

# Illness representations of dementia: a scoping review

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Shiri Shinan-Altman<sup>1</sup>  
Perla Werner<sup>2</sup>

<sup>1</sup>The Louis and Gabi Weisfeld School of Social Work, Faculty of Social Sciences, Bar Ilan University, Ramat Gan, Israel; <sup>2</sup>Department of Community Mental Health, University of Haifa, Haifa, Israel

**Abstract:** As the number of persons with dementia grows, an increasing number of families, professionals, and laypersons will come into contact with persons with cognitive deterioration. Assessing dementia illness representations (IRs) among these groups may have great importance for understanding their responses to dementia. The purpose of this study was to summarize and critically review the literature on dementia IRs. A total of 25 articles that satisfied the inclusion criteria were identified. The review revealed that conceptually, research attention on dementia IRs has increased over the past several years as a result of changes in the notion of IRs and in the dementia discourse. Regardless of the population examined, dementia was mostly described as a chronic condition, presenting more cognitive than behavioral symptoms, and as being caused mainly by age, heredity, and abnormal brain changes. Methodologically, the area of dementia IRs is characterized by design, sample, and data collection weaknesses. Findings suggest that although the literature in the area of dementia and IRs is increasing, several conceptual and methodological limitations still have to be resolved in order to advance knowledge in the area. The research and clinical implications of these findings stress the importance of IRs in the area of dementia.

**Keywords:** dementia, illness representations, scoping review

## Introduction

The Self-Regulation Model (SRM)<sup>1</sup> is an empirically validated model for understanding beliefs and coping processes related to illness. The model describes the ways in which individuals perceive illness (cognitive illness representations [IRs]) and react to it emotionally (emotional representations). Cognitive IRs consist of seven dimensions of subjective beliefs about the illness<sup>2</sup>: Identity – perceptions of symptoms; Causes – the perceived causes of the symptoms; Timeline – beliefs about the course of the illness; Consequences – the perceived impact of the illness; Control – the perceived ability to control the illness; Illness coherence – the extent to which patients perceive that they understand the illness and its implications; and Cyclical timeline – beliefs about the temporal changeability of the illness. Emotional representations refer to the production of emotional responses to the disease, such as worry and anxiety.<sup>2</sup> Overall, it has been shown that intervention programs, mapping and challenging maladaptive IRs, while at the same time forming alternative representations, can change both IRs and functioning, leading to improved psychosocial outcomes.<sup>3</sup> Indeed, IRs have received considerable attention in the literature over the past several years in relation to a variety of diseases, such as cancer and chronic pain.<sup>3,4</sup> However, surprisingly, only few studies have examined the concept in the area of dementia.

Dementia is an umbrella term encompassing a variety of diseases characterized by cognitive deterioration, with Alzheimer disease (AD) being the most common

Correspondence: Shiri Shinan-Altman  
The Louis and Gabi Weisfeld School of Social Work, Faculty of Social Sciences, Bar Ilan University, Max and Anna Web Street, Ramat-Gan 52900, Israel  
Tel +972 3 531 7806  
Fax +972 3 738 4042  
Email shiri.altman@biu.ac.il

type of dementia.<sup>5</sup> Accordingly, AD and other dementias are characterized by decline from a previously attained level of cognitive functioning.<sup>5</sup> Over time, these cognitive changes compromise the person's ability to manage everyday activities, leading to increased levels of dependency on those around them.<sup>6</sup> Overall, studies examining the prevalence of dementia consistently show a remarkable increase over time in the number of persons affected,<sup>7</sup> as well as in the costs of health care provided to persons with dementia and their caregivers.<sup>8</sup> Moreover, lately increased attention is being paid to the prevention of dementia through the involvement in health behaviors aimed at decreasing and managing risk factors associated with its development.<sup>9</sup> Given these developments and in light of the accumulated knowledge regarding other diseases and the associations between IRs and health behavior,<sup>10,11</sup> it is surprising that up until now the topic has not been widely examined in relation to dementia.

To address this gap, we performed a scoping review, a method widely used to understand and summarize knowledge about complex concepts.<sup>12</sup> This type of review provides a preliminary assessment of the potential size and scope of available research literature. It aims to identify the nature and extent of research evidence.<sup>13</sup> Using this method, we will attempt to understand the development of the concept of IRs in the area of dementia, paying specific attention to conceptual, methodological, and clinical aspects. We hope this review will provide the basis for directing future research on this important subject.

