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Dementia in metaphors: A qualitative study among informal caregivers of people with dementia from migrant and ethnic minority groups

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ABSTRACT

Introduction: People with dementia from migrant and ethnic minority (MEM) groups often receive suboptimal care. Differences in perceptions, values and preferences, and linguistic barriers may complicate communication between persons with dementia, their families and healthcare professionals. Metaphor analysis can provide unique insight into the lifeworld of people with dementia and their informal caregivers. This study identified the metaphors with which informal caregivers of persons with dementia from diverse cultural-linguistic backgrounds understand and discuss dementia.

Methods: We conducted 7 focus groups ($n = 42$) and 12 interviews ($n = 13$) with informal caregivers of persons with dementia living in the Netherlands from six different cultural backgrounds: Dutch, Chinese, Turkish, Moroccan, Surinamese, and Dutch-Antillean. Interviews, in the native tongue of participants, were analyzed for the presence of direct and indirect metaphor.

Results: The results indicate a conspicuous lack of metaphor to reflect on the nature and experience of having dementia. Two typical conceptual metaphors in health communication (journey/war) are virtually absent in all MEM groups. Furthermore, results suggest a one-sided and negative outlook on dementia, with an emphasis on persons with dementia as 'childlike' or 'crazy'.

Conclusion: Our results suggest a lack of extensively available sophisticated (metaphorical) language to consider daily life with persons with dementia. There is a clear need to address the stigma and lack of medical knowledge surrounding dementia in these MEM groups and to carry out more cross-linguistic and cross-cultural research to explore which metaphors aid understanding and lead to the empowerment and restoration of self-worth of people with dementia.

1. Introduction

In the Netherlands, more than 10% of people with dementia have a migrant background. In the next decade, the number of people with dementia from migrant and ethnic minority (MEM) groups is expected to rise twice as fast as among native Dutch people (Alzheimer Nederland, 2014; Parlevliet et al., 2016; Selten et al., 2021). This increase is caused by an ageing of the population, a limited 'cognitive reserve' and higher prevalence of risk factors such as high blood pressure and diabetes (Aichberger et al., 2010; Parlevliet et al., 2016; van Campen & Goudsmit, 2016; van Laer et al., 2020). Persons with dementia and their families from MEM groups often struggle with an unfamiliarity with Dutch healthcare, limited health literacy, a language barrier and cultural differences (van Campen & Goudsmit, 2016).

There is a dearth of empirical studies on dementia care for MEM populations. Authors acknowledge how crucial the relation between health, well-being, and culture is and yet little attention has been paid to culture and cultural differences in health research (Kagawa Singer et al., 2016; Napier et al., 2014). Cultural and linguistic factors play an important role in the way dementia is perceived and experienced (Gorska et al., 2018; Iliffe & Manthorpe, 2004). Differences in perceptions, values and preferences, as well as linguistic barriers may complicate communication between persons with dementia, their families and healthcare professionals (Ahmad et al., 2020; Olthuis & van Heteren, 2003; Schouten & Meeuwesen, 2006; Suurmond & Seeleman, 2006).

One essential but often overlooked instrument in communication is metaphor. Metaphors have been identified as a fundamental cognitive tool for understanding complex, abstract and unfamiliar notions (the so-

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called target domains) in terms of simpler, more concrete and familiar notions (the so-called source domains) (Gibbs, 1994; Kövecses, 2002; Lakoff and Johnson, 1980, 1999; Sontag, 1978). As such, metaphors allow us to think and talk about one domain, for instance TIME, in terms of another domain, for instance MONEY, giving us the conceptual metaphor TIME IS MONEY, which is why we say that something has *cost* us a lot of time and we should not *waste* time but *budget* it carefully.[1] Similarly, because we understand complex illnesses such as cancer in terms of the conceptual metaphor CANCER IS WAR, we use metaphorical expressions such as 'He *lost the battle to* cancer' (disease as enemy) and 'The cancer cells have *attacked* every part of her body' (body as battleground, and treatment as defense weaponry).

Metaphors are important because "they express, reflect, and reinforce different ways of making sense of particular aspects of our lives" (Semino et al., 2016). They have the potential to provide access to a different dimension of experiential knowledge: a preconceptual orientation regarding thoughts and experiences hardly accessible through rational discussion (Schmitt, 2005; Van Wijngaarden, 2016). As such, metaphor analysis may give unique insight into the lifeworld of people with dementia and their informal caregivers. Additionally, they are important not only for our own individual sense-making, but on a collective, societal level as well – metaphors are "anchored in the flesh and embedded in culture" (Van Wijngaarden, 2016). Research shows that there is substantial cultural and linguistic variation in metaphor use (Kövecses, 2005); for illnesses such as dementia, this may seriously complicate person-centred caregiving.

Research has shown which metaphors are used when dementia is discussed in scientific literature and popular media (George, 2010; George et al., 2016; Zimmermann, 2017). A small number of studies has also focused on metaphor use by informal caregivers of people with dementia (Golden et al., 2012; Lovenmark, 2020) and young people with dementia (Castaño, 2020; Johannessen et al., 2014). Yet most existing research focuses on English language data, with little attention to the ways in which language and culture influence how dementia is experienced and understood. So far, no studies have focused on metaphor use by MEM groups. Gaining more insight into how these groups talk and think about dementia may offer vital clues to enhance culturally-sensitive communication about dementia and thus support decision-making processes. This study therefore aimed to identify metaphors with which Chinese, Turkish, Moroccan, Surinamese, Dutch-Antillean and Dutch informal caregivers of persons with dementia in the Netherlands understand and discuss dementia, focusing on metaphors describing dementia and metaphors describing people with dementia.

