespread (and possibly increasing) phenomenon in our rapidly ageing society but also a personal experience that may hinder or promote successful and healthy ageing and development in both individuals and society.

In this conceptual review, we attempt to better integrate the phenomenon of DW into current and future ageing research. Given the limited empirical research available in the area, we suggest a *conceptual platform* for DW with the potential to derive empirically testable hypotheses (some we raise ourselves) and to prepare a future research program on DW. We start by reporting on existing evidence on the prevalence of DW and conclude that DW appears to be a relatively widespread and probably increasing phenomenon in Western populations in mid-life and old age. The key objective of this paper is to explore potential reasons underlying the occurrence of DW, as well as to identify the implications of DW for research as well as practice and prevention. As a first step in establishing DW as a construct, we propose a heuristically useful definition of DW and examine some aspects of the philosophical and cultural background of DW. Inspired by prominent social-cognitive models of health behaviour (Health Belief Model; Rosenstock 1974) and health anxiety (Warwick and Salkovskis 1990), we then examine factors that may contribute to the relatively high prevalence of DW on the population level and outline possible adaptive as well as maladaptive consequences that may result from DW. This examination leads to suggestions for future research and some final conclusions.

Prevalence of DW in the general population

Several landmark surveys have examined the prevalence of concerns about developing dementia (for a review, see

Anderson et al. 2009). Typically, DW-related constructs have been operationalised as responses to the single-item question ‘How concerned are you about developing dementia?’, which has to be answered on a four- or five-point Likert scale; variations in response typically range from ‘very concerned’ to ‘not at all concerned’. Among three US-American surveys (Alzheimer’s Association 2003; Alzheimer’s Association and American Heart Association 2008; Connell et al. 2007), the percentage of respondents categorised as concerned about developing Alzheimer’s disease (AD) ranged from 26 to 49 %. In a random sample of Australians ($N = 2000$), 48 % of participants said that they were at least a little worried about developing dementia (Low and Anstey 2009). In two studies in Israel (Werner 2002) and the US (Cutler and Hodgson 2001), nearly half of a convenience sample of adults with no family history of AD were ‘somewhat’ or ‘very concerned’. Furthermore, according to a recent British survey, dementia was second only to cancer among the most feared diseases/conditions (Alzheimer’s Research Trust 2008). Overall, 26 percent of the respondents reported that they were more afraid of dementia than of any other condition. Among respondents over the age of 55, dementia was the most feared condition with 39 % of the respondents reporting that they were most afraid of dementia, and 30 % reporting that they were most afraid of cancer. These latter figures regarding the most feared diseases/conditions are very much in line with data from a survey conducted in the United States (MetLife Foundation 2006, 2011). In this survey, the percentage of those who feared getting dementia increased between 2006 (20 %) and 2010 (31 %). In the same survey, 66 % of respondents reported to be at least ‘somewhat concerned’ regarding the provision of care for a loved one with dementia.

Sociodemographic correlates of dementia worry

A review of the small body of empirical research on DW shows that only a small amount of interindividual variation in DW can be explained by sociodemographic factors. DW seems to be related to neither income nor marital status (Werner 2002; Cutler and Hodgson 2001). Most cross-sectional studies have found that DW (as well as perceived dementia risk) is not higher at higher ages in the second half of life (Werner 2002; Cutler and Hugson 2001; Suhr and Kinkela 2007; Yeo et al. 2007) although these findings may be partly due to the small age spectrum of these studies (middle adulthood and ‘young old age’). The online survey by the Alzheimer’s Association and American Heart Association (2008) indicated no differences between racial/ethnic groups, whereas Roberts and colleagues (2003) reported that among middle-aged Americans (mean age 47), Caucasian Americans perceived AD to pose a greater concern than did African Americans. Across several

studies, level of education has not been associated with DW (Cutler and Hodgson 2001; Low and Anstey 2009; Werner 2002) even though in one study, more highly educated people perceived less threat of dementia (Yeo et al. 2007). There is some evidence that DW is more pronounced for women (e.g., Cutler and Hodgson 1996, 2001; Low and Anstey 2009).