## Method

### Search strategy

A computer-based literature search was performed to identify publications on the topic of dementia (including neurocognitive disorders, dementia, AD, mild cognitive impairment (MCI), cognitive deterioration, and cognitive decline) and IRs from inception up until November 2018. PubMed, PsycINFO, and CINHALL databases were chosen for the search, as they contain publications that cater to a wide range of health conditions including dementia. In an attempt to locate "gray literature," additional searches were conducted through Google Scholar.

The following search terms were used: ("illness representation\*" OR "self regulation model" OR "illness cognition" OR "illness perception\*") AND ("neurocognitive disorder\*" OR "Alzheimer\*" OR "dementia" OR "mild cognitive impairment" OR "cognitive deterioration" OR "cognitive decline").

The search was restricted to publications in the English language on human subjects and was supplemented by the

manual searching of reference lists. Two researchers independently reviewed the titles and abstracts of the identified articles. Articles that appeared to meet the inclusion criteria were read in full.

### Inclusion and exclusion criteria

Studies that identified the key terms in the title, abstract, or MeSH heading were retained. Inclusion criteria were studies that applied IRs to dementia, articles written in English, and articles published in peer-reviewed journals. Articles were excluded if they were not written in English or were published as book chapters, comments, or dissertations.

### Data extraction and analysis

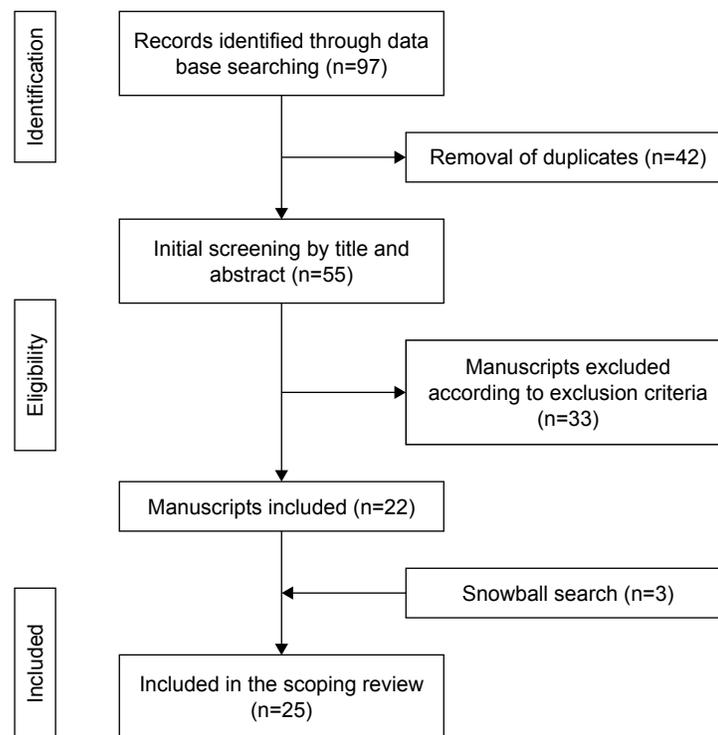
Search results for all databases were merged. Duplicates and nonrelated papers were excluded. Titles and abstracts of the remaining papers were assessed against the inclusion and exclusion criteria independently by both authors. The resulting papers were pooled, and disagreements were resolved through discussion based on the full text article. A standardized form was used to summarize the content of each article. The variables extracted were reference/country, aim of the study, study design, participants, and main finding/results.

## Results

Figure 1 demonstrates the study flow chart according to PRISMA guidelines.<sup>14</sup> The PRISMA diagram maps the flow of information through the various review stages. The diagram outlines the number of articles retrieved, number of articles kept for full review, number of articles excluded, reasons for exclusion, and number of articles kept for analysis. A total of 97 records were retrieved into an endnote library from the three data sets searched. Of these, 55 records remained after the removal of duplicates. Four additional records were obtained through Google Scholar search of already identified articles. Details concerning study flow and reasons for exclusion are shown in Figure 1. Table 1 summarizes the extracted information regarding: country, study aims, study design, year of publication, participants, and main findings. Several interesting findings emerge from the table in terms of the chronological and conceptual development of this area of research, as well as regarding its methodological aspects.

