UNIVERSITÄT AUGSBURG
Universitätsbibliothek

OPEN ACCESS
OPUS AUGSBURG

Fear about Alzheimer's disease among Israeli and German laypersons, persons with Mild Neurocognitive Disorder and their relatives: a qualitative study

Perla Werner, Natalie Ulitsa, Daphna Shephet, Hanan Abojabel, Zümrüt Alpinar-Sencan, Silke Schicktanz

Angaben zur Veröffentlichung / Publication details:

Werner, Perla, Natalie Ulitsa, Daphna Shephet, Hanan Abojabel, Zümrüt Alpinar-Sencan, and Silke Schicktanz. 2021. "Fear about Alzheimer's disease among Israeli and German laypersons, persons with Mild Neurocognitive Disorder and their relatives: a qualitative study." *International Psychogeriatrics* 33 (10): 1019–34. https://doi.org/10.1017/s1041610220003397.

Nutzungsbedingungen / Terms of use:

CC BY-NC-ND 4.0

Dieses Dokument wird unter folgenden Bedingungen zur Verfügung gestellt: / This document is made available under these conditions:
CC-BY-NC-ND 4.0: Creative Commons: Namensnennung - Nicht kommerziell - Keine Bearbeitung
Weitere Informationen finden Sie unter: / For more information see:
https://creativecommons.org/licenses/by-nc-nd/4.0/deed.de

International Psychogeriatrics (2021), 33:10, 1019–1034 © International Psychogeriatric Association 2020
doi:10.1017/S1041610220003397

Fear about Alzheimer's disease among Israeli and German laypersons, persons with Mild Neurocognitive Disorder and their relatives: a qualitative study

Perla Werner,[1] Natalie Ulitsa,[1] Daphna Shephet,[2] Hanan Abojabel,[3] Zümrüt Alpinar-Sencan,[4] and Silke Schicktanz[4]

[1]*Department of Community Mental Health, University of Haifa, Haifa, Israel*
[2]*Shalvata Mental Health Care Center, Faculty of Medicine, Tel Aviv University, Tel Aviv, Israel*
[3]*Department of Community Mental Health, University of Haifa, Haifa, Israel*
[4]*Department of Medical Ethics and History of Medicine, University Medical Center, Göttingen, Germany*

ABSTRACT

Objectives: Alzheimer's disease (AD), the most common type of dementia, is one of the most feared diseases, obstructing help-seeking, and leading to discrimination. While research interest in fear of developing AD is increasing, little is known about its characterization, triggers, and consequences, especially among different cultures. In this study, we aimed at exploring and characterizing AD fear as experienced by laypersons (LP), persons with Mild Neurocognitive Disorder (MND), and their relatives, in Israel and Germany.

Design: A qualitative study using focus groups (FGs) and semi-structured interviews was used. Thematic content analysis was conducted to extract key themes.

Setting: Israeli and German not yet diagnosed people.

Participants: The study included a total of 130 participants (63 Israeli and 67 German participants) representing 3 groups: LP ($n = 82$), persons with MND ($n = 28$), and relatives of persons with MND ($n = 20$).

Results: Two overarching themes were identified across groups and countries: fear of developing AD and fear of stigmatization. Other types of fear, such as fear of a person with AD, fear about the impact of a diagnosis of AD on family members, fear of becoming a caregiver, and fear of losing one's self-determination because of developing AD, were specific to a group type or country. Different types of fear were awakened by different triggers, and were dealt with different coping strategies.

Key words: dementia fear, dementia worry, fear of Alzheimer's disease, fear, cross-cultural

Introduction

Driven by the growth in the number of people with dementia and its associated consequences, Alzheimer's disease (AD) – the most common type of dementia – has been defined as a public health priority worldwide (Wright and O'Connor, 2018). Consequently, the World Health Organization has adopted a global action plan for the years 2017–2025 (Barbarino *et al.*, 2019). One of the plan's main goals is to reduce the fear associated with AD.

This is not surprising, as quantitative studies conducted among laypersons (LP) showed that dementia in general, and AD, in particular, is one of the most feared diseases, usually second to cancer (Awang *et al.*, 2018; MetLife Foundation, 2011; Phillipson *et al.*, 2012), sometimes even preceding it (Alzheimer's Association, 2014; Bystad *et al.*, 2016). These feelings are shaped and reinforced by the media that tends to describe the disease as a dreaded and tragic disease, showing mostly its end-stage symptoms (Van Gorp and Vercruysse, 2012).

Correspondence should be addressed to: Perla Werner, Department of Community Mental Health, University of Haifa, Mt. Carmel, Haifa, Israel. Phone: +972 54 3933066. Email: pwerner@univ.haifa.ac.il. Received 10 Apr 2020; revision requested 30 Jul 2020; revised version received 20 Aug 2020; accepted 27 Aug 2020. First published online 13 Oct 2020

Literature review

Despite its importance, the phenomenon of AD fear remains conceptually, methodologically, and culturally underdeveloped. The first researchers to define *dementia fear* were Cutler and Hodgson (1996), who used the term "*anticipatory dementia*" to describe the

fear of perceiving normal cognitive changes as indications of dementia. Since then, the terms "dementia fear" (Cantegreil-Kallen and Pin, 2011; Ebert *et al.*, 2019; Norman *et al.*, 2019; Page *et al.*, 2019), "dementia worry" (Fresson *et al.*, 2017; Kessler *et al.*, 2012; Kinzer and Suhr, 2016; Molden and Maxfield, 2016; Phillips *et al.*, 2017; Ryu and Park, 2019; Wong *et al.*, 2019), and "concerns about dementia" (Tang *et al.*, 2017; Werner *et al.*, 2013) have been used interchangeably, and almost exclusively to examine concerns about developing AD.

Kessler and colleagues (2012) were the first to provide a clearer conceptualization of the construct by defining dementia fear as a multidimensional concept composed of cognitive (i.e. thoughts and beliefs) and affective factors (i.e. dementia fear), and as varying in intensity – from mild worries to severe phobias or anxiety. Recently, researchers have suggested that worries about becoming depressed or embarrassed (Wong *et al.*, 2019), or fear of becoming a burden to others (Page *et al.*, 2019) might be considered additional types of fear associated with AD.

Studies showed that fear of AD is often a barrier to seeking a timely diagnosis (Devoy and Simpson, 2017; Harada *et al.*, 2017; Takeda *et al.*, 2017), and one of the most common emotions provoked by a person with AD, leading to stigmatic beliefs and discrimination (Werner *et al.*, 2019). However, similar to studies about fear, worry, and anxiety in general, a few studies (Harada *et al.*, 2017; Jang *et al.*, 2018; Tang *et al.*, 2017) have demonstrated that dementia fear may also have an adaptive role (such as promoting healthy behaviors and preparations to avoid or cope with the source of threat). However, as stated by Kessler *et al.* (2012), these arguments are awaiting further empirical confirmation.

Methodologically, most studies examining AD fear are quantitative, although only a few used structured, validated scales (Kessler *et al.*, 2012; Page *et al.*, 2019). Finally, culturally, to the best of our knowledge, no studies have cross-culturally examined the meaning of AD fear. This is surprising because perceptions of AD are culturally determined (Calia *et al.*, 2019; Hillman and Latimer, 2017), and we can expect that the emotional reactions to the disease vary in different societies, as well as among different groups.

Objective and importance of the study

In sum, despite the increase in the amount of studies examining AD fear, there is still a need for additional research to fully understand this complex and prevalent phenomenon. Hence, as part of a larger study, which examines how moral and psychosocial attitudes regarding early diagnosis of dementia are embedded in social and cultural contexts, the current study intended to explore and characterize the meaning of AD fear among persons without a diagnosis of AD.