In contrast to the socio-demographic variables reported above, having a family history of AD has consistently emerged as a central predictor of DW. Adult children with a parent who has been diagnosed with dementia are more likely to be concerned about developing dementia themselves than are adults with no parental history of dementia (e.g., Axelman et al. 2003; Hodgson et al. 1999; Roberts and Connell 2000; Yeo et al. 2007). For example, in the Cutler and Hodgson study (2001), 92 % of the adult children with parental history of dementia were either ‘very’ or ‘somewhat’ concerned about developing AD, as compared with 47 % of the comparison group. Further research has shown that any personal experience with dementia, be it genetic or non-genetic (such as caregivers, close, non-genetically related family members, or friends of individuals with dementia), is associated with higher levels of DW (Alberts et al. 2011; Low and Anstey 2009; Suhr and Kinkela 2007).

In sum, there is emerging evidence that DW is a relatively widespread and probably increasing phenomenon in Western societies and that DW is at the top of all disease worries. With the exception of a family history of dementia, sociodemographic variables have been shown to only be loosely related to DW.

Defining DW

Although DW has found some pragmatic definition and operationalization in previous survey studies, we believe that more investment is needed to come to terms with a satisfactory and heuristically useful definition of DW. The notion of DW was first introduced in 1996 when Cutler and Hodgson (1996) coined the term ‘anticipatory dementia’ to describe the fear among middle-aged persons that cognitive changes may be a harbinger of the onset of AD. We define DW more generally as an emotional response to the perceived threat of developing dementia, independent of chronological age and cognitive status. Importantly, we suggest that DW constitutes an overlap of affective components (e.g., fear) as well as more cognitive components (e.g., associations, thoughts images) related to the perceived threat of developing dementia. We propose that DW can vary in terms of intensity, ranging from passing concerns or worries (‘mild’) to strong preoccupation and phobia (‘severe’). Even mild levels of DW may have significant consequences for individual ageing and development, as we

will discuss later. In contrast to the few studies related to DW, we do not restrict DW to concerns about developing specifically AD. Rather, we use DW to describe concern about developing *all* types of dementia, including AD.

Conceptually, DW can be considered a specific type of *health worry*. Some other types of health worries, such as cancer worry (e.g., Hay et al. 2005) and heart-focused anxiety (Eifert et al. 2000), have been intensively investigated in health and clinical psychology. In its most severe form, DW may show overlap with *health anxiety/hypochondria*, that is, an intense preoccupation with the idea that one has, or will contract, a particular physical disease or illness. Some clinicians have described a few cases of patients with very high levels of DW who ‘report and appear convinced of the presence of significant cognitive abnormalities (memory deficits) in the absence of any evidence of cognitive impairments on neuropsychological exam’ (Boone 2009). Among ‘neurocognitive hypochondriacs’ (Boone 2009), patterns of symptom-seeking and checking behaviour seem to be similar to that of other hypochondriacs: As demonstrated in one study (Hodgson et al. 1999), such participants repeatedly check for signs of dementia, interpret symptoms as signs of dementia and seek external validation for their concerns. However, we emphasise that such extreme cases of DW represent only one end of the spectrum.

Because dementia is closely associated with old age, it seems that DW constitutes not only more concern about developing a disease or condition but also more generalised concern about the ageing process itself. Similarly, George and Whitehouse (2007) noted that ‘nowhere has our insecurity about ageing been made more manifest than in Western culture’s collective fear of AD’ (p. 343). We argue that DW might not only overlap with health worry/health anxiety but also with *ageing anxiety*, a construct investigated within gerontological research (e.g., Lynch 2000). We therefore conceptualise DW and ageing anxiety as overlapping yet distinct constructs: Whereas ageing anxiety involves concerns about age-related declines in various domains, including health and physical functioning, financial well-being, changes in physical appearance and cognitive abilities (Lynch 2000), we argue that DW is more strongly focused on (but not limited to) concerns about memory decline, as well as concerns about losing one’s identity (Barrett and Robbins 2008). Given not only overlap but also divergence in the conceptualisation, we would like to argue that DW is an important construct of its own.