2. Methods

2.1. Design and participants

To elicit the everyday thinking and talking about dementia of persons with dementia and their families, we conducted focus groups and interviews with informal caregivers of persons with dementia from six cultural backgrounds: Dutch, Chinese, Turkish, Moroccan, Surinamese and Dutch-Antillean.

Before the start of the study, contact was established with two organizations with knowledge of and experience in dementia-focused research among MEM groups: Pharos, Dutch Centre of Expertise on Health Disparities, and NOOM, Network of Organizations of Elderly Migrants. Additionally, an advisory group of formal and informal caregivers from various cultural backgrounds was involved throughout the design and conduct of the empirical study. Through these organizations, we recruited key persons with an extensive network in the Chinese, Turkish, Moroccan, Surinamese, or Dutch-Antillean population. These populations were selected as they represent five of the largest non-Western MEM groups in the Netherlands. Via these key persons and using snowball sampling, participants were recruited. The prospective participants were informed in person, via telephone, or by email about the objective of the study, and were invited to participate.

We recruited native speakers of Cantonese, Turkish, Berber and Arabic, Sranan Tongo and Papiamentu to conduct the interviews. Interviewers were selected based on native language, experience with persons with dementia, and experience with interviewing and/or group facilitation. They were trained in eliciting metaphors and conducting interviews and focus groups by the researchers and a representative of Pharos in March 2019. Training consisted of an introduction into metaphor theory, purpose and contents of the interviews, and discussion of different scenarios and pitfalls. The interview guide with open-ended questions was developed based on literature research and conversations with informants. It invited participants to speak about their interactions with their loved one with dementia, interactions with formal care, and language used to speak about (persons living with) dementia. The final question prompted different metaphors regarding dementia, asking participants to reflect on them. After several interviews, the interview guide was evaluated and modified to better reflect the aim of the study. (See interview guide in appendix.)

2.2. Data collection

Focus groups took place at a location easily accessible for participants. They were led by an interviewer, all but one in the presence of an assistant to observe and assist. If it proved impossible to recruit a sufficient number of focus group participants, we opted for interviews. These interviews were conducted at the participant's home by one interviewer. The interviewer stressed that participation in this study was voluntary and withdrawal was possible at any time. All participants gave their written informed consent at the start of the session. Each session commenced by explaining the goal of the study, introducing the interviewer and the participant(s). The sessions were semi-structured, with the interviewers starting with questions to elicit responses on how people with dementia describe their experiences, but also allowing interviewees to contribute their own topics and concerns.

The interviews and focus groups were conducted in the native tongue of the participants (Dutch, Cantonese, Turkish, Berber and Arabic, Sranan Tongo or Papiamentu) and were audio-recorded. Some of the Moroccan participants spoke Moroccan-Arabic instead of Berber. The Surinamese sessions were held in Dutch at the request of the participants, with only occasional code-switching into Sranan Tongo. All sessions showed occasional codeswitching into Dutch and English. For the purposes of the current study, it was the cultural background of the participants – and its inherent system of norms, values and beliefs, including religious beliefs – that was considered fundamental in determining how people understand and talk about dementia, rather than the specific language they spoke during the session. The decision to conduct the interviews and focus groups in the different languages associated with the caregivers' backgrounds rather than Dutch was made to create a safe environment and make the participants feel they could use the language they felt most comfortable in to discuss their experiences. Participants received a small gift after participation.

2.3. Ethical approval

Ethical approval was sought from the Research Ethics Committee of [anonymized] (registration number: 2018–4615), who determined ethical approval was not required under Dutch law.

2.4. Data transcription, translation, and analysis

Native speakers were recruited for the transcription and translation of

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[1] In Conceptual Metaphor Theory, conceptual metaphors in our thinking are written in small caps, while linguistic metaphors in our language are written in italics.

the audio recordings. They were selected based on their native language, proficiency in Dutch, experience with linguistics and transcription, and affinity with the topic of dementia in MEM groups. In addition, a professional transcription service was used for the transcription of the Dutch and Surinamese interviews. The anonymity of participants was maintained in all transcripts and translations.

The interviews were translated into Dutch in their entirety and then analyzed for the presence of metaphor by the lead linguist] on the research team [AGD, who is an experienced researcher in both metaphor studies and translation studies and was involved in the development of the Metaphor Identification Procedure Vrije Universiteit (MIPVU) (Nacey et al., 2019). Only passages directly relevant for metaphor analysis were transcribed in the native languages, that is passages in which interviewees talked specifically about dementia, people with dementia or caring for someone with dementia. These transcriptions allowed the lead analyst to confirm with the transcriber-translators the metaphors that had been identified based on the translations into Dutch. For example, one metaphor that was identified by the lead analyst was HAVING DEMENTIA IS MOVING BACKWARDS, in Dutch "*hij gaat achteruit*" [lit. he goes backwards]; the transcriber-translator for Cantonese then confirmed that in Cantonese the metaphor works the same way, with a contextual meaning referring to a deterioration in mental and physical health and a more basic meaning that refers to physical movement backwards. In the example "唔 … 冇嗰，我覺得呢，任何一個人，老咗吖都會退化。我認爲。*Ja?*" [Not really, everyone that gets old simply goes backwards [= deteriorates], that's what I think, yes?], the character "退" means "backwards" and the suffix "化" indicates a process, so a backwards process. Other translations include 'move back', recede', 'give back', 'refund', 'return'.