We expect the current study to provide us with the knowledge to build an empirical basis to understand how sociocultural attitudes in this field can differ or not between countries. Although challenged by methodological and logistic complexities, expanding cross-cultural studies in the area is an important aim if we want to promote experiences and data exchange between countries, as has been suggested by several European dementia initiatives. Moreover, given the scarce and mostly descriptive state of the literature in the area of fear of AD, our study might help guiding the development of future research and hopefully of interventions to reduce its negative and increase its positive consequences.

Thus, our primary research question was: What are the main perceptions and experiences of dementia fear among LP, persons with Mild Neurocognitive Disorder (MND, previously called Mild Cognitive Impairment), and their relatives in Israel and Germany. Recent conceptualizations of AD as a continuum starting with a preclinical phase before the appearance of clinical symptoms (Dubois *et al.*, 2019), make these groups of particular interest and relevance to the study topic, as they represent unaffected individuals, who might provide a more generalized view of feelings of fear which are not directly influenced by the experiences of the disease and/or by the caregiving situation.

We chose to compare Israel and Germany for several reasons. Both countries share some of the basic characteristics of Western modern countries, but differ in regards to others. For example, based on Hofstede's model, Israel is characterized by a lower level of individualism (54 and 67, respectively), but by a much higher level of uncertainty avoidance (81 and 65, respectively), than Germany (Hofstede Insights, 2020). This means that, compared to Germany, Israel is a more collectivistic culture with closer family ties, and higher tendency to belong to "groups" and to rely on them. Moreover, with one of the highest levels of uncertainty avoidance, Israeli culture is characterized by a stronger desire for rules, ritual, and tradition than the German culture (Hofstede Insights, 2020), and a higher tendency to be more expressive and less open to change and innovation (de Mooji and Hofstede, 2010) than Germany.

In terms of AD, the proportion of persons aged 51 and over having a diagnosis of dementia was 1.0% in Germany and 4.1% in Israel (Goncalves-Ferreira *et al.*, 2018). Finally, the topic of early

Table 1. Participants' sociodemographic characteristics by group and country

	LAYPERSONS		PERSONS WITH MND		FAMILY MEMBERS OF PERSONS WITH MND	
CHARACTERISTIC	ISRAEL ($N = 39$)	GERMANY ($N = 43$)	ISRAEL ($N = 16$)	GERMANY ($N = 12$)	ISRAEL ($N = 8$)	GERMANY ($N = 12$)
Age (%)						
18–35	25.6	53.5	0	0	0	0
36–50	17.9	11.6	0	0	25.0	16.6
51–70	12.8	25.6	0	41.7	50.0	41.7
71 +	43.7	9.3	100.0	58.3	25.0	41.7
Gender (% female)	59.0	60.5	50.0	41.7	63.0	91.7
Years of education (%)						
0–9	7.7	0	0	25.0	0	8.3
10–13	20.5	48.8	31.2	58.3	25.0	25.0
14–22	71.8	51.2	68.8	16.7	75.0	16.7
No information						50.0
Marital status (%)						
Married/with partner	38.5	30.5	56.2	58.3	50.0	75.0
Single/divorced/widowed	61.5	67.5	43.8	41.7	50.0	8.3
No information						16.7

diagnosis and prediction of dementia have gained increasing attention in both countries. This includes the initiation of National Strategic Plans to increase awareness of AD and other types of dementia in Israel (Brodsky *et al.*, 2013), as well as recently in Germany (DZNE 2020; Federal Ministry of Education and Research, 2020).

Finally, and specifically to the current study, fear of dementia is a relevant topic for ethical and social reflection on dementia research and aging care provision. Various studies have highlighted very striking differences between German and Israeli debates on health care ethics (Raz and Schicktanz, 2016). For example, while in ethics of begin of life and reproductive medicine, Israeli culture has been characterized as very permissive and embracing compared to Germany, in end-of-life issues, such as passive euthanasia or advance directives, Germany is more liberal and supportive of patient's interest than Israeli culture. Therefore, it would be interesting to see, where to locate these cultures' attitudes toward aging medicine, including diagnosis of dementia, on this spectrum of health care across the life span.

Methods

Study design

A qualitative methodology and cross-sectional design were adopted. Given the complexity of the phenomenon under study, and the abovementioned limitations of the quantitative studies, we adopted this methodology as the most appropriate way of attaining an in-depth understanding of participants' perspectives, opinions, and experiences about AD fear. Thus, focus groups (FGs) and face-to-face, semi-structured interviews were used to elicit participants' experiences of fear regarding a diagnosis of AD. Intrigued by the new developments in AD risk prediction and presymptomatic biomarkers testing for AD, and by the yet scarce number of studies in this area, we were especially intrigued in eliciting participants' perceptions of fear regarding an early diagnosis of AD.

Participants

The study included 63 Israeli and 67 German participants representing 3 groups: LP ($n = 82$ [Germany $n = 43$, Israeli $n = 39$]), persons with MND ($n = 28$ [Germany $n = 12$, Israel $n = 16$]), and family members of people with MND ($n = 20$ [Germany $n = 12$, Israel $n = 8$]).

As can be observed in Table 1, with the exception of family members of persons with MND, participants' characteristics were similar in both countries in terms of gender and marital status. In terms of their age, German participants were younger in all of the groups, and individuals with MND and their family members had a lower level of education compared to Israeli participants in these groups.

Procedure and data collection

As is common in cross-national qualitative studies (Chapple and Ziebland, 2018), slightly different

methods were used to comply with the two countries' cultural and legal differences. In Israel, nine FGs were conducted from October 2018 to March 2019: three with people with MND ($n = 16$), one with family members of people with MND ($n = 8$), and five with LP ($n = 39$). In Germany, five FGs were conducted in four German cities in Middle and West Germany from June 2017 to February 2018 with family members of people with advanced dementia ($n = 20$) and MND ($n = 7$). For this study's purpose, the latter were included as participants. Additionally, seven FGs were conducted with LP from June to November 2016 ($n = 43$). Finally, following the request of potential participants, 12 face-to-face, semi-structured interviews were conducted with people with MND from August to December 2017 instead of FGs. Five face-to-face interviews were held with the participation of their family members, whose answers were included in the study.

In Germany, data collection started earlier because of the availability of additional funding and research capacities. However, FGs and face-to-face interviews were conducted following a semi-structured interview guideline common to all groups. The guideline was developed jointly by the teams in both countries in English, and later translated into Hebrew and German. All researchers agreed that the meaning of each question should be identical, even if it was not a literal translation. Interviews started by asking the participants to introduce themselves and relate their personal experience with AD and with persons with the disease. This was followed by the presentation of a vignette (see Appendix 1), portraying a person in the early stages of the disease. Probes were used to prompt the experiences, emotions, and thoughts provoked by the person in the vignette. FGs and face-to-face, semi-structured interviews lasting an average of 90 min were conducted in each country by a member of the research team with experience in qualitative research, until saturation was reached.

To ensure data trustworthiness, FG discussions and face-to-face interviews were audio recorded and then transcribed verbatim. Transcriptions were pseudonymized (Metschke and Wellbrock, 2002). However, because of limited budget and time issues, it was not possible to translate all of them into English. Instead, researchers in each country prepared detailed coding guidelines, including verbatim quotes translated into English and representative of the participants' answers and discussions. These were discussed in a personal work meeting held between the teams; upon agreement, they guided the analysis in each country.

Sampling and recruitment

Purposive sampling was used in both countries. In Israel, people with MND and their relatives were recruited from a Mental Health Medical Center in the central part of Israel. The aims and importance of the study were explained to the director of the Third Age Clinic at the center, who on time contacted potential participants. If a verbal consent was obtained, they were contacted by the research team and informed about the time and meeting of the FGs. All the participants signed an informed consent before the initiation of the groups. LP were recruited via researchers' professional and personal connections. The research coordinator selected potential participants with an effort to achieve diversity regarding age, gender, educational, and social background.