### Chronological development of research in the area of IRs and dementia

The bulk of research in the field of dementia IRs was gradually developed over the last two decades. The first two studies



**Figure 1** Study selection flow diagram.

were published in 2000 and 2003 and were conducted among children and siblings of people with AD and among the lay public. The four subsequent studies, published in 2006, were all conducted among people with MCI or in the early stages of dementia.<sup>15–18</sup>

## Conceptual aspects of IRs of dementia

Overall, the IR dimensions examined in most previous studies were identity, causes, cure/control, consequences, timeline (chronic/acute/cyclical), coherence, and emotional representations. Four studies<sup>19–22</sup> assessed other dimensions such as preventability, responsibility, and social comparison.

Studies assessing people with dementia showed that they are more likely to use descriptive terms such as “memory decline” and “confusion” to refer to their condition than diagnostic terms such as “Alzheimer disease.” People with dementia may attribute the cause of their condition to one of a diverse range of factors (eg, aging, heredity, abnormal brain changes) and may identify multiple consequences of having the condition (such as familial and financial).<sup>15,16,23–25</sup> In terms of timeline and control, people with dementia believed that dementia is a chronic condition,<sup>15,16,24–28</sup> while some perceived dementia as uncontrollable condition.<sup>16,20,26</sup>

Studies concentrating on family caregivers found that they mentioned memory decline and confusion with time

and place as symptoms of dementia. The causes of dementia, according to family caregivers, included biological hereditary, aging, and lifestyle factors.<sup>21,29,30</sup> Some viewed dementia as having serious consequences,<sup>21</sup> while the findings regarding the ability to control dementia were not uniform.<sup>22,29</sup> Studies assessing formal caregivers showed that they also mentioned memory decline and confusion with time and place as symptoms of dementia. Formal caregivers perceived dementia as a chronic disease associated with severe consequences, while the main causes of dementia stem from risk factors followed by psychological factors.<sup>31,32</sup> Finally, it was found that among the lay public, cognitive deficits were more readily identified as dementia than noncognitive symptoms.<sup>33,34</sup> In addition, the lay public believed that the main causes of dementia stem from risk factors, followed by psychological factors. They perceived dementia as being chronic with serious consequences, and as a disease that is not controllable, but moderately dependent on treatment effectiveness.<sup>35</sup>

It should be noted that little work has been carried out to examine dementia IRs among different ethnic groups.<sup>19,36</sup> The findings of these studies suggest that despite a potential shift in dementia IRs such as the believing that early recognition of MCI is beneficial, there are still misconceptions in regard to dementia among minority ethnic groups, such as believing