DW as an *emotional* reaction to the perceived threat of developing dementia is also conceptually distinct from *dementia cognitions*, such as the perceived risk of developing dementia or knowledge and beliefs about dementia (see Anderson et al. 2009, for a review on these latter constructs). Finally, DW is not equivalent to *subjective*

cognitive impairment (SCI) as indicated by subjective memory complaints (Reisberg et al. 2008). An individual who believes that her/his memory is poor may not necessarily attribute clinical significance to his/her symptoms; in turn, an individual with good subjective memory functioning may nonetheless fear that he/she will develop dementia in the future. Even though empirical research suggests that DW might be particularly pronounced in older people with objective and subjective memory complaints (see below), according to our conceptualisation of DW, young adults with no memory impairment (both objectively and subjectively) also may demonstrate DW.

A look at the philosophical and cultural background of DW

Serious conditions arouse deep human fears (Becker 1973). The symptomatology of dementia may be particularly fear arousing. In line with the philosophical accounts on the identity in dementia (Hughes et al. 2006), we propose that developing dementia deeply and existentially threatens two defining characteristics of human identity. First, unlike other fatal diseases, dementia not only threatens the physical self but also aspects of the ‘symbolic self’ (Becker 1973), the very aspect of human identity that separates humans from other animals. Terror-management theory (Solomon et al. 1991) argues that people have a need to distinguish themselves from animals and seek a higher and more meaningful existence. Accordingly, people seek and find comfort in the existence of the immortal, symbolic self in the face of the death of the physical self. In Western culture, cognitive capacities, autonomy and internal control are central aspects of the symbolic self (Post 2000). Qualitative studies on the experience of dementia have revealed that both healthy participants, as well as people with dementia, emphasise the themes of loss of independence, identity and control, as opposed to more physical aspects of dementia (Corner and Bond 2004; see also Steeman et al. 2006, for a review). Dementia thus seems to threaten the very idea of individuals’ identity as human beings.

Second, dementia poses a threat to the perception of an *inter-subjective reality* (Berger and Luckmann 2007). The cognitive and verbal symptoms associated with dementia seriously threaten perceptions of a shared reality with others, which functions as a fundamental basis of everyday social communication. Even though it has been demonstrated that people with dementia—even in the late stages of the disease—are still able to accurately appraise and respond to various domains of their personal and environmental reality (Clare et al. 2008), they are often perceived by others as living in an isolated ‘dementia world’. Metaphors like ‘the living dead’ have been commonly used

to describe people in the advanced stages of dementia (Aquilina and Hughes 2006). It has been suggested that any single incident of unawareness tends to bias the perception of social interaction partners such that interaction partners perceive the person with dementia as more *generally* impaired as opposed to appraising the incident of unawareness as an isolated event (Clare et al. 2008). Indeed, healthy people often underestimate the ability of people with dementia to participate in social life, depersonalising their present existence (Sabat 2006). In one study, participants used the past tense to speak about people they knew with dementia even though these people were very much part of the participants’ present (Corner and Bond 2004). In any case, the threat to one’s ability to share reality with others is a major existential threat.

Dementia as a threat to an individual’s symbolic self and inter-subjective reality is related to the idea that there is a negative *stigma* associated with dementia (e.g. Shifflett and Blieszner 1988; Vernooij-Dassen et al. 2005; Werner 2008; Werner et al. 2012). Stigma is defined as an attribute that deeply discredits and lowers the status of an individual from a normal person to a person with whom something is wrong (Goffman 1963). A public opinion poll conducted among adult Canadians showed that as many as 81 % of the 1,000 participants felt they would be looked upon or treated differently if others knew they were diagnosed with AD (Alzheimer’s Society of Canada 2003). A sizeable minority of Australians indicated that dementia risk is associated with weakness of character (32 %) and laziness (22 %), which might be indicative of a stigma associated with dementia (Low and Anstey 2009). Unfortunately, to date, empirical research on the stigma attached to dementia has been scarce and mostly atheoretical (Werner et al. 2012), and little quantitative work on the stigma surrounding dementia was available at the time of writing. It is therefore currently difficult to say on the basis of empirical research to which extent people with dementia are objectively ostracized from society.

