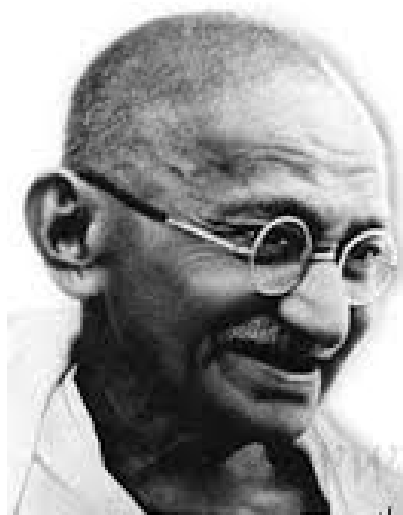


FEAR OF DEMENTIA: AN ENABLER OR AN IMPEDIMENT TO PREDICTION?



More people die of the
fear of disease than of
disease itself.

Mahatma Gandhi

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Background

- Dementia inspires fear
- One of the most feared diseases
- Fear is a central component in models of:
 - Health behavior – deters help seeking
 - Stigma – increases stereotyping, prejudice and discrimination

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What is dementia fear?

Conceptualizing dementia fear

- Lack of conceptual clarity
- Anticipatory dementia (Cutler and colleagues in 1996)
- Dementia worry, fear, concerns, anxiety, and anticipatory dementia are frequently used interchangeably
- Dementia worry was defined as a response to a perceived threat (Kessler and colleagues, 2012)
- Fear is the affective component of dementia worry
- Might vary in intensity – from mild (concerns) to severe (anxiety)

Research question

- What is the understanding and the role of dementia fear among different stakeholders?



Aim of the study

- To explore and characterize the fears provoked by dementia among
 - **Lay persons**
 - **Persons with Mild Neurological Disorder (MND)**
 - **Relatives of persons with MND**
- using a cross-national qualitative approach

Participants and Methods

Focus groups with 63 Israelis and 67 German participants representing 3 groups

Lay persons

Israel (n=39); Germany (n = 43)

Persons with MND

Israel (n=16); Germany (n =12)

Family members of persons
with MND

Israel (n=8); Germany (n = 12)



Participants' experiences were elicited using an interview guide and the presentation of vignettes.

Thematic content analysis was used to extract key themes.

The research protocol was approved by the Ethics Committee of the University and the medical institution

Dementia fear

Sources

Cognitive
deterioration

Family history

Familiarity

No cure

**Fear of losing
self-
determination**

Sources of dementia fear

Main themes	Lay persons	Persons with MND	Relatives of persons with MND
Cognitive deterioration	<i>"Its my worse fear...that I will not know what is going on with me, that my brain will collapse..." (S)</i>	<i>"There are a lot of things I don't remember ... and then I remember, it all comes back to me. When I have a bad time - then it happens to me more. When I'm calm - it happens less to me. But it happens. I was scared all the time ... and it worried me a lot. (..) it's scary" (E).</i>	<i>I feel memory decline by myself, but not in remembering ...But more than that ... I can listen to you, and I can't always repeat it, I have some kind of disconnection, which worries me a lot. (...) (R)</i>
Familiarity with dementia	<i>"I knew a man, he was our neighbor, he had dementia. We witnessed his deterioration. He eventually passed away.. It's a terrible disease. And when I saw him like that... I was terrified, it's scaring, It's scaring..." (M)</i>	<i>"I have a friend (...). He was "blessed" with three diseases: A. the back - surgery was unsuccessful, B. - Alzheimer's, and C. - dementia. When I see him while visiting him at least once a month, that's what scares me about the future...(s)</i>	<i>"When I see my friend (with dementia), I am terribly afraid. How to deal with it?" (S)</i>
Family history	<i>"If you have someone in your family with dementia, you realize that there is something that also increases your chances.(Sh)"</i>	<i>"My sister and my mother had dementia, my mother died of dementia, by the way, that was mental dementia (...) Now I think:" My sister and my mother were in such situation, and what? Am I an exception? What if I will also get it?" (SI)</i>	<i>And this genetic thing (predisposition) is really scary, too. I'm afraid of myself, too. My dad's side, everyone there (libe) up to the age of 90 with a clear mind. So, hopefully my genes are from this side... (E)</i>
No cure	<i>"Also AIDS is a terrible disease. (O) But today they have these cocktails... I'll rather get AIDS than dementia (J)</i>	<i>"Cancer can be cured sometimes ... That's what scares people — that if you get sick (dementia), there's no turning back, there's no cure. A one-way ticket..." (S)</i>	<i>"Dementia would scare me more (than cancer)if I knew I had it" (WAL811)</i>
Losing self-determination (Germany only)	<i>"Sometimes I get really scared...if you become dependent on someone or get AD, then it is better to have someone it you on the head" (F21L)</i>	<i>"What scares me is the idea of getting manipulated, no longer being able to do what I think is right.." (WBS1)</i>	