The transcriber-translators were trained by the lead linguist in using the metaphor identification procedure (Johannessen et al., 2014; Nacey et al., 2019; Steen et al., 2010) and in direct translation (i.e. word by word) to prevent shifts in meaning from occurring during translation. The transcriber-translators added explanations as well as idiomatic translations to their direct translations where necessary for clarification purposes (see box 1).

The Dutch translations were analyzed by the lead linguist for the presence of metaphor-related expressions describing the experience of having dementia, describing people with dementia, or describing the experience of caring for someone with dementia. Following the basic steps of the MIP (Nacey et al., 2019; Pragglejaz Group MIP, 2007; Steen et al., 2010), we first read each entire interview "to establish a general understanding of the meaning" (MIP step 1) and then established the lexical units (i.e. words or phrases) for analysis (MIP step 2). Subsequently, we determined each lexical unit's contextual meaning, "how it applies to an entity, relation, or attribute in the situation evoked by the text" (MIP step 3a), and then determined whether the unit "has a more basic contemporary meaning in other contexts than the one in the given context" (MIP step 3b), a meaning that is more concrete, physical, human-oriented, precise and/or historically older. If the contextual meaning was sufficiently distinct from this basic meaning but could also be understood in comparison with it (MIP step 3c), then the unit was marked as metaphorically used (MIP step 4).

The presence of the identified metaphors was subsequently confirmed by the native-speaker transcriber-translators using the transcriptions in the respective native languages. For example, in the first Turkish focus group, one caregiver says "*Babam babam ya … Ama işte babamı 2011′e kayıp ettiğimizde annem resmen eh kendini unuttu yani.* ***Kendini kapattı.***" (TUR-FG1; emphasis added), which translates into "My father my father yes … But we lost our father in 2011 and then she truly forgot herself. **She closed herself off.**" Here, the contextual meaning of *kendini kapatti* [closed herself off] refers to the fact that she was no longer able to talk about her feelings and connect with people, which can be understood in comparison and contrast to the more basic meaning of physically closing something such as a container so that nothing can move in or out; this expression was therefore marked as being related to metaphor.

Following MIPVU (Nacey et al., 2019; Steen et al., 2010), we also identified metaphor-related expressions that work via topical rather than referential incongruity, as is the case in similes and metaphorical comparisons and analogies. For example, in the second Cantonese focus group, one caregiver describes his father as behaving "like a small child" (細路仔) (CAN-FG2). Here the word 'child' is not metaphorically used itself, but it does set up a direct metaphorical comparison between the behaviour of the person with dementia and the behaviour of a small child.

2.5. Trustworthiness

The fact that this was an empirical study among six different cultural-linguistic groups of participants meant that its execution came with challenges. Ideally, this study would be conducted by a research team proficient in all languages, with the same cultural-linguistic background as its target population, with experience in qualitative data collection, transcription, translation, and metaphor analysis, so that recruitment, data collection, transcription, translation and analysis would be performed by the same researcher. Because this was impossible, research tasks were shared among a large team of researchers, which introduced vulnerabilities into our study. We safeguarded the trustworthiness of this study through several strategies. We recruited and trained native speaker interviewers with the same MEM background as the participants, to enhance credibility and transferability. Participants were recruited by key persons with an extensive network in specific MEM communities, enhancing transferability. To increase the dependability of our findings, interviewers were trained to use an interview guide, and a systematic and transparent procedure for metaphor analysis with high replicability was used. The research team met frequently to develop the analysis, and an advisory group of experiential experts was involved in the design of the study and regularly gave feedback on preliminary results to improve credibility and confirmability.

3. Results

Between May 2019 and March 2020, a total of 20 interviews and focus groups were conducted with informal caretakers of people with dementia. We held seven focus groups attended by a total of 42 participants. In addition, a total of 12 interviews were held (13 participants; one interview was a dyadic interview). An overview is provided in Table 1. Most interviewees were women who cared for parents (-in-law). Interviews lasted an average of 45 min (18–90 min), focus groups lasted 84.7 min on average (75–97 min).

Throughout the sessions the informal caregivers talked about what the person they cared for was like before the onset of dementia, how they

Box 1
Example of transcript translation

Berber transcription: *umi ruḥen ɣaa weđ̣bib inn as qa d Alzheimer i dayes*

Dutch direct translation: *toen zij gingen naar arts, hij zei: er zit Alzheimer in hem* [then they went to doctor, he said: there is Alzheimer in him]

Dutch idiomatic translation: *toen ze bij de dokter waren, zei hij: hij heeft Alzheimer* [when they were at the doctor's, he said: he has Alzheimer's.

Table 1
Overview of interviews and participants.

Language	Number of focus groups	Total number of focus group participants	Number of interviews	Total number of interview participants	Gender of person with dementia		Relation of interviewee with person with dementia	
Dutch	2	8	0	0	Female	5	Child	2
					Male	3	Partner	5
							Neighbor	1
Turkish	2	16	0	0	Female	12	Child	9
					Male	4	Child-in-law	6
							Niece/nephew	1
Berber/Arabic	0	0	9	9	Female	5	Child	9
					Male	4		
Cantonese	2	11	0	0	Female	5	Child	9
					Male	3	Partner	2
Sranan Tongo/Dutch	1	5	2	3	Female	2	Child	2
							Partner	2
							Sibling	2
							Niece/nephew	1
							Friend	1
Papiamentu	0	0	2	2	Male	2	Partner	2
Total	**7**	**40**	**13**	**14**	**Female**	**7**	**Child**	**31**
					Male	**6**	**Child-in-law**	**6**
							Partner	**11**
							Sibling	**2**
							Niece/nephew	**2**
							Friend	**6**
							Neighbor	**1**

changed over time, and whether they had ever expressed how it feels to have dementia. However, it was clear that the caregivers also felt a great need to talk about their own experiences and how caring for someone with dementia affected their lives. In the analyses below, we focus on two main metaphor clusters, namely:

- metaphors describing dementia and the experience of having dementia (expressed indirectly via the caregivers, mostly via anecdotes and direct quotes); and
- metaphors describing the person with dementia.