In Germany, several strategies were used. LP were recruited by means of flyers and posters distributed and posted at local public institutions and public hospitals in the respective cities, providing genetic testing and counseling. Social media (Facebook), mailing lists, and online advertisements were used for additional recruiting. Relatives of persons with MND were recruited by disseminating flyers and posters at collaborating memory clinics, as well as via email to patients' organizations in West and Middle Germany. Additionally, an advertisement was placed in regional newspapers in two mid-sized cities in Middle Germany.

Data analysis and triangulation

The analysis included several recommended steps for thematic content analysis (Braun and Clarke, 2006). In the first step, FGs discussions and face-to-face interviews were transcribed and read several times. In the second step, the whole data set was systematically coded according to the main study topic: participants' experiences of fear regarding AD. Coding was developed both inductively and deductively. Fear and related topics emerged as an inductive theme, as it was not initially part of the research agenda. The analysis software Atlas.ti™ supported the German data coding and analysis.

Given the exploratory nature of this bilingual, cross-cultural study, it was decided to capture the different types of experience of fear that emerged. We used participants' explanations for their elicited reactions, expressions, and feelings to understand their meaning; identify categories and codes through inductive coding; and to discover main themes. Coding sheets (compiled in tables) enabled quotations to be organized by themes, categories, and codes. Categories and codes were discussed within and across research groups in both

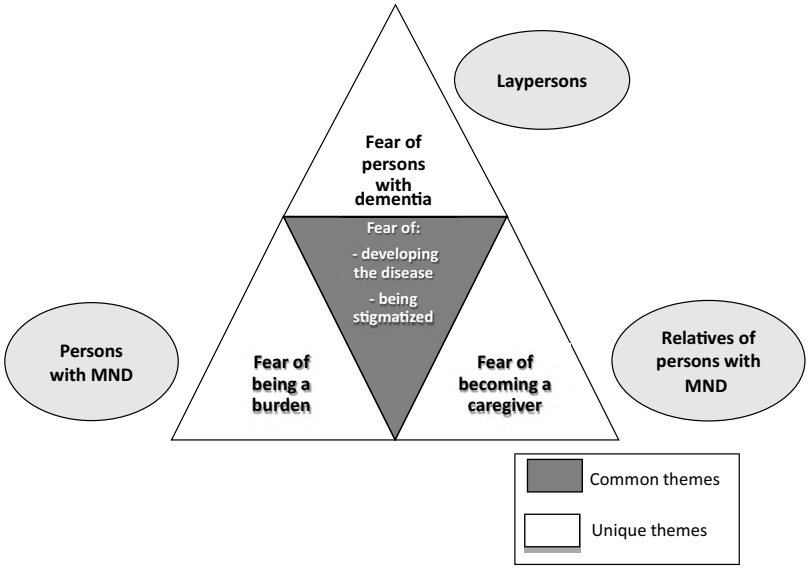


Figure 1. Common and unique themes.

countries until a consensus was reached. Participants' triangulation was conducted after the main themes were identified and an agreement was attained among the members of the research teams via discussions and consultation of the current literature (Howe, 2012).

Ethical considerations

The study protocol was approved by the University of Haifa's Ethics Committee (Ref. Nr. 384/17; 12/11/2017) and the University Medical Center Göttingen's Ethics Committee (Ref. Nr. 16/10/14) and (Ref. Nr. 17/12/16).

Results

The results are presented in two sections: first, we present themes that were common to all groups in both countries. Second, we relate to themes that were unique to a single group or a single country. Figure 1 illustrates the relationships between these common and unique themes. Common and unique themes, together with subthemes and example quotations are presented in Tables 2 and 3, respectively. Each quotation is followed by a unique participant reference relating to group membership, i.e. LP, persons with MND (P_MND), and relatives of persons with MND (R_MND).

Common themes

Two overarching themes – labeled "*Fear of developing AD*", and "*Fear of being stigmatized*" – were identified across all groups and countries.

Fear of developing AD

Concerns about developing AD pervaded across groups and countries. Participants used terms varying in intensity, such as *fear*, *worry*, and even *shock* to express the frightening emotions aroused when confronting the possibility of developing AD.

Two subthemes, reflecting triggers to these feelings and coping strategies, composed this theme:

Triggers of fear of developing AD

Participants described three triggers: cognitive deterioration; AD as an incurable disease; and having a family history of the disease.

Cognitive deterioration. In all groups, prospects of cognitive decline were mentioned as one of the main reasons prompting feelings of fear and despair. However, memory problems were the only symptom of cognitive decline associated with the concerns expressed. Some of the participants shared experiences of occasional memory lapses, describing them as a "*frightening experience*" or their "*worst fear*".

No cure Notions of dementia as an incurable and untreatable disease were associated with profound feelings of fear. Israeli participants reported being more frightened of developing AD than cancer or AIDS, because of the availability of treatments for these diseases as opposed to AD. Among German participants, feelings of hopelessness and futility regarding receiving a diagnosis of dementia were the main sources of fear of developing the disease.

Family history. Having a close relative with dementia (usually a parent or sibling) was also associated in all

Table 2. Common themes across groups and countries

THEME	SUBTHEMES AND CATEGORIES		TYPE OF GROUP	EXAMPLE QUOTATION (ISRAEL)	EXAMPLE QUOTATION (GERMANY)
Fear of developing the disease	Triggers of the fear of developing AD	Cognitive deterioration	LP	*"It's my worst fear . . . that I won't know what's going on with me, that my brain will collapse." (S)*	*"What can I do about my memory? [. . .]. I'd just be scared [. . .]. You turned around, forgot what you were about to do. Do I really have Alzheimer's disease now?" (F9M)*
			P_MND	*"There are a lot of things I don't remember . . . and then I remember, it all comes back to me. . . . I'm scared all the time . . . and it worries me a lot (. . .) it's scary." (E)*	*"It's totally crazy. [. . .] That is, yes, just fear, that you forget more and remember less. [. . .] It's sometimes so embarrassing for me." (WBS7)*
			R_MND	*"I feel memory decline by myself (. . .) I can listen to you, but I can't always repeat [what I've heard]. There is some kind of disconnection, which worries me a lot." (R)*	*"Although the cancer is (scary), but [. . .] everything that's in the head seems worse, doesn't it?" (WAM4II)*
		No cure	LP	*"AIDS is also a terrible disease, (O) but today they have these cocktails . . . I'd rather get AIDS than dementia." (J)*	*"Well, if this form of Alzheimer's disease isn't treatable yet (. . .). Then a genetic test wouldn't help me either. I would have to accept my fate, either way. Although, I could escape before [it gets too bad] by committing suicide . . . That would be a possibility, yes." (M9L)*
			P_MND	*"Cancer can be cured sometimes . . . That's what scares people — that if you get sick [with AD], there's no turning back; there's no cure. It's a one-way ticket . . . " (S)*	
			R_MND		*"I had a cancerous disease a couple of years ago and . . . I only had to go to a follow-up appointment every four months (. . .). But even that becomes normal at some point. [. . .] Dementia would scare me more if I knew I had it]." (WAL8II)*
		Family history	LP	*"If you have someone in your family with dementia, you realize that it also increases your chances [of developing it]." (Sh.)*	*"I already know that AD runs in the family. I know that, either way, without the test. The only thing I don't know is how likely it is that it will affect me. But for me, that makes a difference. Now, I'm scared." (F9M)*
			P_MND	*"My sister and my mother had dementia; my mother died of dementia (. . .) Now, I think:" My sister and my mother were in this situation, and what? Am I an exception? What if I also get it?" (Sl.)*	*"[M]y mom died of [dementia]. [. . .] [She] had a stroke [. . .] and afterwards, it started. Mom didn't know anything anymore . . . . And that's when I thought to myself: 'Well, well, well . . . How will it be for you?" (WBS4)*
			R_MND	*". . . This genetic thing (predisposition) is really scary. I'm afraid for myself, too. On my dad's side, everyone (lived) up to the age of 90 with a clear mind. So, hopefully my genes are from his side . . . " (E)*	*"Is [dementia] genetic? Just something we wait for . . . ? Because if it is, then it would be terrible for the kids. Then they would think: 'It will eventually happen to me.' [. . .] That would be terrible." (WAS23V)*