There is some indication that dementia might pose a particular threat within Western cultures. In the US, a majority of laypeople correctly acknowledge that dementia is not a normal part of ageing. For example, the Alzheimer’s Association (2003) found that 75 % of respondents aged 35 years and older correctly stated that AD is not the term for normal memory ageing (Anderson et al. 2009). In contrast, in one study, Chinese lay people viewed dementia as a natural aspect of ageing (Ikels 2002). According to the author of the study, older adults seemed less fearful and family members less appalled by the prospect of dealing with dementia than is the case in countries like the United States. In another study conducted in Hong Kong, family carers tended to use external events and personal experiences to explain the occurrence of dementia (Chung 2000).

In a study undertaken in Goa, India, most people viewed dementia as a more or less normal part of ageing; people with dementia were not perceived as requiring medical care (Patel and Prince 2001). In addition to differences in scientifically based knowledge about dementia, cultural variations in concepts of selfhood and identity may contribute to these cultural variations in the understanding and meaning of dementia, and thus reactions to dementia (Hashmi 2009; Whitehouse et al. 2005).

Explaining DW in the general population in an antecedents-consequences conceptual framework

We argue that social-cognitive models of health behaviour offer a heuristically fruitful guide for postulating the antecedents of, correlates to, and consequences of DW.

Possible antecedents

According to the Health Belief Model (Rosenstock 1974), the perceived threat of a condition depends on both perceptions of the risk of getting a condition and perceptions of the seriousness of the condition. In addition to these two factors, the social-cognitive model of health anxiety (Warwick and Salkovskis 1990) proposes that health anxiety depends on the degree to which people perceive that they have coping resources (e.g. not only individual coping styles but also medical and informal support) to help them to influence the course of a condition. Building on these two models, we propose that inter-individual differences in DW may be related to (1) perceptions of being at risk of dementia, (2) perceptions about the consequences of developing dementia and (3) perceived coping resources for both preventing dementia as well as preparing for and or managing the consequences of dementia. We argue that the relatively high and probably increasing prevalence of DW is related to an exaggeration of risk perceptions, overly pessimistic perceptions about life with dementia and a lack of coping resources (both individual and contextual).

Perceptions of dementia risk

Subjective memory impairment is the most well-known psychological variable associated with DW and related constructs. Memory complaints are reported by 50 % of older individuals (e.g. Jonker et al. 2000). Across studies, various assessments of subjective memory functioning have consistently shown strong associations with memory-related anxiety (Verhaeghen et al. 2000) and DW (Werner 2002; Cutler and Hodgson 1996, 2001). Like family history and/or personal encounters with dementia, subjective

memory impairment seems make people aware of their own dementia risk—even though, according to epidemiological research, subjective memory impairment is only a weak (but significant) predictor of mild cognitive impairment (MCI) and dementia (Reisberg et al. 2010). At the same time, people's risk perception for developing AD/dementia is only weakly related to more significant objective risk factors such as cardiovascular disease, diabetes, level of physical activity and objective cognitive functioning (Chung et al. 2009; Werner, 2002; Yeo et al. 2007). Empirical research in Australia also supports the notion that scientific evidence about the specific risk factors for dementia has not yet been effectively translated into the general public's knowledge of how they can prevent dementia (Low and Anstey 2007). In sum, a significant proportion of individuals seems to have poor awareness of objective risk factors for dementia, while overestimating the meaningfulness of subjective memory impairment.