Metaphors that were not directly related to dementia have been disregarded. For the above clusters all relevant metaphorical expressions were grouped on the basis of the source domain evoked by the expression, such as WAR, JOURNEY, LOSS or CHILD. The identified semantic groupings were then related to common conceptual metaphors (Lakoff and Johnson, 1980, 1999), in line with previous research on metaphors for dementia (Castaño, 2020; Zimmermann, 2017) and illness discourse more generally, such as cancer (Gibbs & Franks, 2002; Semino et al., 2016), mental health problems (Tay, 2013), diabetes (Arduser, 2013, pp. 95–114) or pregnancy loss (Littlemore & Turner, 2020).

The sections below will first present general findings on the discourse used in the interviews and focus groups, followed by the results for the metaphors describing dementia and the experience of having dementia, and metaphors describing people with dementia. Examples have been translated into English by the lead analyst for the sake of reading comprehension and to facilitate comparison across the different cultural backgrounds.[2]

3.1. General findings

The interviews showed considerable variation in how dementia was named. In the Turkish data, the Dutch word '*dement*' was used, but also the Turkish word '*demans*', which was conjugated to indicate a process which has begun: *babamın* ***dementliği*** *başladı* = my father's **dementia has begun** (TUR-FG2). The Turkish speakers also used 'Alzheimer', which was occasionally conjugated (e.g. '*Alzheimerlar*'), but was predominantly used in its base form:

> Interviewer: *Dement annen.* [Your mother has dementia.]
>
> Caregiver: *Evet, Alzheimer.* [Yes, Alzheimer's.]
>
> (TUR-FG2)

In the Berber data, the Dutch word '*Alzheimer*' was sometimes used, but the interviewees indicated that most people, especially those back in Morocco, do not use words such as 'dementia' or 'Alzheimer's' but simply say 'that disease':

> Really, if it is the bad disease or Alzheimer's, they always say that disease, the disease of forgetting, or the bad disease. But we talk about it normally, about that disease. But when people from the outside come they say: that disease, that's it. They do not give it a name.
>
> (BER-INT3)

In the Cantonese data, both Alzheimer (老人痴呆症) and dementia (認知障礙症) were used. Importantly, a number of Chinese interviewees indicated that many Chinese people do not consider dementia a disease, but rather, they treat it as a natural result of ageing:

> No, you know, every person who ages, they go backwards [= deteriorate], I think, right? But this is quite common, people know that every person will experience this. (CAN-FG2)

In the Dutch-Antillean (Papiamentu) interviews, the words Alzheimer and dementia were never used, only 'the disease' (*e malesa*):

> What happened is that he is, was at home for four years, with the disease, but he built it up bit by bit. (PAP-INT2)

The Dutch-Antillean caregivers used different euphemistic descriptions such as 'the process' (*e proces*), 'what happened to his sister' (*e suseso di su ruman*) and 'how she became' (*kon e ruman a bira*) to talk about dementia. Such euphemistic descriptions were also common in the other cultural groups, with variations on 'become/be **like that**' and become/be **such a** person'.

In both the Dutch-Dutch and Surinamese-Dutch interviews, the words '*dementie*' and '*Alzheimer*' were used extensively and without reservation,

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[2] The original spoken data, transcripts and translations into Dutch are available upon reasonable request.

in addition to frequent references to much more specific indications of different types of dementia, such as ‘vascular dementia’, ‘Parkinson’, ‘apraxia’ and ‘Lewy body’, suggesting these groups have a higher health literacy in this domain.

> A second important observation is that in all interviews the caregivers consistently expressed that you cannot ask someone with dementia how it feels to have dementia, either because they will deny having dementia, or they are no longer able to reflect on their situation, or because the topic is simply too embarrassing or taboo. This was illustrated in the first Turkish focus group:
>
> Interviewer: Alright friends, let’s move on. The people who are ill, fathers and mothers, did they ever talk about their own feelings? I mean about what it’s like to have dementia? Did they ever tell you?
>
> Caregiver 4: They never accepted it.
>
> Caregiver 3: My father never accepted it.
>
> Interviewer: Never accepted it?
>
> Caregiver 3: Did not accept it at all. […]
>
> Caregiver 4: Felt embarrassed.
>
> Caregiver 3: Felt embarrassed, he felt uncomfortable. For example, he does not even want to go outside. Like, why would other people have to see me like this?
>
> Caregiver 4: That’s because he’s aware of it, if they are unaware …
>
> Caregiver 6: We never asked them how they felt …
>
> Caregiver 5: You cannot ask them, it really is not possible to ask them.
>
> (TUR-FG1)

There appears to be a general consensus across all cultural groups that for as long as possible, everyone involved pretends that nothing is wrong, that someone is just getting old, even though the caregivers indicate they always knew what was happening long before any official diagnosis was made. This suggests that when people with dementia are still at a stage at which they would be able to reflect on how they experience having dementia, this topic is carefully avoided. By the time everyone realizes that it must be dementia, the person with dementia can no longer formulate complex thoughts on what they are experiencing.