Table 2. Continued

THEME	SUBTHEMES AND CATEGORIES		TYPE OF GROUP	EXAMPLE QUOTATION (ISRAEL)	EXAMPLE QUOTATION (GERMANY)
	Coping strategies used to deal with the fear of developing AD	Engaging in preventive measures	LP	*"When you get (EPD), it's a shock, you have a lot of fears. But then you can also prepare financially, and prepare your family." (S)*	*"... If you learn at some point that you will suffer from AD, then you [...] have time to take care of things. To take out insurance. To talk about it, with friends, explain what awaits you. [It's better than] if it suddenly happens and you're completely unprepared." (F25M)*
			P_MND	*"... [Getting AD] causes a certain amount of worry. But then, I think that what can help is more activity, going out more, becoming more involved in society." (ShF3)*	*"Still, I'm willing to do [an examination] again next year, even if my family doctor might make things difficult. [...] I'm registered. We've made a start. Then, we can determine whether or not the deterioration is harmless. Or, I don't know, [whether it already is] more extreme and more serious. I'd like to do that, yes." (MBS8)*
			R_MND		*"So, the earlier you know, the better you can prepare yourself for it. [...] [A]n early diagnosis at least [...] for the patient as well as for the relatives can only be an advantage." (WAM6III)*
		Acceptance	LP	*"Some people are optimistic and say: "Well, I'll keep on living, no matter what — I'll keep on living. "(Sh.)*	*"In any case, I can't control ... what will happen in ten years' time. [...] I might be able to plan it and do this and that, but the most important thing is to enjoy the here and now." (M3L)*
			P_MND	*"To continue living without... thinking (worrying) about it... it's hard to escape these thoughts. But to accept it... to try hard to accept it... maybe with the help of friends, family – to take it more lightly and not become overwhelmed by it..." (D)*	*"So, I hope for some more training of cognitive functions by going to lectures..., I mean and I hope, it is a hope, that it doesn't get worse. This is my inner conviction." (MBS8)*
			R_MND		*"We look at it more from a more humorous perspective (laughs). Because I'm not very young anymore, I'm over 80 and we both have memory problems... sometimes we know exactly what we want to say, but we can't think of the name [...] But luckily those are only slight disturbances and we both actually try [to improve our memories], through physical training, as much as we can." (MAS27V)*
Fear of being stigmatized			LP	*"The person (with EPD) worries about those around him, his friends.... He worries that others will notice that something is wrong with him." (Msh)*	*"AD affects the person completely, right? And that's why I wouldn't spread it (the diagnosis) around. I mean, I'd only tell my closest confidants." (F17L)*

Table 2. Continued

THEME	SUBTHEMES AND CATEGORIES	TYPE OF GROUP	EXAMPLE QUOTATION (ISRAEL)	EXAMPLE QUOTATION (GERMANY)
		P_MND	*"I think that if we are talking about a concern, then I wouldn't tell anyone [about the EPD] . . . not even my wife. (. . .) It would only cause a lot of people to stay away., the friends . . . the people . . . they will move away. "(M)*	*"I didn't want anybody to notice that I was forgetting things at work, which had been happening constantly . . . So, I started going [to work] at night to sort things out, so that nobody would notice in the morning." (WBS1)*
		R_MND	*"[. . .] because people know the background and the genetics, they (other people) judge a person too fast, give him a diagnosis too fast. They seem to know that it will inevitably happen (the person will get dementia)." (S)*	*"[. . .] You get put into the dunce's corner, when you say you have Alzheimer's. Oh God, oh God, yeah? (. . .) You don't want to put a sign around your neck, but there you are. I imagine it like that, sent to the dunce's corner. And of course, you're a bit scared of that (. . .) I don't want others to know." (WIAM5)*

Abbreviations: LP, layperson; P_MND, person with MND; R_MND, relative of a person with MND.

groups with feelings of fear and worry. This was not based on a deep understanding of the increased risk associated with having a family history of the disease, but rather on having vaguely heard about "*this genetic thing*". Having a family history of dementia aroused feelings of fatalism and worry among participants – for themselves and for future generations.

Coping strategies used to deal with the fear of developing AD

This subtheme summarizes the techniques used by the participants to manage their fear of developing AD. Two subthemes, reflecting different coping strategies, emerged from the data.

Engaging in preventive measures. Participants in all groups voiced the possibility of managing the fear and shock aroused from anticipating developing dementia by being involved in activities that might, in their opinion, decrease this risk such as in physical, social, or cognitive activities. Others commented on organizing financial issues, or simply sharing their concerns with their loved ones, as ways to alleviate their concerns about the future.

Acceptance. Coping with the fear by accepting the situation was another strategy discussed by the participants. Some mentioned that, in an effort to deal with their feelings of fear, they relied on humor and laughter as ways to come to terms with the possibility of getting sick.

Fear of being stigmatized

The second theme common among the groups related to concerns regarding other people's reactions. Participants mainly worried about what others would think about them if they developed AD. They particularly emphasized the fear of being secluded by others, including their loved ones. Some participants also expressed concerns about an early diagnosis of dementia affecting their social and work lives.

Unique themes

In addition to the abovementioned themes, which were common to all groups in both countries, several unique thematic emphases emerged – either for one of the groups or one of the countries.

Groups' distinctive fears

These included – LP *fears of a person with dementia*; persons with MND *fears about the impact of a diagnosis of AD on family members*; relatives of a person with MND *fear of becoming a caregiver;* and *fear of losing one's self-determination.*

Table 3. Unique themes to some groups or country

THEME	SUBTHEME	TYPE OF GROUP	EXAMPLE QUOTATION (ISRAEL)	EXAMPLE QUOTATION (GERMANY)
Fear of a person with AD		LP	*"I remember that his (the neighbor with AD) wife, our neighbor, went out to buy something. (. . .) Suddenly he began to bang on the door loudly. This was really scary!" (S)*	
Fear about the impact of a diagnosis of AD on family members	Fear of being a burden	P_MND	*"It scares me to think I will be a burden on the children or the family." (E)*	*"I don't want to be a burden on our children, my children. So, [at a certain point], there's nothing left to do). [. . .]" (WIAS7)*
	Fear of being neglected	P_MND	*"And I was thinking of myself, "What? Will I be in a situation where they (the children) will neglect me? Will I be left alone? With no one to worry about me?" That's a very serious question. And that's what I'm afraid of." (M)*	
Fear of becoming a caregiver		R_MND	*"I have a 70-year-old friend who has Alzheimer's . . . and she keeps asking: "How are the kids?" When she says something, she asks [the same question]15 times. I look at her husband and think: Is this what awaits me? And it scares me." (Sh.)*	
Fear of losing one's self-determination or autonomy because of developing AD		LP		*"Sometimes I get really scared. [. . .] Okay, you can fall and break something, et cetera, all that's still all right, but if you become dependent on [someone else's] care . . . or get AD . . . Yes, then it would be better to have someone hit you over the head with a rock." (F21L)*
		P_MND		*"[What scares me] is the idea of getting manipulated, no longer being able to do what I think is right. If I want to stay in bed, I won't be not allowed to . . ., I'll be forcibly taken out of bed. [. . .] [T]hose are the only fears that I have. Not being able to decide what happens to my persona, to my own body anymore." (WBS1)*

Abbreviations: LP, layperson; P_MND, person with MND; R_MND, relative of a person with MND.