Table 1 Reviews of papers on IRs of dementia

Reference/year/ country	Aims	Study design	Participants	Findings/results
Anderson et al, 2011/USA <sup>37</sup>	Study 1: To compare common-sense beliefs about the prevention of AD held by older and younger adults, and the connections between such beliefs and reports of preventative behaviors. Study 2: To manipulate young adults' beliefs about AD preventability in order to determine causal relationships in the data	Quantitative; using vignette methodology	Study 1: 57 community-dwelling adults; mean age = 74 years; 82 students; mean age = 20 years. Study 2: 63 young adults who completed study 1	In study 1, it was found that compared with younger adults, older adults perceived themselves as less at risk, were more likely to believe that AD is preventable, and were more likely to report engaging in behaviors to prevent AD. Manipulating beliefs in Study 2 caused those who said that AD was preventable to see themselves as less at risk, report more prevention behaviors, and hold those with the disease more responsible for their fate.
Clare et al, 2016/UK <sup>24</sup>	To clarify the nature and implications of the IRs held by people with dementia using constructs from the SRM	Qualitative; semistructured interviews and quantitative; with questionnaires	Sixty-four people with dementia; mean age = 78.41 years; 64 primary caregivers; mean age = 66.48 years	Cluster analysis based on responses about identity and cause identified three profiles. "Illness" cluster participants perceived themselves as living with an illness and used diagnostic labels; "aging" cluster participants did not use diagnostic labels and viewed their difficulties as related to aging; and "no problem" cluster participants believed they did not have any difficulties. "Illness" cluster participants had better cognition and better awareness, but lower mood, and perceived more practical consequences than "aging" cluster participants.
Clare et al, 2006/UK <sup>15</sup>	To explore the way in which people who have received a diagnosis of dementia conceptualize their condition and its implications	Qualitative; semistructured interviews	Twenty-two people who had a diagnosis of mild-to-moderate AD or mixed dementia; mean age = 73.95 years	Representations covering illness identity, cause, course, cure/control, and consequences were successfully elicited, but diverged from professional constructs in some important respects. Most participants regarded their difficulties as part of normal aging, and one-third viewed their condition as stable or improving. Almost all participants described some positive coping strategies; participants who believed that nothing could be done to help were more likely to score above clinical cutoffs for depression or anxiety.
Giebel et al, 2017/UK <sup>29</sup>	To explore the perceptions of dementia (symptoms, causes, consequences, treatments) held by South Asians and to discern how these understandings vary by age and by the self-recognition of memory problems	Quantitative	Seventy-two younger and middle-aged adults aged 30–59 years; 55 older adults aged 60 years or older without memory problems; 33 older adults aged 60 years or older with subjective memory problems	Although all participants had similar understandings of the common symptoms of dementia (such as forgetting and confusion), perceptions of associated symptoms, causes, consequences, and preferred treatments of dementia varied among South Asians in different circumstances and in different age cohorts.
Glidewell et al, 2012/UK <sup>23</sup>	To explore whether one health care triad (a person with a diagnosis of dementia [PWD], their caregiver and primary care doctor) spoke about diagnosis in terms of IRs and to consider whether PWD IRs are understood	Qualitative; in-depth semistructured interviews	Three participants: person with a diagnosis of dementia (over 60 years old), his nominated informal caregiver (aged 67 years) and his doctor	All participants talked about IRs without prompting, with the exception of cause. There were areas where participants shared IRs, but also areas of discrepancy, which could have implications for health outcomes.
Gleason et al, 2016/USA <sup>19</sup>	To clarify processes promoting timely diagnosis of MCI for African Americans	Quantitative	187 African Americans; mean age = 60.44 years	Two commonsense model (CSM) factors influenced willingness to discuss MCI symptoms with providers. Anticipation of beneficial consequences and perception of low harm associated with an MCI diagnosis predicted a person's willingness to discuss concerns about cognitive changes. No association was found between perceived controllability and causes of MCI and willingness to discuss symptoms with a provider.