Quite a few interviews centred on what the caregivers said they can only describe as “weird” behaviour, for example when people with dementia see things that are not there, or do strange things:

> I remember he was even eating coats, I could not get them out of his hands because he thought they were bread.
>
> (TUR-FG1)
>
> Or sometimes he says to me “There goes a cat”, he sees strange things. But then I just say it’s his imagination, right.
>
> (PAP-INT1)

There was also a clear opposition between “good” and “bad” cases, with examples of people with dementia being aggressive versus those who are sweet and cute:

> Really very cute she is, she’s got nothing, she doesn’t bother anyone.
>
> (CAN-FG2)
>
> Very rude, or that she hits you, or grabs a knife to chop you, that kind of thing.
>
> (CAN-FG2)

These anecdotes were strikingly similar across all cultural backgrounds, illustrating that the typical behaviour and complaints associated with dementia may very well be shared across cultures, even though people’s ways of understanding and explaining that behaviour and its causes and consequences may not be. Such differences in understanding and interpretation stand out even more through the metaphors that were used by the different cultural groups.

3.2. *Metaphors describing dementia and the experience of having dementia*

Based on previous research into metaphors for dementia and other medical conditions (e.g. (Arduser, 2013, pp. 95–114; Castaño, 2020; Gibbs & Franks, 2002; Littlemore & Turner, 2020; Semino et al., 2016; Tay, 2013; Zimmermann, 2017) we had expected to find many WAR metaphors in the data, but these were noticeably absent, except for the Dutch groups. In the other groups, no war-related words (e.g. fight, battle, struggle, win, etc.) were used to describe how people with dementia feel or behave, and any references made to fighting or aggression concerned actual physical violence. Only in the Dutch data did we find a number of metaphorical expressions that can be attributed to the WAR domain, such as *strijd* [conflict/fight/battle]*, aangevallen* [attacked] and *verweer* [defense]*, verzet* [resistance]*,* and *overgegeven* [surrendered]:

> So only if you … when she sort of feels attacked, so to say … then … then … then there’s the defense: ‘that brain disease’.
>
> (NED-FG1)
>
> Because she had to be admitted as well, but it was just all resistance.
>
> (NED-FG1)
>
> She was a smart woman, so she must have known something, but she surrendered.
>
> (NED-FG1)

Our data show that the WAR metaphors were not used to describe the experience of having dementia as a war, or the person with dementia as fighting the disease and trying to win the battle, but rather, to describe how people resist the diagnosis, their caregivers and changes to their daily routines. When people finally accept that they have dementia, this is described as surrendering.

The other cultural groups did not show a similar use of WAR-related vocabulary, though the anecdotes did reveal similar behaviour of people not wanting to acknowledge having dementia and not wanting to move out of their own homes.

For the Dutch group, it was the diagnosis that was the main point in the illness trajectory that invited framing in terms of RESISTANCE or SURRENDER. Interestingly, one of the Dutch caregivers suggested that it is not the person with dementia that needs to fight, but their loved ones:

> Caregiver 1: If you fight something? That’s one of those images you hear with cancer.
>
> Caregiver 2: It’s you, their loved one, who’s fighting.
>
> (NED-FG2)

None of our groups showed descriptions of people with dementia as ‘keeping up the fight’, and there was also no explicit use of such war or fighting metaphors to express the hopelessness of the situation or the fact that it is pointless to fight.

It may not only be the physiological circumstances of the disease that counter the use of such metaphors and the resulting framing in terms of winning and losing. A closer look at the Berber data, for example, made clear that it is widely believed that Allah gives you this disease, and the suffering in this life washes you of your sins for the afterlife, so you should always be thankful:

> What were we supposed to tell my mother? She doesn't know. And my father. I would say to him: "Dad, thank Allah, Allah gave this to her. What can you do?" And he would say: "Yes, I am grateful to Allah, but still, we could get medicine for her. And we could do other things to make her better." He could not accept it. Healing her with the Quran and things. And then we would say: "Mum has this, final. We cannot do anything about it."
>
> (BER-INT5)

If an illness has been given to you by Allah, it could well be considered inappropriate to resist or fight it, and this may be one reason why WAR metaphors were not used in describing the experience of having dementia in cultures where religion plays an important role in how people understand events and experiences and how they should react. For the Chinese group, it was not religion that appeared to make WAR metaphors less suitable, but the fact that many people do not see dementia as a disease at all, but rather as a natural result of growing old. Though originating from a very different perspective on dementia, the outcome is actually the same as for the Moroccan group: if dementia is simply part of life, a natural result of growing old, then it is not something that needs to be resisted or fought.