LP fear of a person with AD. This fear was prominent among Israeli participants who reported experiencing anxiety when encountering a person with AD, especially as this person was described as being "*different*" or someone who might behave unexpectedly, and even "*aggressively*".

Persons' with MND fear about the impact of a diagnosis of AD on family members. These participants expressed two types of concerns about how developing AD might affect their loved ones, and especially their children. Participants in this group raised concerns about becoming a burden to their relatives. Israeli participants in this group also expressed worries about being neglected by their relatives.

Relatives' of persons with MND fear of becoming a caregiver. This theme was particularly evident among Israeli spouses, mainly regarding worries about the frightening possibility of acquiring a new role, i.e. becoming a caregiver, and about how this would affect their lives.

Fear of losing one's self-determination or autonomy because of developing AD. This theme emerged only among German LP and persons with MND, who expressed deep worries about the prospect of losing their right to self-determination and autonomy because of AD. Participants described the frightening situation of having someone else care for their needs, and even "*manipulating*" their body and identity.

Discussion

This study yielded important conceptual and methodological insights into better understanding of the fears associated with AD. Our results showed that fear of AD includes different types of fear – some common across groups and countries, and others unique to only some of them.

Fear of developing AD

The first notable finding was that the fear of developing AD permeated the lives of all participants in both countries. Its magnitude was reflected in the words used by the participants to describe the emotions elicited by the hypothetical experience of developing AD, such as "terrifying" and "shocking". This is not surprising, as studies conducted among healthy populations showed that between 13 and 60% of the participants reported being worried or very worried about developing the disease (Bowen *et al.*, 2018; Cantegreil-Kallen and Pin, 2011; Cutler and Bragaru, 2015; Tang *et al.*, 2017). Our study showed that individuals with MND and their relatives in both countries share a similar fear. More importantly, the qualitative methodology used in the current study led to a more profound understanding of this emotion. Listening directly to the participants' voices allowed us to shed light on the causes or triggers of the fear of developing AD, and to identify the strategies used to manage it.

Three causes were identified as triggering feelings of fear about developing AD across groups and countries. Two depicted internal triggers – cognitive deterioration and beliefs of AD as an untreatable disease. The third was an external trigger – family history of the disease. *Cognitive impairment* is one of the leading symptoms of dementia, in general, and of AD, in particular (Hugo and Ganguli, 2014). Participants' perceptions of cognitive deterioration – as one of the main activators of feelings of fear – are consistent with the literature on cancer fear, demonstrating that physical symptoms are a common trigger of this type of fear among symptomatic (Almeida *et al.*, 2019), as well as asymptomatic individuals (Vrinten *et al.*, 2017). However, when evoking cognitive impairment as a trigger, participants in both countries referred almost exclusively to *memory problems* rather than to other cognitive deficits. The fact that memory loss is recognized as the key sign of AD by LP (Cahill *et al.*, 2015), and is the main complaint presented to clinicians when seeking help (Hugo and Ganguli, 2014), might explain the fear elicited by this symptom.

Moreover, *perceptions of AD as a disease without a foreseeable cure* promoted feelings of fear and worry among the participants. While it is true that there is, as yet, no cure for the disease (Arvanitakis *et al.*, 2019), expressing this notion was associated with a sense of hopelessness, leading to emotions of fear and even distress. Similar associations were reported in regard to cancer fear (Vehling and Kissane, 2018), suggesting that fear associated with life-threatening illnesses is a universal phenomenon – not only across groups and cultures as demonstrated in our study, but also across diseases.

Finally, *having a family member with AD* was another discriminable source of worry among Israeli and German participants. While studies have consistently shown a genetic predisposition for developing AD, in general, and in early-onset familial dementia, in particular (Durmaz *et al.*, 2019), this trigger seemed to be based on vague, rather than fact-related, knowledge about the role of genetic risk factors. This conclusion is supported by findings of a systematic review on knowledge about AD, showing that knowledge about AD genetic risk was quite modest across different populations (Cahill *et al.*, 2015).

Losing one's self-determination was an additional source of fear, although it was expressed only by German participants. Indeed, German LP and persons with MND frequently mentioned the fear of losing control over one's own self and self-determination. They expressed strong emotional reactions, sometimes even followed by contemplating suicide, as a way to remedy the situation before it was too late. It should be noted that the German guardianship law is quite restrictive regarding ensuring as far as possible a citizen's right for participation, information, and decision-making. The interest in suicide found in our study correlates with an increasing trend in the German public toward acceptance of suicide and active euthanasia in case of a serious incurable disease (IfD Allensbach, 2016). Indeed, the right to assisted suicide was recently categorized as a fundamental human right by the Federal Constitutional Court (2020). Moreover, differences in both countries' cultural and religious beliefs, regarding the balance between the sanctity of life and self-determination (Schweda *et al.*, 2017), might also explain the unique findings in Germany.

Similar to Jang and colleagues (Jang *et al.*, 2018), two adaptive strategies – engaging in preventive measures and acceptance – were discussed as the main mechanisms to cope with the consequences of fear of developing AD. These coping strategies were also reported in studies assessing fear of cancer recurrence (Lebel *et al.*, 2018), and are in accordance with social cognitive models of disease prevention (Conner *et al.*, 2015). However, unlike the management of cancer fear, participants in our study did not overtly discuss maladaptive strategies, such as avoidance and reassurance seeking (Almeida *et al.*, 2019). Several explanations might clarify this discrepancy. First, cancer fear studies mostly examined fear of recurrence. Therefore, they were based on symptomatic participants with a previous diagnosis of cancer. The fact that our participants had not yet received a diagnosis of AD for themselves or their relatives, might explain their reliance on adaptive strategies. Second, not explicitly mentioning avoidance as a way of dealing with the fear associated with developing AD might itself reflect avoidance behavior. Future studies should further explore the feasibility of this explanation.

Fear of stigmatization

Similar to dementia worry studies (Kessler *et al.*, 2012; Phillipson *et al.*, 2016), as well as cancer fear studies (Vrinten *et al.*, 2017), worries about being the target of other persons' stigmatic beliefs was central among all groups in both countries. This is an important finding, especially since stigmatic beliefs were found to be a deterrent to initiating health behaviors, such as help-seeking (Herrmann *et al.*, 2018; Phillipson *et al.*, 2015). However, while reducing stigma has been mentioned anecdotally as a potential way to manage dementia fear (Bowen *et al.*, 2018; Ryu and Park, 2019; Scerri and Scerri, 2017), this association still awaits empirical examination.

In addition to these almost universal types of fear associated with AD, it was possible to discern in our data several types of fear that were more prominent in specific groups or countries. For example, Israeli LP expressed being scared when meeting a person with AD, especially if the person acted aggressively or "*out of control*". This is an interesting finding since, to the best of our knowledge, experiences of fear evoked by aggressive behavior displayed by individuals with AD were examined among professional and nonprofessional caregivers (Scott *et al.*, 2011; Spencer *et al.*, 2019), but not among the general public. Moreover, it might reflect the cultural differences between the countries, especially in the uncertainty avoidance dimension. As stated above, with a very high score in this dimension, Israelis might tend to express more openly and freely certain types of fear, such as being afraid by someone else's behavior, especially in reference to a person with a disease. Alternatively, it might be associated with the low tendency to change that characterizes cultures with high levels of uncertainty avoidance (de Mooji & Hofstede, 2010). Indeed, a recent study comparing German and Israeli dementia advocacy groups, showed that German groups are more heterogeneous, allowing for self-advocacy, while Israeli groups are more traditional focusing strongly on caregivers (Schicktanz *et al.*, 2018).