<p>Hamilton-West et al, 2010/UK<sup>23</sup></p>	<p>1) To examine the potential utility of the CSM of IRs for understanding lay perceptions of dementia and predicting intentions to seek help in relation to possible signs and symptoms; 2) to develop a measure of dementia-related IRs.</p>	<p>Quantitative; using the vignette methodology</p>	<p>One hundred eighteen undergraduate psychology students; mean age = 20.27 years</p>	<p>Results indicated that cognitive deficits were more readily identified as dementia than noncognitive symptoms; these were commonly attributed to stress or depression. Participants were more likely to indicate an intention to seek professional help if they identified the problem in the vignette as dementia, perceived symptoms as severe, as having serious consequences, and as likely to be permanent, but less likely to do so if they identified the problem as stress or attributed symptoms to psychological causes.</p>
<p>Harman and Clare, 2006/UK<sup>16</sup></p>	<p>To explore IRs and how these related to daily lived experience</p>	<p>Qualitative; semistructured interviews</p>	<p>Nine people who had a diagnosis of early-stage dementia; mean age = 65 years</p>	<p>Two overarching themes emerged: it will get worse, reflecting an understanding of dementia; and I want to be me, reflecting a desire to maintain one's sense of identity. Participants faced a number of personal and interpersonal dilemmas.</p>
<p>Hurt et al, 2012/UK<sup>26</sup></p>	<p>1) To assess differences in IRs, coping styles, and effect between people with SMC who have sought help and those who have not; 2) to determine the relative contribution of these factors to help-seeking; 3) to assess the role of personal experiences of another person with severe memory problems</p>	<p>Quantitative</p>	<p>Ninety-eight people with SMC, among them 60 help-seeking; mean age = 71.6 years and 38 nonhelp-seeking; mean age = 76.1 years</p>	<p>Both groups perceived SMCs to have a chronic timeline and a deteriorating course. Logistic regression revealed illness perceptions including social comparison and causal attributions to predict help-seeking behaviors. More general coping styles did not predict help-seeking.</p>
<p>Hurt et al, 2010/UK<sup>20</sup></p>	<p>1) To investigate whether the dimensions drawn from illness perception CSM provide a valid model of perceptions held by patients with SMCs; 2) to develop a questionnaire to measure these perceptions.</p>	<p>Qualitative and quantitative</p>	<p>Thirty-two participants recruited from a memory clinic and community groups</p>	<p>The dimensions of illness perception measured by the IPQ-Revised were present in participant accounts of SMCs with the exception of timeline cyclical. The adapted measure (IPQ-Memory) showed good validity and reliability.</p>
<p>Lin et al, 2012/USA<sup>28</sup></p>	<p>To describe beliefs about MCI in people diagnosed with the condition and examine the correlates (demographic and health) of those beliefs</p>	<p>Quantitative + cognitive interview</p>	<p>Thirty individuals diagnosed with MCI; mean age = 77 years</p>	<p>Participants correctly identified symptoms related to MCI; generally attributed MCI to aging, heredity, and abnormal brain changes; and believed MCI to be chronic, predictable, and controllable, causing little emotional distress. However, there were no consistent beliefs regarding the negative consequences of MCI or whether MCI was understandable. There were few significant correlates of beliefs. People with MCI are able to report their beliefs about their illness. Participants endorsed an average of seven symptoms that they experienced and believed were related to MCI and an average of seven potential causes of MCI. Participants tended to believe MCI was chronic, not cyclic, and controllable, but they differed in their beliefs about the consequences, understandability, and emotional impact of MCI. Participants used many dementia prevention behaviors and memory aids, some problem-focused and emotion-focused coping strategies, and a few dysfunctional coping strategies. Cluster analysis identified three clusters of beliefs about MCI: "few symptoms and positive beliefs," "moderate symptoms and positive beliefs,"</p>
<p>Lin and Heidrich, 2012/USA<sup>27</sup></p>	<p>1) To describe the IRs of older persons with MCI; 2) to describe how older adults cope with MCI; 3) to examine the relationships between IRs and coping</p>	<p>Quantitative</p>	<p>Sixty-three older adults with MCI; mean age = 81.16 years</p>	<p>Participants correctly identified symptoms related to MCI; generally attributed MCI to aging, heredity, and abnormal brain changes; and believed MCI to be chronic, predictable, and controllable, causing little emotional distress. However, there were no consistent beliefs regarding the negative consequences of MCI or whether MCI was understandable. There were few significant correlates of beliefs. People with MCI are able to report their beliefs about their illness. Participants endorsed an average of seven symptoms that they experienced and believed were related to MCI and an average of seven potential causes of MCI. Participants tended to believe MCI was chronic, not cyclic, and controllable, but they differed in their beliefs about the consequences, understandability, and emotional impact of MCI. Participants used many dementia prevention behaviors and memory aids, some problem-focused and emotion-focused coping strategies, and a few dysfunctional coping strategies. Cluster analysis identified three clusters of beliefs about MCI: "few symptoms and positive beliefs," "moderate symptoms and positive beliefs,"</p>

(Continued)

Table 1 (Continued)