Dementia fear

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**Fear of losing
self-
determination**

Anxiety/depression

Stigma

Optimism/carpe
diem

Risk reduction

Consequences of “bad and good” fear



Consequences of fear

Main themes	Lay persons	Persons with MND	Relatives
Bad fear			
Depression/ Anxiety	<i>"(when you get EPD)-woman or man, no matter...(she feels like) her world was destroyed. And the sky fell on her. And he'll really get into depression and shut himself up.".(O)</i>	<i>In addition, she (her sister with dementia) was hysterical... She worried, worried, worried, about our parents (who started with dementia) and about herself...And she got it, got it (dementia).(ShF1)</i>	<i>"Besides anxiety, EPD doesn't do any good" (R)</i>
Stigma	<i>"The person (with EPD) worries about those around him, friends...those around him. Worries that others will notice that something is wrong with him (M)"</i>	<i>"I think that if we are talking about a concern, I would not tell anyone (about the EPD). I would not even tell my wife. (...) It will only distance a large part of the people away, they will move away from me "(M)</i>	<i>" ... because people know the background and genetics, they judge a person too fast, give him a diagnosis too fast. They seem to know that it will happen unavoidably (the person will get dementia). (S)</i>
Good fear			
Preventive measures	<i>"When you get a positive (EPD), is a shock, you get into a lot of fears. But then you can also prepare financially, and with your family" (S)</i>	<i>" (getting a diagnosis of dementia) causes a certain amount of worry. But then I think that what can help is more activity, to go out more, to be more involved in society.".(ShF3)</i>	<i>(Its scary but) the earlier you know the better you can prepare yourself for it" (WAM6111)</i>
Optimism	<i>"Some people are going to take it to their hands and will say, "Well, I keep living, no matter what I have — I keep living."(Sh)</i>	<i>"To continue living without...it's impossible to say without thinking (worrying) about it...it's hard. But to accept it...to try hard to accept it...maybe with the help of friends, family – to take it more lightly and not to sink into it..." (D)</i>	<i>"We look it from a more humorous perspective...." (MAS27V)</i>

Summary and discussion

- The first qualitative study using a diverse, multi-stakeholder, bi-national approach to seek an intricate understanding of the concept of dementia fear
- Dementia fear permeates the lives of laypersons, persons with MND and their relatives
- We were able to identify the sources and the consequences of dementia fear

Summary and discussion

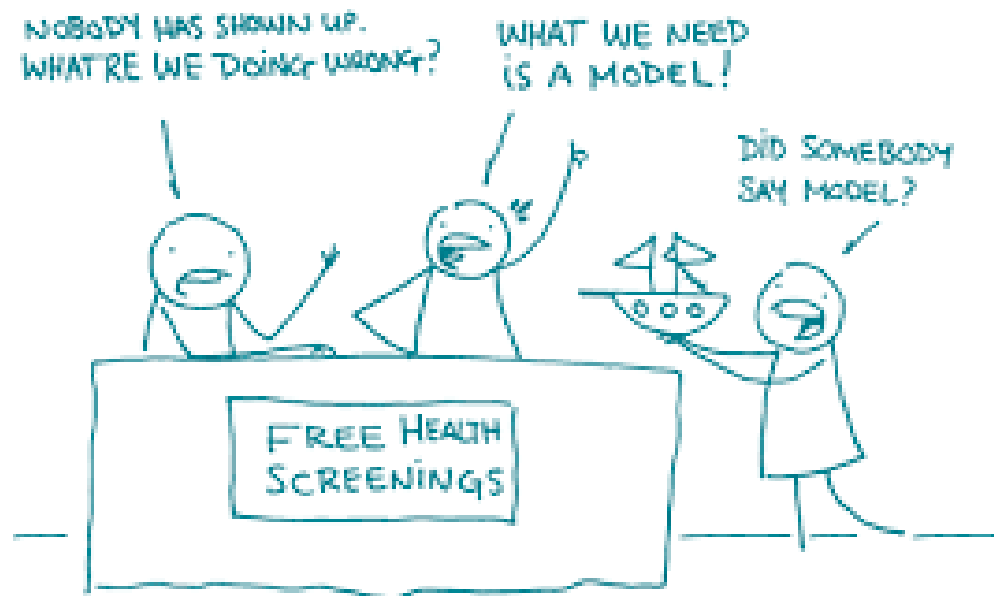
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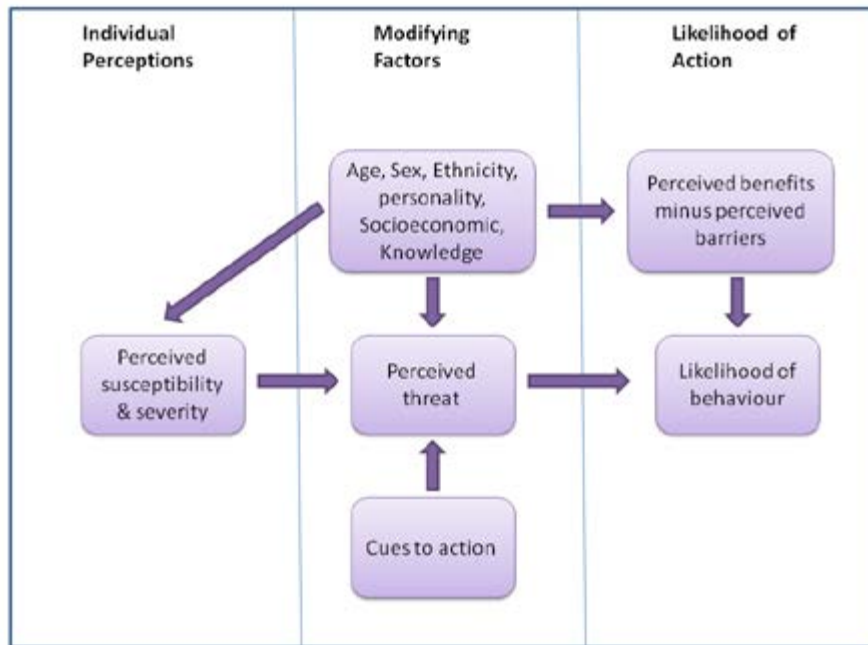
How can (or should) this knowledge contribute to develop interventions to increase EPD.