Worries about becoming a burden to others is a common theme evoked by persons with mild cognitive impairment in qualitative studies in several countries (Gomersall *et al.*, 2017; Vernooij-Dassen *et al.*, 2006). Similar worries were expressed in our study by Israeli and German participants with MND, but also by German LP. These emotions might be associated with general feelings of worry and anxiety about confronting a debilitating condition and increased dependence (Lloyd-Williams *et al.*, 2007).

Finally, relatives of persons with MND in both countries expressed fears of becoming a caregiver. This is not surprising, as there is a universal understanding that assuming a caregiver role – a realistic possibility for relatives of persons with MND (Carlozzi *et al.*, 2018; Seeher *et al.*, 2013) – is a stressful experience, impacting the caregiver's quality of life and wellbeing (Cross *et al.*, 2018; Hooper and Collins, 2019). Interestingly, in a recent quantitative study conducted among 2,609 Asian American LP,

aged 18–98, around a quarter of the participants expressed similar concerns (Jang *et al.*, 2018). While LP in our study did not express these worries, future studies should further explore them in other cultural groups.

Study limitations

Before discussing the study's implications, its limitations must be acknowledged. First, despite the advantages of the triangulation of multiple groups' views in two countries, as with any qualitative research, the generalization of our findings is limited. Having additional FGs with other relevant groups, such as family members of persons with a diagnosis of AD, might have shed more light on additional experiences of fear associated with the disease. Second, participants in all of the groups were selected through convenience sampling. In Israel, participants were mainly recruited from one clinic; some of them even knew each other. Finally, we did not examine the participants' level of knowledge about AD. Given the inconclusive findings of the relationship between knowledge and fear of AD (Werner *et al.*, 2020), examining this variable in our study could provide us with important information.

Study strengths

Despite these limitations, this study has important strengths. First, theoretically, it supports and even expands recent conceptualizations about dementia fear as a multidimensional concept (Page *et al.*, 2019). Our findings demonstrated that although general feelings of fear about developing the disease are common among different groups and countries, there are also unique experiences not shared by all of them. This stresses the importance of attending to the needs arising from the shared, as well as the unique worries of each group. Moreover, our data revealed, for the first time, the causes or triggers of the fear of developing AD. This is an important contribution, which might guide the development of interventions aimed at preventing, rather than reducing, the adverse consequences of this emotion, and increasing its positive ones.

Second, the comparison between the two countries showed that although fear of dementia is universal, it is also shaped by cultural and social experiences. Finally, the use of a qualitative methodology proved to be particularly well-suited to understanding such complex and sensitive emotions.

Practically, we expect our findings of the ubiquity of the phenomenon of fear of dementia to guide health care professionals and policy-makers in national and international settings. However, not of lesser importance, attention should be paid to the unique themes that emerged in our study. For example, the media could ease LP fear of a person with AD by presenting a more positive, hopeful counter-frame to the dominant negative and stigmatizing bio-medical views presented today. To manage the fears expressed by persons with MND and their family members, clinicians should pay increased attention to how they communicate the diagnosis. Since approximately 20–40% of the cases diagnosed with MND improve over time, and only 10–15% per year progress to dementia (Mishra and Singh, 2019), fears could be reduced if this information is provided, or if services providing support to them were available.

In conclusion, our study revealed that fear of AD is a complex phenomenon with some commonalities and differences among groups and cultures. These findings hold implications for interventions stressing the need to delineate specific strategies to different groups and cultures. Moreover, attention should be paid not only to the detrimental consequences of fear of AD, but also to its role as a promoter of health behavior and an enabler for action.

Finally, we suggest national dementia plans to stress the importance of addressing these fears. For example, reasonable coping strategies can be strengthened, such as developing sociopolitical concepts of dementia-friendly communities.

Conflict of interest

None.

Source of funding

This study was funded by a grant from the German–Israeli Foundation for Scientific Research and Development (GIF) (grant number G-1413-119.4/2017) to Perla Werner and Silke Schicktanz. Data collection conducted with laypersons in Germany was funded by the Swedish Riksbankens Jubileumsfond (grant number 1351730).

Description of authors' roles

Perla Werner designed the study, supervised data collection and data analysis in Israel, and wrote the first draft of the paper. Natalie Ulitsa collected the data and conducted data analysis in Israel. Daphna Shephet assisted in data collection in Israel. Hanan Abojabel assisted in the writing of the manuscript. Zümrüt Alpinar-Sencan helped in collecting the

data and conducted data analysis in Germany. Silke Schicktanz designed the study, supervised data collection and data analysis in Germany, and assisted with writing the paper.

Acknowledgments

We thank Mr. Leopold Lohmeyer for conducting the face-to-face interviews and Dr. Ile Kermel Schiffman and Sabine Wöhlke for their support in conducting part of the focus groups in Israel and Germany, respectively.

References

Almeida, S.N., Elliott, R., Silva, E.R. and Sales, C.M.D. (2019). Fear of cancer recurrence: a qualitative systematic review and meta-synthesis of patients' experiences. *Clinical Psychology Review*, 68, 13–24. doi: 10.1016/j.cpr.2018.12.001

Alzheimer's Association. (2014). Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 10(2), e47–e92. doi: 10.1016/j.jalz.2014.02.001

Arvanitakis, Z., Shah, R. and Bennett, D.A. (2019). Diagnosis and management of dementia: review. *JAMA*, 322(16), 1589–1599. doi: 10.1001/jama.2019.4782

Awang, H., Mansor, N., Nai Peng, T. and Nik Osman, N.A. (2018). Understanding ageing: fear of chronic diseases later in life. *Journal of International Medical Research*, 46(1), 175–184. doi: 10.1177/0300060517710857

Barbarino, P., Lynch, C., Bliss, A., Dabas, L. and Alzheimer's Disease International (ADI). (2019). From plan to impact II. The urgent need for action. *Alzheimer's Disease International*. Retrieved from https://www.alz.co.uk/adi/pdf/from-plan-to-impact2019.pdf

Bowen, C.E., Kessler, E.M. and Segler, J. (2018). Dementia worry in middle aged and older adults in Germany: sociodemographic, health-related and psychological correlates. *European Journal of Ageing*, 16(1), 39–52. doi: 10.1007/s10433-018-0462-7

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. doi: 10.1191/1478088706qp063oa.

Brodsky, J., Bentur, N., Laron, M. and Ben-Israel, S. (2013). *Addressing Alzheimer's and other types of dementia: Israeli National Strategy*. Jerusalem: Myers-JDC-Brookdale Institute and Ministry of Health.