Research on metaphors and illness has shown that the main alternative to WAR and FIGHTING metaphors are JOURNEY metaphors. In our data, it was difficult to determine whether particular expressions established JOURNEY metaphors or more general MOVEMENT or DIRECTION metaphors, especially since words such as 'journey' or 'travel (er)' were not used. One Dutch focus group was the only one in which the notion of a journey was explicitly contemplated, after the interviewer asked the participants whether they see dementia as a journey to a country where you don't speak the language. Interestingly, their conclusion was that this metaphor does not apply to the person with dementia but to the caregivers, similar to the fighting metaphor:

> Caregiver 3: I would rather say that you go on a journey without an end goal. In my case, that is.
>
> Caregiver 1: You can't do anything anymore.
>
> Caregiver 3: If you would call it a journey?
>
> Caregiver 2: It is a journey of sorts.
>
> Caregiver 4: There are better metaphors.
>
> Caregiver 2: There is no end to it. It is endless. It is actually endless.
>
> Caregiver 3: I feel like it is us who make that journey.
>
> Caregiver 1: Yes. We are the ones who make that journey.
>
> (NED-FG2)

They also concluded that it is not a journey you take willingly and happily, but a forced journey, like being abducted:

> Caregiver 1: It is almost as if he's being abducted. You do not get in voluntarily.
>
> Caregiver 2: No. We have just been put in a vehicle, to make the best of it.
>
> (NED-FG2)

Though the other groups did not show such references, there were recurring instances of DIRECTION or MOVEMENT metaphors. All of the interviews contained instances of metaphors expressing backwards movement (DETERIORATING IS GOING BACKWARDS) and metaphors describing people with dementia as being (too) far gone (NO LONGER BEING AWARE OF YOUR SITUATION IS BEING FAR GONE / TOO FAR GONE).

> I went to her mother with her one time. And when I saw her, I was really shocked. Her mother was really far gone.
>
> (BER-INT5)
>
> And now his brain is going backwards step by step. He is going backwards more and more.
>
> (CAN-FG2)
>
> Well, in principle we have of course noticed that she is really going backwards a lot the last few years and it is getting worse.
>
> (SRA-INT2)

The Turkish speakers also used 'that direction' and 'that way' to indicate a person's dementia becoming recognizable as dementia or getting worse:

> She is going backwards a lot and her disease is going more and more in the direction of dementia.
>
> (TUR-FG2)

These rather general DIRECTION metaphors can be related to the rather euphemistic way of talking about dementia that was common in all of the groups, where people with dementia were being talked about as 'being like that' or 'going that way'. They often talked about dementia in terms of a 'process' that 'begins' or 'starts' and then sometimes 'speeds up' or 'slows down' or 'remains stable', but finally it always 'goes backwards' and 'in that direction' so that people end up 'like that' and finally 'too far gone'. This relates to the dementia journey being a one-way journey, and may be one of the reasons why people resist the diagnosis so much, since it is the diagnosis that in many ways is "the point of no return".

3.3. Metaphors describing people with dementia

One interesting result of interviewing caregivers rather than persons with dementia was that many of the metaphors in the data were not metaphors for dementia itself but for people with dementia, demonstrating how caregivers and others talk and think about them. These descriptions provide valuable insights into people with dementia's position in society. Rather than describing them as fighters or brave warriors, they were most commonly compared either to children or the mentally ill across all of the cultural groups.

In the Chinese group the use of child metaphors to describe the behaviour of people with dementia was strongly linked to the notion of naughty and funny behaviour:

> Then she counts again, counts her fingers. [...] In any case, it's very comical. Like a child. Like a child. I think she's just like a small child like that.
>
> (CAN-FG1)
>
> Just like a child that is getting a scolding, she's standing in the corner of the room like that, but then she forgets again every day. And back to hiding things and hiding things again.
>
> (CAN-FG1)

By contrast, the Moroccan caregivers focused much more on the need to feed and wash people with dementia; as a result, they compared people with dementia to babies rather than children:

> Interviewer: You just said that she's like a little girl.
>
> Caregiver: I see my mother as a baby.
>
> Interviewer: Why?

> Caregiver: I change her, I feed her. Just like a baby. That's also how I explain it to my father. A baby cannot walk, a baby cannot eat independently. See her as a baby. Just like her sweetness.
>
> (BER-INT5)

A number of Moroccan caregivers also pointed out that this need to care for them like they are babies is sometimes degrading or dehumanizing because it leads to a loss of respect and status, especially for men:

> My father was always a respected man. […]. It is difficult to see and hear that he is behaving like a small child now. He was such a strong, big man.
>
> (BER-INT6)

They also pointed out that it is hard to take care of people with dementia because, unlike babies, they are big and therefore too heavy to lift and they often do not want to be helped. By contrast, the Turkish caregivers also compared people with dementia to both babies and small children, but seemed to focus more on their emotions and innocence:

> Caregiver 6: Just like a child. He looked so innocent.
>
> Caregiver 4: Something in between innocent and funny.
>
> Caregiver 6: And very emotional. His facial expression was childlike innocence. When he saw me his lip was trembling.
>
> Caregiver 4: Like a baby they want attention. […] One moment they are like a baby, and then if you say something they resent it like a child.
>
> (TUR-FG1)

There were no explicit references to people with dementia being like children or like babies in the two Dutch-Antillean interviews, though the way some of the anecdotes were structured indicated a similar kind of parenting behaviour, especially relating to eating and washing:

> Right, as for showering, we each have one wash cloth. I put a little soap on his, because he does not know what soap is any more. I put it on. I stand there and say to him: "Now remember, wash wash everywhere. Remember, we should not smell like poop. Wash your bum." And so on.
>
> (PAP-INT1)

In the Surinamese group, rather than explicit comparisons there were frequent references to the Sranan Tongo word *'kinsie'*, meaning 'childlike'. Moreover, the Surinamese interviews showed a clear connection being made by the participants between people with dementia being called *'kinsie'*, childlike, and *'lauw'*, crazy. One group even discussed whether *'kinsie'* does not actually mean or entail crazy, which may be the main reason why many considered *'kinsie'* such an insult:

> Caregiver 2: In Surinam 'kinsie' [childlike] right?
>
> Caregiver 3: Yes, kinsie. Yes, yes.
>
> Caregiver 2: Kinsie is crazy!
>
> Caregiver 1: No, that's what people think.
>
> Caregiver 2: That's what I think yes.
>
> Caregiver 3: No, no 'lauw' [crazy]
>
> Caregiver 2: Yes, but also 'kinsie'. Kinsie is someone, a child.
>
> (SRA-INT2)

> No, it's true that Dutch people also say like you become childlike. Then they also say like: "Are you crazy? I'm an adult woman." […] So, but they do things that a child does. The nagging, getting your way, and just going on and on. You do experience that. That you think "mum, stop acting like a child".
>
> (SRA-INT2)

In all of the groups there was frequent reference to the fact that what caregivers have to do when the person they are caring for is behaving like a child is to "go with it": what caregivers have to do is *'meebewegen'* [with-move > move together], not try to correct or punish them. Caregivers have to behave like patient and nurturing parents.

Interestingly, the same kind of behaviour – asking repetitive questions, eating uncontrollably, not going to the bathroom on time, being excessively angry or scared – can be framed either as childlike behaviour or as crazy behaviour. Our data show that across all of the cultural groups, words relating to insanity were also used to describe people with dementia, their actions and behaviour:

> Caregiver: Yes, he became very aggressive towards my mother. But my mother did not know this disease.
>
> Interviewer: What did your mother call the disease?
>
> Caregiver: A madman.
>
> Interviewer: That's what she called him?
>
> Caregiver: Yes, haha.
>
> Interviewer: And how did she describe it?
>
> Caregiver: She would say: he is possessed or he's doing it on purpose, he's pretending. (BER-INT6)
>
> In general they say, that person is crazy, they ate their head [= go crazy], is old. They don't want to say it. They kept it a secret. […] They would not even talk to such a person. There were old people that they hid. If there were visitors then they were hidden in the barn, I remember. I was 8–9 years old. We were not allowed to go there. There was one who was loved but because everyone had been made afraid so much we were not allowed to go near them because they might hurt us. Crazy, she ate her head. Her own grandchildren were not allowed to go near grandma. Very sad.
>
> (TUR-FG2)

The underlying assumption appears to be that both children and crazy people do not behave appropriately and are not able to act rationally. Yet while the framing of this behaviour as childlike behaviour may lead to people being patient and forgiving, the framing in terms of crazy behaviour is more likely to lead to people being locked up and hidden away. In addition to anecdotes discussing how people with dementia were hidden away, there were also several instances in which caregivers told stories about people with dementia being ridiculed:

> Caregiver: Yes, I remember that people were laughing at him. When he had Alzheimer's. He wasn't very sick, but the symptoms were there. And then I was asked for my hand in marriage. And that boy came together with his father. Yes, and they were mocking him.
>
> Interviewer: When he came to ask for your hand in marriage?
>
> Caregiver: Yes, they were laughing at him. He had done something. I thought it was horrible.
>
> (BER-INT6)

Similarly, it is noteworthy that the context surrounding insanity metaphors and anecdotes concerning "strange" behaviour often contained references to people with dementia "pretending" or "acting as if":

> "What is this place?" I say to him "Your home." When we go to bed at night he asks "Right. Which room … in which room should I sleep?" You know? Sometimes he pretends it's not his house.

(PAP-INT1)

This suggests that even the caregivers may sometimes feel that their loved ones could just stop acting crazy and behave normally, that this behaviour is temporary or all just an act.

4. Discussion

Though our dataset was relatively small and heterogeneous, and we interviewed caregivers rather than people with dementia themselves, this study provided valuable insights about cultural-linguistic conceptualizations of dementia and people with dementia. It is striking that all of the interviews focus heavily on anecdotes that illustrate how people with dementia behave, emphasizing examples of people with dementia repeating certain types of actions, forgetting things, disappearing, becoming aggressive, not recognizing people, not being able to talk, or not having proper hygiene. The caregivers rarely reflect on how people with dementia feel and experience their illness. There is a general consensus across the different cultural groups that you cannot ask people with dementia how they feel, and the caregivers indicate that stating explicitly that someone has dementia remains taboo even after someone has officially been diagnosed.

Though research into first-person narratives (Castaño, 2020; Zimmermann, 2017) has addressed the personal experiences of people with dementia, it should be noted that for these particular MEM groups, and vulnerable groups more generally, talking about such personal experiences may still be largely taboo (van Campen & Goudsmit, 2016; Ahmad et al., 2020; van den Broeke et al., 2021). Our data indicate that explicitly naming and discussing dementia may be avoided in certain cultures, and dementia is not always recognized as a medical condition. As a result, it may be difficult for people to express their feelings, experiences and perspectives in such a way that they can be taken into consideration in culturally sensitive and person-centred healthcare.

Furthermore, our results indicate a rather one-sided and negative outlook on dementia, with metaphors such as ‘DEMENTIA IS GOING BACKWARDS’ and an emphasis on persons with dementia as ‘childlike’ or ‘crazy’. These observations relate to other Dutch studies into experiences with dementia in culturally diverse populations (Ahmad et al., 2020; van Wijngaarden et al., 2018, 2019). On the one hand these studies show that these disruptive, ambiguous experiences are shaped by negative social imageries of dementia as an abject and fearful disease (van Wijngaarden et al., 2019; Zeilig, 2014). On the other hand this implies that individually adapting to the circumstances of living with dementia depends on the recognition from the wider social environment and should be considered a social-ecological enterprise (Ahmad et al., 2020; van Wijngaarden et al., 2018). This is complemented by a recent metasynthesis (Gorska et al., 2018), emphasizing that the experience of living with dementia emerges from a transactional relationship between ‘living with change’, ‘striving for continuity’, and the both positive and negative ‘impact of the social environment’.