Fear campaigns



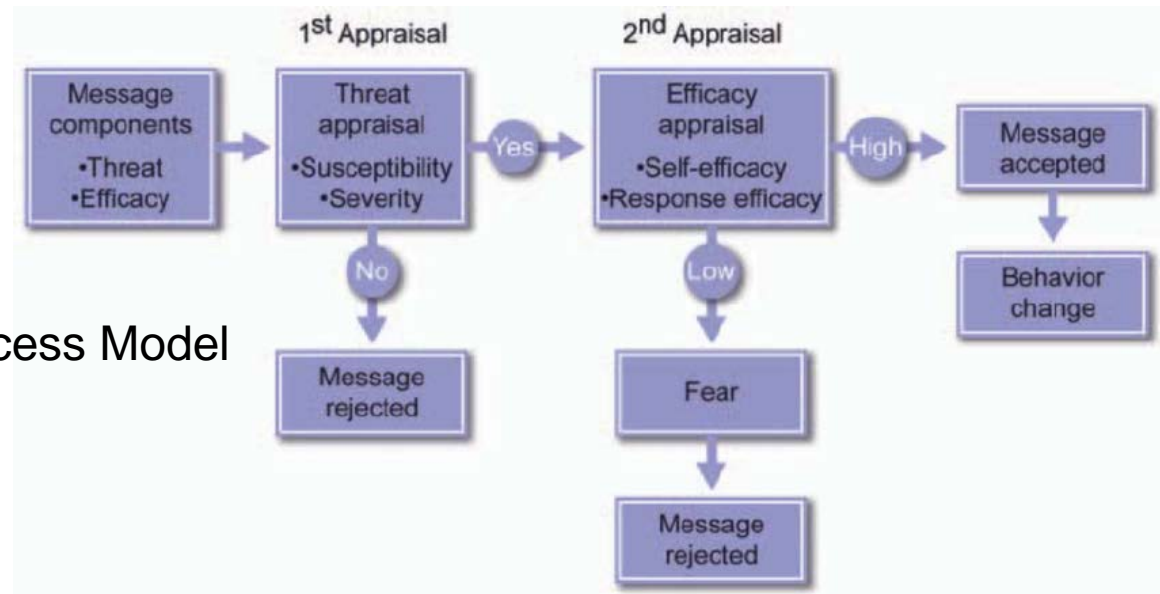
We need a model





The Health Belief Model

The Extended Parallel Process Model



Conclusions and further questions

- Dementia fear is a multi-dimensional and complex concept
- With different and even contradictory consequences
- There is need to define its moral/ethical bases before moving into the development of interventions

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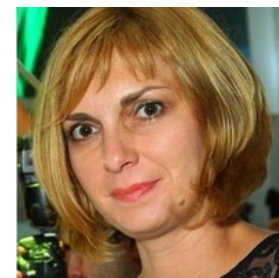
Disclosure and Collaborators

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Thank you