Bystad, M., Gronli, O., Lilleeggen, C. and Aslaksen, P.M. (2016). Fear of diseases among people over 50 years of age: a survey. *Scandinavian Psychologist*, 3:e19. Retrieved from https://psykologisk.no/sp/2016/12/e19/

Cahill, S., Pierce, M., Werner, P., Darley, A. and Bobersky, A. (2015). A systematic review of the public's knowledge and understanding of Alzheimer's Disease and Dementia. *Alzheimer Disease & Associated Disorders*, 29(3), 255–275. doi: 10.1097/WAD.0000000000000102

Calia, C., Johnson, H. and Cristea, M. (2019). Cross-cultural representations of dementia: an exploratory study. *Journal of Global Health*, 9(1), 1–11. doi: 10.7189/jogh.09.011001

Cantegreil-Kallen, I. and Pin, S. (2011). Fear of Alzheimer's disease in the French population: impact of age and proximity to the disease. *International Psychogeriatrics*, 24(1), 108–116. doi: 10.1017/S1041610211001529

Carlozzi, N.E. *et al.* (2018). Caring for an individual with mild cognitive impairment: a qualitative perspective of health-related quality of life from caregivers. *Aging & Mental Health*, 22(9), 1196–1204. doi: 10.1080/13607863.2017.1341468

Chapple, A. and Ziebland, S. (2018). Methodological and practical issues in cross-national qualitative research: lessons from the literature and a comparative study of the experiences of people receiving a diagnosis of cancer. *Qualitative Health Research*, 28(5), 789–799. doi: 10.1177/1049732317736284

Conner, M., McEachan, R., Taylor, N., O'Hara, J. and Lawton, R. (2015). Role of affective attitudes and anticipated affective reactions in predicting health behaviors. *Health Psychology*, 34(6), 642–652. doi: 10.1037/hea0000143

Cross, A.J., Garip, G. and Sheffield, D. (2018). The psychosocial impact of caregiving in dementia and quality of life: a systematic review and meta-synthesis of qualitative research. *Psychology & Health*, 33(11), 1321–1342. doi: 10.1080/08870446.2018.1496250

Cutler, S.J. and Bragaru, C. (2015). Long-term and short-term predictors of worries about getting Alzheimer's disease. *European Journal of Ageing*, 12(4), 341–351. doi: 10.1007/s10433-015-0350-3

Cutler, S.J. and Hodgson, L.G. (1996). Anticipatory dementia: a link between memory appraisals and concerns about developing Alzheimer's disease. *Gerontologist*, 36(5), 657–64. doi: 10.1093/geront/36.5.657

de Mooji, M. and Hofstede, G. (2010). The Hofstede model: applications to global branding and advertising strategy and research. *International Journal of Advertising*, 29(1), 85–110. doi: 10.2501/S026504870920104X

Deutsches Zentrum Für Neurodegenerative Erkrangungen (DZNE) [Website]. "DZNE Welcomes Federal Government's National Dementia Strategy." Press Releases, July 1. (2020). Retrieved from https://www.dzne.de/en/news/press-releases/press/dzne-welcomes-federal-governments-national-dementia-strategy; last accessed 22 July 2020.

Devoy, S. and Simpson, E.E.A. (2017). Help-seeking intentions for early dementia diagnosis in a sample of Irish adults. *Aging & Mental Health*, 21(8), 870–878. doi: 10.1080/13607863.2016.1179262

Dubois, B. *et al.* (2019). Preclinical Alzheimer's disease: definition, natural history, and diagnostic criteria. *Alzheimer & Dementia*, 12(3), 292–323. doi: 10.1016/j.jalz.2016.02.002

Durmaz, A., *et al.* (2019). Genetic factors associated with the predisposition to late onset Alzheimer's disease. *Gene*, 707, 212–215. doi: 10.1016/j.gene.2019.05.030

Ebert, A.R., Kulibert, D. and McFadden, S.H. (2019). Effects of dementia knowledge and dementia fear on comfort with people having dementia: implications for dementia-friendly communities. *Dementia*, doi: 10.1177/1471301219827708

Federal Constitutional Court. Leitsätze [Guiding Principles]. (2020). Retrieved from https://www.bundesverfassungsgericht.de/SharedDocs/Entscheidungen/DE/2020/02/rs20200226_2bvr234715.html; last accessed 17 August 2020.

Federal Ministry of Education and Research. Kabinet Beschließt Nationale Demenzstrategie. Press Release, July 1. (2020). Retrieved from https://www.bmbf.de/de/kabinett-beschliesst-nationale-demenzstrategie-11963.html; last accessed 22 July 2020.

Fresson, M., Dardenne, B., Geurten, M. and Meulemans, T. (2017). The effect of stereotype threat on older people's clinical cognitive outcomes: investigating the moderating role of dementia worry. *The Clinical Neuropsychologist*, 31(8), 1306–1328. doi: 10.1080/13854046.2017.1307456

Gomersall, T., Smith, S.K., Blewett, C. and Astell, A. (2017). "It's definitely not Alzheimer's": perceived benefits and drawbacks of a mild cognitive impairment diagnosis. *British Journal of Health Psychology*, 22(4), 786–804. doi: 10.1111/bjhp.12255

Goncalves-Ferreira, R., Brandao, M.P. and Fonseca Cardoso, M. (2018). An update of the profile of older adults with dementia in Europe: findings from SHARE. *Aging and Mental Health*. doi.org/10.1080/13607863.2018.1531385.

Harada, K. *et al.* (2017). Psychological predictors of participation in screening for cognitive impairment among community-dwelling older adults. *Geriatric and Gerontology International*, 17(8), 1197–1204. doi: 10.1111/ggi.12841

Herrmann, L., *et al.* (2018). A systematic review of dementia-related stigma research: can we move the stigma dial? *The American Journal of Geriatric Psychiatry*, 26(3), 316–331. doi: 10.1016/j.jagp.2017.09.006

Hillman, A. and Latimer, J. (2017). Cultural representations of dementia. *PlosMedicine*, 14(3), e1002274. doi: 10.1371/journal.pmed.1002274.

Hofstede Insights. (2020). Country comparison. https://www.hofstede-insights.com/country-comparison; last accessed 7 August 2020.

Hooper, E.K. and Collins, T. (2019). An occupational perspective of the lived experience of familial dementia caregivers: a thematic review of qualitative literature. *Dementia*, 18(1), 323–346. doi: 10.1177/1471301216672489

Howe, K.R. (2012). Mixed methods, triangulation and causal explanation. *Journal of Mixed Methods Research*, 6(2), 89–96. doi: 10.1177/1558689812437187

Hugo, J. and Ganguli, M. (2014). Dementia and cognitive impairment: Epidemiology, diagnosis, and treatment. *Clinical Geriatric Medicine*, 30(3), 421–442. doi: 10.1016/j.cger.2014.04.001

IfD Allensbach. (2016). *ROLAND Rechtsreport 2016 – Vorbereitung der Bevölkerung auf eine mögliche Pflegebedürftigkeit und ihre Einstellung zur aktiven und passiven Sterbehilfe*. [ROLAND legal report – preparation of the population for a possible need for long-term care and its attitude to active and passive euthanasia.]

Jang, Y., Yoon, H., Park, N.S., Rhee, M.K. and Chiriboga, D.A. (2018). Asian Americans' concerns and plans about Alzheimer's disease: the role of exposure, literacy and cultural beliefs. *Health and Social Care*, 26(2), 199–206.

Kessler, E.M., Bowen, C.B., Baer, M., Froelich, L. and Wahl, H.W. (2012). Dementia worry: a psychological examination of an unexplored phenomenon. *European Journal of Ageing*, 9(4), 275–284. doi: 10.1007/s10433-012-0242-8

Kinzer, A. and Suhr, J.A. (2016). Dementia worry and its relationship to dementia exposure, psychological factors, and subjective memory concerns. *Applied neuropsychology: Adult*, 23(3), 196–204. doi: 10.1080/23279095.2015.1030669

Lebel, S. *et al.* (2018). Towards the validation of a new, blended theoretical model of fear of cancer recurrence. *Psycho-Oncology*, 27(11), 2594–2601. doi: 10.1002/pon.4880

Lloyd-Williams, M., Kennedy, V., Sixsmith, A. and Sixsmith, J. (2007). The end of life: a qualitative study of the perceptions of people over the age of 80 on issues surrounding death and dying. *Journal of Pain and Symptom Management*, 34(1), 60–66. doi: 10.1016/j.jpainsymman.2006.09.028

MetLife Foundation. (2011). What America thinks: MetLife Foundation Alzheimer's survey [Online]. Available at http://www.metlife.com/assets/cao/contributions/foundation/alzheimers-2011.pdf; last accessed 22 July 2020.