These observations underscore the importance of a broader perspective on dementia. A small, biomedical perspective seems insufficient to meet the large variety of issues inherent to the complexities of this disease (Winblad et al., 2016). Dutch dementia research for example has a strong focus on techno-fixing dementia, surrounded by societal and political hopes and promises that consider dementia as a solvable biomedical puzzle (Winblad et al., 2016). Techno-fixes are understood as interventions that centre around organismic aspects of a disease and try to cure it from inside, with a pharmaceutical or high-tech intervention or device (Jongsma and Sand, 2017). Such a small biomedical outlook on dementia seems reductionist and provides a narrow understanding of the condition, also influencing the policy and research agenda's and societal narratives on dementia. Zeilig notes that public perception of dementia is highly influenced by biomedical assumptions and emotional responses to dementia (Zeilig, 2014). Cultural stories of dementia are interwoven with metaphors such as a ‘monstrous force that we must fight’ and ‘silent tsunami’ and present persons with dementia generally as ‘victims’ (Kövecses, 2005; Zeilig, 2014).

Several recently developed approaches to dementia try to overcome the primarily biomedical and emotionally charged representations of dementia. For example by understanding dementia from a social health approach (de Vugt & Dröes, 2017; Vernooij-Dassen & Jeon, 2016), which attempts to develop a more balanced view of dementia focusing on the potential of persons with dementia and their participation in social life. Another broader approach suggests that dementia may best be thought of as an ecology that arises from the interaction between neuropathological change, and human relations, language and meaning (Chapman et al., 2019). Both in The Netherlands and in the UK, Alzheimer Societies have taken up these broader approaches and developed programmes to promote and stimulate dementia friendly communities to create a more inclusive society for people with dementia (Alzheimer's Society, 2023; Alzheimer Nederland and Ministerie van VWS, 2023). Furthermore, people with dementia themselves initiated several advocacy groups (e.g. Dementia Advocacy and Support Network International, DASNI) which aim to assert empowerment for people with dementia and improve their quality of life (Weetch et al., 2021). Our results suggest, however, that in extension to these broader perspectives and societal initiatives there is yet a lack of extensively available sophisticated (metaphorical) language to consider these perspectives in daily life with persons with dementia.

A lot of research on metaphor in health communication has focused on whether metaphors, especially WAR and MACHINE metaphors, are inherently harmful in medical practice and should be avoided or substituted by alternative metaphors, such as JOURNEY metaphors (e.g. (Annas, 1995; Nie et al., 2016; Shalev, 2018; Smith, 1992; Sontag, 1978)). On the other hand, other studies have shown that while WAR metaphors may be harmful to some patients, others use them in empowering ways (e.g. (Gustafsson et al., 2019; Magaña, 2020; Semino et al., 2016)). Yet one noticeable outcome of our current focus on other languages than English has been that all of the most commonly identified metaphors in medicine appear to be virtually absent, even though previous studies on dementia discourse using English data did find them (e.g. (Castaño, 2020; Zimmermann, 2017)). There is thus a clear need to investigate how the use of such metaphors varies across languages and cultures and how this variation impacts on medical practice, on societal and institutional care approaches, and how it influences the general positioning of elderly people. Experiments have shown that people are not consciously aware that metaphors influence their reasoning in complex situations (e.g. (Thibodeau & Boroditsky, 2011)). We argue that understanding the linguistic and cultural embeddedness of such metaphors will therefore help medical practitioners understand why particular metaphors are preferred or avoided in specific contexts and will as such foster clinical empathy.

4.1. *Strengths and limitations*

Our study benefited from a unique and varied sample representing the main MEM groups in the Netherlands. A systematic and rigorous analysis approach – MIPVU – focusing on metaphor use in natural communication provided new insights into participants' thoughts and experiences. Credibility and transferability were enhanced by employing native speaker interviewers and recruiting participants through key persons with strong community ties, increasing the depth of experience shared by the participants. Limitations to our study include the single national context, and the involvement of many different researchers, possibly endangering the dependability of our findings. The main research team (authors) consisted of native Dutch persons, not proficient in any of the non-Dutch languages spoken by participants. This may have hampered our findings in two ways: we were unable to assess the results before translation and our positionality as non-MEM persons may have negatively influenced the credibility of our interpretations. Finally, we resorted to a proxy perspective on our main interest – the lifeworld of persons with dementia – by including informal caregivers rather than persons with dementia themselves.

4.2. Implications

Although the current dataset is limited, we feel this is an important issue that warrants further investigation into which behaviour is labelled as being childlike or insane in different cultural contexts and which behaviour caregivers recommend in response: should people with dementia who are nagging, running away, throwing tantrums, or imagining things be corrected, punished, nurtured or simply ignored? Which metaphor is selected may play a crucial role in framing how we evaluate and respond to this behaviour. As such, these metaphors may have serious repercussions on how healthcare professionals, informal caregivers and society in general assess a person with dementia's right and ability to think and act independently. There is a clear need to address the taboo, stigma and lack of medical knowledge surrounding dementia in these MEM groups and to carry out more cross-linguistic and cross-cultural research to explore which metaphors aid understanding and lead to the empowerment and restoration of self-worth of people with dementia.

Privacy statement

We conform all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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Declaration of competing interest

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Appendix A. Supplementary data

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