Reference/year/ country	Aims	Study design	Participants	Findings/results
Lingler et al, 2016/USA <sup>21</sup>	To characterize illness perceptions among persons with MCI (PWWMI) and their family care partners, and to examine whether PWWMI's and their family care partners' illness perceptions were associated with their own, as well as the other member of the dyads emotional reactions to MCI	Quantitative	Sixty persons with MCI; mean age = 71 years; 60 family care partners; mean age = 64.2 years	and "many symptoms and negative beliefs." Those in the "many symptoms and negative beliefs" cluster had significantly more negative beliefs about the consequences, unpredictability (cyclic timeline), and emotional impact of MCI than those in the other clusters. Participants in the "few symptoms and positive beliefs" cluster used significantly fewer memory aids, problem-focused coping strategies, emotion-focused coping strategies, and dysfunctional coping than those in the other two clusters. Compared with family members, PWWMI perceived MCI to be less potentially serious and more within their personal control, but dyads otherwise shared similar perceptions of MCI. Among PWWMI, perceived seriousness of the potential consequences of MCI was the only dimension found to be significantly correlated with emotional distress. For family members, increased MCI-related emotional distress was significantly associated with perceptions of MCI as potentially serious, permanent, or confusing. A dyadic analysis showed that MCI-related emotional distress, in both PWWMI and family members, was linked to the PWWMI's perception of the seriousness of MCI. Understanding and coming to terms with the syndrome, or assigning meaning, constituted a fundamental aspect of living with a diagnosis of MCI. This process comprises interrelated emotional and cognitive dimensions. Participants employed a range of positive, neutral, and negative phrasing in order to depict their emotional reactions to receiving a diagnosis. Cognitive representations of MCI included both prognosis-focused and face-value appraisals. Expectations of normal aging, personal experience with dementia, and concurrent health problems were key contextual factors that provided the backdrop against which participants assigned meaning to a diagnosis of MCI. Three main themes emerged indicating that participants were trying to make sense of their AD by comparing it with their previous experience of physical illnesses. All participants acknowledged their diagnosis of AD, but engaged with it in a graded way because of a lack of tangible diagnostic evidence. Participants developed pragmatic emotional responses to their situation. Most of the older people awaiting assessment described their lives as having purpose, meaning, and pleasure for themselves and others. However, these individuals, who later received a diagnosis of dementia, and their family members, perceived dementia as a loss of mind, associated with loss of bodily functions (continence and mobility), and considered that it would negatively affect personal relationships and pleasure. For many, the consequences of dementia
Lingler et al, 2006/USA <sup>17</sup>	To examine the experience of living with and making sense of the diagnosis of MCI from the patient's perspective	Qualitative; in-depth, semistructured interviews	Twelve older adults with amnesic or nonamnesic MCI; mean age = 76 years	
Matchwick et al, 2014/UK <sup>25</sup>	To explore cause and control IRs in older adults with AD	Qualitative; semistructured interviews	Six individuals diagnosed with AD; mean age = 77 years	
Moniz-Cook et al, 2006/UK <sup>18</sup>	To understand the meanings of dementia held by people awaiting assessment at a memory clinic and their families	Qualitative; semistructured interview	Eighty-four persons who underwent assessment at a memory clinic; mean age = 76.7 years and their 84 family members; mean age = 70 years	