Perceptions of consequences

Empirical evidence suggests that people tend to have an overly pessimistic view on the conditions of living with dementia. In a sample of 186 Jewish and Arab adults with no family history of AD, the mean hypothetical emotional stress that participants *expected* to experience if they were to develop AD was 4.0 (SD = 1.0) on a five-point scale (Werner 2002). When forced to imagine that they had developed dementia, Lawton et al. (1999) found that people over the age of 75 reported wanting to live only a few days longer in such a condition. Significant proportions of a large sample of third generation Australians (27 %) and Australians with Italian (54 %), Greek (60 %) and Chinese (46 %) backgrounds indicated that people with dementia no longer enjoy life (Low et al. 2011).

Although depressive states and negative emotions occur frequently in patients with dementia, healthy people tend to overestimate the frequency of these symptoms (Teri and Wagner 1991). Quantitative studies on self-reported, health-related quality of life (HRQL) (see Banerjee et al. 2009, for a review) have revealed little or no statistically significant relationship between severity of cognitive impairment and HRQL. Likewise, longitudinal studies have demonstrated that patterns of self-reported HRQL did not match downward curves of cognitive outcomes (Misttöten et al. 2007; Selwood et al. 2005). Furthermore, most studies have not found higher risks of completed suicide in those with dementia compared to the general population (e.g. Erlangsen et al. 2006; Peisah et al. 2007). Finally, although persons with dementia are widely assumed to be victims of stigmatisation (see above), preliminary evidence points to rather positive emotional reactions and helping

behaviour from others towards persons with dementia (Cohen et al. 2009; Wadley and Haley 2001). Overall, there seems to be a ‘negativity bias’ about the quality of life with dementia, possibly contributing to relatively high levels of DW.

Lack of coping strategies

Finally, the high level of DW in Western populations may reflect a widespread lack of perceived coping resources in preventing and dealing with dementia, including internal control beliefs, knowledge about treatment options and formal and support structures. Although the Alzheimer’s Association (2003) reported that only 17 % of respondents of their study of DW agreed that there is ‘nothing a person can do to help maintain a healthy memory and reduce the chance of AD’, knowledge about specific ways to prevent dementia and perceived control particularly in influencing the course of dementia once diagnosed seems to be rather limited. For instance, although 72 % of Australians believed that the risk of dementia could be modified, 15 % of the participants were unable to generate specific ways to reduce the risk. Respondents who were able to generate behaviours to reduce dementia risk tended to suggest behaviours associated with maintaining a healthy lifestyle *in general* as opposed to factors specifically associated with dementia (Low and Anstey 2009). A review study showed that most adults in the US lack specific information about treatment of Alzheimer’s disease (Anderson et al. 2009). In another study conducted in the UK, older participants concerned about their memory felt there was little point contacting health professionals (e.g. general practitioner), as they perceived there was little that could be done (Corner and Bond 2004). Less than one quarter of respondents reported believing they were ‘well prepared’ to handle a family member’s AD diagnosis (Connell et al. 2007). A lack of coping resources may also be indicated by the finding that even though a large majority of Americans think that it is at least somewhat important to plan for AD, 82 % have not made plans for the possibility of getting AD (MetLife Foundation 2011).

Indeed, there is currently no cure for dementia. At the same time, many people seem not to perceive and/or make use of the full range of resources and strategies that help to prevent and/or cope with dementia. Symptoms can be constrained for 1 or 2 years with antidementive drugs (Deutsche Gesellschaft für Psychiatrie, Psychotherapie und Nervenheilkunde/Deutsche Gesellschaft für Neurologie 2009). Furthermore, there is consensus that improving diagnostic and treatment and social support options for dementia can enhance quality of life and prolong independence, particularly when begun as soon as possible. Emerging evidence including results based upon

longitudinal data support the notion that people themselves can reduce their dementia risk by exercising regularly, keeping weight within healthy limits, reducing high blood pressure and participating in social life (e.g. Sattler et al. 2011; Wang et al. 2002).