Metschke, R. and Wellbrock, R. (2002). *Datenschutz in Wissenschaft und Forschung* (3rd ed.). Berliner Beauftragter für Datenschutz und Informationsfreiheit. Berlin: Druckerei Conrad GmbH.

Mishra, V.N. and Singh, V. (2019). Mild cognitive impairment: a comprehensive review. *International Journal of Biological & Medical Research*, 10(2), 6773–6781.

Molden, J. and Maxfield, M. (2016). The impact of aging stereotypes on dementia worry. *European Journal of Ageing*, 14(1), 29–37. doi: 10.1007/s10433-016-0378-z

Norman, A.L. *et al.* (2019). The fear of Alzheimer's disease: mediating effects of anxiety on subjective memory complaints. *Aging & Mental Health*, 24(2), 308–314. doi: 10.1080/13607863.2018.1534081

Page, K.S., Jr, Hayslip, B., Wadsworth, D. and Allen, P.A. (2019). Development of multidimensional measure to examine fear of dementia. *The International Journal of Aging*, 89(2), 187–205. doi: 10.1177/0091415018784737

Phillips, A., Muller, S., Preische, O. and Laske, C. (2017). Worries about Alzheimer's disease and subjective cognitive decline in proxies of AD patients and controls. *Journal of Alzheimer's Disease & Parkinsonism*, 7(1), 302. doi: 10.4172/2161-0460.1000302

Phillipson, L., Hall, D. and Cridland, L. (2016). Dementia Friendly Kiama pilot project evaluation 2016 [Online]. Available at http://dementiaillawarra.com/wpcontent/uploads/2016/12/DFK-Evaluation-Flyer-WEB.pdf; last accessed 22 July 2020.

Phillipson, L., Magee, C.A., Jones, S.C. and Skladzien, E. (2012). Correlates of dementia attitudes in a sample of

middle-aged Australian adults. *Australasian Journal on Aging*, 33(3), 158–163. doi: 10.1111/j.1741-6612.2012.00624.x

Phillipson, L., Magee, C.A., Jones, S.C., Reis, S. and Skaldzien, E. (2015). Dementia attitudes and help-seeking intentions: an investigation of responses to two scenarios of an experience of the early signs of dementia. *Aging & Mental Health*, 19(11), 968–977. doi: 10.1080/13607863.2014.995588

Raz, A. and Schicktanz S. (2016). *Comparative Empirical Bioethics: Dilemmas of Genetic Testing and Euthanasia in Israel and Germany*. Springer International Publishing.

Ryu, S.I. and Park, Y.H. (2019). Factors related to dementia worry: comparing middle-aged and older adults in South Korea. *Research in Gerontological Nursing*, 12(6), 299–310. doi: 10.3928/19404921-20190823-02

Scerri, A. and Scerri, H. (2017). Training older adults about Alzheimer's disease – impact on knowledge and fear. *Educational Gerontology*, 43(3), 117–127. doi: 10.1080/03601277.2016.1266445

Schicktanz, S., Rimon-Zarfaty, N., Raz, A. and Jongsma, K. (2018). Patient representation and advocacy for Alzheimer disease in Germany and Israel. *Journal of Bioethical Inquiry*, 15, 369–380.

Schweda, M., Schicktanz, S., Raz, A. and Silvers, A. (2017). Beyond cultural stereotyping: views on end-of-life decision making among religious and secular persons in the USA, Germany and Israel. *BMC Medical Ethics*, 18(1), 1–11. doi: 10.1186/s12910-017-4

Scott, A., Ryan, A., James, I.A. and Mitchell, E.A. (2011). Psychological trauma and fear for personal safety as a result of behaviors that challenge in dementia: the experiences of healthcare workers. *Dementia*, 10(2), 257–269. doi: 10.1177/1471301211407807

Seeher, L., Low, L.F., Reppermund, S. and Brodaty, H. (2013). Predictors and outcomes for caregivers of people with mild cognitive impairment: a systematic literature review. *Alzheimer's & Dementia*, 9(3), 346–355. doi: 10.1016/j.jalz.2012.01.012

Spencer, D., Funk, L.M., Herron, R.V., Gerbrandt, E. and Dansereau, L. (2019). Fear, defensive strategies, and caring for cognitively impaired family members. *Journal of Gerontological Social Work*, 62(1), 67–85. doi: 10.1080/01634372.2018.1505796

Takeda, S., Ota, M. and Taniguchi, T. (2017). Factors affecting intention to undergo dementia screening. *Journal of Medical Sciences*, 60(1), 47–51.

Tang, W. *et al.* (2017). Concern about developing Alzheimer's disease or dementia and intention to be screened: an analysis of national survey data. *Archivers of Gerontology and Geriatrics*, 71, 43–49. doi: 10.1016/j.archger.2017.02.013

Van Gorp, B. and Vercruysse, T. (2012). Frames and counter-frames giving meaning to dementia: a framing analysis of media content. *Social Science & Medicine*, 74, 1274–1281. doi: 10.1016/j.socscimed.2011.12.045

Vehling, S. and Kissane, D.W. (2018). Existential distress in cancer: alleviating suffering from fundamental loss and change. *Psycho-Oncology*, 27(11), 2525–2530. doi: 10.1002/pon.4872

Vernooij-Dassen, M., Derksen, E., Scheltens, P. and Moniz-Cook, E. (2006). Receiving a diagnosis of dementia: the experience over time. *Dementia*, 5(3), 397–410. doi: 10.1177/1471301206067114

Vrinten, C.H. *et al.* (2017). What do people fear about cancer? A systematic review and meta-synthesis of cancer fears in the general population. *Psycho-Oncology*, 26(8), 1070–1079. doi: 10.1002/pon.4287

Werner, P., Goldberg, S., Mandel, S. and Korczyn, A.D. (2013). Gender differences in lay persons' beliefs and knowledge about Alzheimer's disease (AD): a national representative study of Israeli adults. *Archives of Gerontology and Geriatrics*, 56(2), 400–404. doi: 10.1016/j.archger.2012.11.001

Werner, P., Kalaitzaki, A.E., Spitzer, N., Raviv-Turgeman, L., Koukouli, S. and Tziraki, C. (2019). Stigmatic beliefs towards persons with dementia: comparing Israeli and Greek college students. *International Psychogeriatrics*, 31(10), 1393–1401. doi: 10.1017/S104161021900070X

Werner, P., AboJabel, H. and Maxfield, M. (2020). Conceptualization, measurement and correlates of dementia worry: a systematic review. *Archives of Gerontology and Geriatrics* (submitted). doi: 10.1016/j.archger.2020.104246

Wong, S., Smith, S. and Jacova, C. (2019). Older adults with subjective cognitive decline worry about the emotional impact of cognitive test results. *Alzheimer Disease & Associated Disorders*, 34(2), 135–140. doi: 10.1097/WAD.0000000000000354

Wright, T. and O'Connor, S. (2018). Reviewing challenges and gaps in European and global dementia policy. *Journal of Public Mental health*, 17(4), 157–167. doi: 10.1108/jpmh-02-2018-0012

Appendix 1. Vignette

Ms. Wagner/Cohen is 62 years old and notices that she occasionally forgets certain things. She visits a memory clinic to be examined. After a few tests – both physical as well as neuropsychological tests, such as repeating a word list – she is told that there would be a higher risk of her developing Alzheimer's disease in the years to come.