Possible consequences of DW

Since there has been almost no research about the potential consequences of DW, this area especially represents *terra incognita*. In what follows, we strive to develop a set of arguments based upon conceptually related phenomena, which may help to derive hypotheses to be tested in future empirical research. In principal terms, DW—like worry, anxiety and fear in general—can result in both adaptive as well as maladaptive responses among individuals and in society, depending on the frequency and intensity of fear, as well as individual and contextual resources at hand. On the one hand, worry, anxiety and fear can exacerbate problems and negative moods, which in turn can have ill effects on an individual’s well-being, physical health and actions. On the other hand, worry can act as a warning signal by focusing attention on a potential threat that can stimulate effective preparations for avoiding as well as coping with the threat (e.g. Davey and Tallis 1994).

First, DW may be associated with different dimensions of well-being and attitudes towards ageing. Frequent and intense fear of dementia may coincide with lower life satisfaction and purpose in life and may undermine a positive future time perspective. Worrying that one may develop dementia may also ‘spill over’ and negatively affect people’s general attitudes towards ageing and the individual experience of one’s own ageing (Diehl and Wahl 2010; Levy et al. 2002; Wurm et al. 2007). In contrast, low levels of DW may be associated with positive attitudes towards ageing.

Second, DW may affect how people perceive their *cognitive functioning* and impact on the interpretation of cognitive changes. Individuals with high levels of DW may be more vigilant for threat cues like memory lapses, as well as be more likely to negatively interpret ambiguous stimuli (e.g. an episode of forgetfulness) as indicative of dementia (Mathews 1990). In turn, biased interpretations of memory lapses or other ambiguous stimuli may increase subjective cognitive complaints. Furthermore, high levels of DW, as a stressor, may even *contribute* to objective cognitive impairments under certain conditions (Eysenck et al. 2007).

DW may also motivate individuals to pursue an *active and healthy lifestyle*. Commercial ‘brain fitness’ products and workshops are perceived by laypeople as beneficial tools to deter or delay the onset of dementia, most probably increasing memory self-efficacy and subjective well-being

(Dittmann-Kohli et al. 1991). Indeed, mental exercise was the most frequently suggested means for reducing dementia risk among Australians (Low and Anstey 2009). Although commercial brain fitness products have been proven to be ineffective in terms of global cognitive outcomes (Owen et al. 2010), there is reason to believe that scientifically based multicomponent cognitive trainings including cognitive and physical activity elements are promising (e.g. Schwenk et al. 2010). Continued effort is needed to educate the public about prevention measures, including exercising regularly, keeping weight within healthy limits, reducing high blood pressure and participating in social life to avoid developing dementia. Importantly, in line with social-cognitive health behaviour models, DW may lead to health-promoting behaviours if (a) individuals perceive the usefulness of these behaviours in decreasing the risk of developing dementia and (b) individuals themselves feel capable of engaging in such behaviours.

DW may also presumably be related to *healthcare decisions and preparations for old age*, including preparations for the prospect of potentially living with dementia. In one study, perceived threat among relatives of patients with AD was a very strong predictor of intentions to be tested for dementia (Roberts 2000). A moderate level of worry/fear arousal is thought to be optimal for engagement in health behaviours such as screening: whereas, too little fear leads to denial and lack of attention and too much fear may lead to avoidance, as people are too afraid to have their fears confirmed (Janis and Feshbach 1953). In line with this assumption, multiple studies suggest that a moderate degree of cancer worry is the most conducive for motivating cancer screening behaviours (Hay et al. 2005). It would be interesting to know if this insight also translates to DW and screening behaviour, given that, unlike cancer, there is currently no chance to cure or recover from dementia. Moderate levels of DW—if individuals feel that there is a benefit of an early diagnosis—might increase the chance of early detection by inciting the people to seek medical attention and participate in early screening measures. Very high levels of DW—to the degree of hypochondria—may lead to avoidance of medical support or, alternatively, to very frequent consultations and compulsively checking one's cognitive abilities (Boone 2009). Similarly, a moderate level of DW may be associated with proactively making financial and caretaking arrangements.

Finally, it seems likely that DW may affect *social behaviour*. Namely, people with high levels of DW may tend to avoid reminders of dementia, including interacting with people living with dementia. Although the current literature suggests relatively positive emotions and social behaviour towards people with dementia, evidence also points to the existence of negative emotions which create distance from and avoidance of people with dementia

(Cohen et al. 2009). Research regarding DW is therefore important for identifying (and ameliorating) problematic relationships between people with and without dementia, including evaluating issues of rejection and stigmatisation.

Suggestions for future research

Given the empirically unexplored nature of DW, an important first step would be to further explore healthy individuals' subjective emotional representations of dementia through in-depth, qualitative interviews. The qualitative step should be linked with efforts towards a more thorough assessment of DW. Previously, extant studies used a single item to measure DW. While this is a convenient way to measure DW, the reliability and validity is questionable. DW is a complex construct that needs a more sophisticated assessment strategy in light of its potential multidimensionality. Future validation studies should investigate the uniqueness of DW with regards to ageing anxiety and health anxiety/worries.

We have argued that the high prevalence of DW may be reflective of the increasing awareness of DW in times of increasing 'dementia encounters', widespread misperceptions of risks and consequences of dementia and a lack of perceived coping resources on the population level. However, there are surely large inter-individual differences in DW. To date, there has been only very limited research on intra-individual differences in DW. Overall, these studies offer only preliminary findings due to restrictions in study design (mostly cross-sectional), the variables considered and a descriptive approach as opposed to an analytical approach that can reveal meaningful relationships between variables. In particular, psychological variables, as proposed in social-cognitive models of health behaviour and health anxiety, have very rarely been investigated in their relationship to DW. The sociodemographic variables investigated so far could only explain a very small amount of variation in DW. Therefore, our framework may be beneficial for a broader understanding DW in terms of key antecedents (like those related to risk perceptions and coping resources) and consequences. Longitudinal studies are needed to understand the possible causal effect of DW on self- and developmental regulation and key endpoints of successful ageing such as well-being or social engagement.

Furthermore, it seems useful—if not imperative—for empirical research to investigate macrostructural factors related to culture and nationality (e.g. health care structures, religion, family structures and inter-generational co-residence) associated with DW. Indeed, we argue that future empirical research on DW should combine individual- and macrostructural factors, thereby integrating research from various research traditions in gerontology, including

sociology, public health, psychiatry, anthropology, philosophy/ethics, as well as cross-cultural studies.

Conclusions

As the population, particularly in many Western countries ages and more and more people, face the possibility of developing dementia, it is of utmost societal importance that emotional reactions to the increasing number of ‘dementia encounters’ are used as productively as possible. Against this background, we have argued that DW continues to be a relatively unexplored phenomenon that calls for closer and more systematic investigation. The object of this paper was to make a first step towards the improvement of this situation, while concentrating on the factors that might explain the high prevalence of DW and why future research on DW is important. We arrive at the conclusion that DW is a *hybrid*, combining elements of ageing anxiety and health anxiety/worries that can best be understood within a multidisciplinary framework combining psychological, philosophical, cultural and other disciplinary elements.

Future research on DW could help to reveal under which conditions DW leads to adaptive or maladaptive responses. As we have argued that DW may affect a range of important behaviours, such as how people interpret evidence of their own or others’ age-related cognitive changes, how they interact with people with dementia, how they anticipate and plan for their future, to which extent they engage in screening and prevention behaviour and how they exploit healthcare resources. However, more empirical research including longitudinal work is needed to learn about the potential and limits of the DW construct. In addition, how diffusion of research findings on dementia to the general public (as addressed, for example, by the US National Plan to Address Alzheimer’s Disease, Department of Health and Human Services 2012) influences DW and its potential consequences requires systematic investigation.

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