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<p>Parveen et al, 2017/UK<sup>36</sup></p>	<p>To explore perceptions of dementia and awareness/use of services among people from British Indian, African and the Caribbean, and East and Central European communities</p>	<p>Discussion groups regarding dementia; awareness-raising road shows; and multiple choice quiz</p>	<p>Sixty-two British Indian, 50 African and Caribbean, and 63 East and Central European</p>	<p>were predicted to be family upset, inactivity, and an inevitable relocation to a care home. Most of the individuals and their family members showed a mutual concern for each other's future well-being. Three main themes are presented: perceptions of dementia, awareness of dementia in the wider family and community, and awareness and use of services. The findings suggest that although groups attributed a biological basis for memory loss, a number of misconceptions prevailed regarding the cause of dementia. Groups also made use of religion, as opposed to medical health care services, as a form of personal and treatment control. Seeking help from health care services was hindered by lack of awareness of services, and culturally specific barriers such as language. The majority of caregivers gave accounts that appeared to endorse a medical/diagnostic label, although many used different terms interchangeably. Caregivers differentiated between direct causes and contributory factors, but the predominant explanation was that dementia had a biological cause. Other perceived causes were hereditary factors, aging, lifestyle, life events, and environmental factors. A limited number of caregivers were able to identify things that people with dementia could do to help manage the condition, while others thought nothing could be done. There were varying views about the efficacy of medication. In terms of timeline, there was considerable uncertainty about how dementia would progress over time. The RADIX demonstrates acceptable psychometric properties and has proven to be a useful measure for exploring people's beliefs about dementia.</p>
<p>Quinn et al, 2017/UK<sup>29</sup></p>	<p>To explore IR components (label, cause, control, and timeline) in caregivers of people with dementia</p>	<p>Qualitative; semistructured interviews</p>	<p>Fifty caregivers of people with dementia; mean age = 66.49 years</p>	<p>Relatives were knowledgeable about AD, had an accurate sense of their disease risk, and endorsed etiologically significant factors as causes. Nonetheless, many participants held misconceptions about AD and what may be unrealistic expectations for future treatment developments. Levels of perceived distress and threat were generally high and associated with the female gender and younger age. AD represented the foremost health concern of approximately one-third of first-degree relatives. African Americans and whites were generally similar in their beliefs about common symptoms, prominent risk factors, and the effectiveness of treatments for AD (although whites expressed greater certainty in these beliefs than African Americans). In comparison with whites, African Americans showed less awareness of facts about AD, reported fewer sources of information, and indicated less perceived threat of the disorder.</p>
<p>Quinn et al, 2018/UK<sup>38</sup></p>	<p>To develop and validate a brief measure called the Representations and Adjustment to Dementia Index (RADIX)</p>	<p>Quantitative and qualitative</p>	<p>Three hundred eighty-five community-dwelling people with mild-to-moderate dementia; mean age = 76.25 years</p>	<p>The RADIX demonstrates acceptable psychometric properties and has proven to be a useful measure for exploring people's beliefs about dementia.</p>
<p>Roberts and Connell, 2000/USA<sup>22</sup></p>	<p>To examine attitudes, beliefs, and experiences regarding AD among patients' first-degree relatives</p>	<p>Quantitative</p>	<p>Two hundred thirty-two children and siblings of people with AD; mean age = 53.5 years</p>	<p>Levels of perceived distress and threat were generally high and associated with the female gender and younger age. AD represented the foremost health concern of approximately one-third of first-degree relatives. African Americans and whites were generally similar in their beliefs about common symptoms, prominent risk factors, and the effectiveness of treatments for AD (although whites expressed greater certainty in these beliefs than African Americans). In comparison with whites, African Americans showed less awareness of facts about AD, reported fewer sources of information, and indicated less perceived threat of the disorder.</p>
<p>Roberts et al, 2003/USA<sup>34</sup></p>	<p>To investigate differences between African Americans and whites in their beliefs, knowledge, and information sources regarding AD</p>	<p>Quantitative</p>	<p>Four hundred fifty-two white and African American; mean age = 47 years</p>	<p>Levels of perceived distress and threat were generally high and associated with the female gender and younger age. AD represented the foremost health concern of approximately one-third of first-degree relatives. African Americans and whites were generally similar in their beliefs about common symptoms, prominent risk factors, and the effectiveness of treatments for AD (although whites expressed greater certainty in these beliefs than African Americans). In comparison with whites, African Americans showed less awareness of facts about AD, reported fewer sources of information, and indicated less perceived threat of the disorder.</p>

(Continued)

Table 1 (Continued)

Reference/year/ country	Aims	Study design	Participants	Findings/results
Shinan-Altman et al, 2014/Israel <sup>31</sup>	To examine and compare AD IRs among social workers and nurses	Quantitative	One hundred twenty-two social workers and 205 nurses; mean age in both groups = 41 years	Participants perceived AD as a chronic disease associated with severe consequences. Nurses attributed more psychological reasons to AD than social workers. Nevertheless, social workers perceived AD as being more chronic and having more severe consequences compared with nurses. Despite some similarities, differences were found between the social workers and nurses' AD IRs.
Shinan-Altman et al, 2016/Israel <sup>32</sup>	To examine the relationship between AD IRs and burnout among social workers and nurses, based on the self-regulatory model	Quantitative and qualitative	In the quantitative method, 327 social workers and nurses; mean age = 40.83 years. In the qualitative method, eight social workers and nurses; mean age = 41 years	In the quantitative method, emotional representations were associated with burnout, while only some of the cognitive IRs were associated with burnout. In the qualitative method, AD characteristics were perceived as affecting participants on both personal and professional levels; the participants expressed negative feelings toward AD and stated that these perceptions and feelings had led them to burnout. Multiple regression analyses showed that AD consequences and perceived threat were the main predictors of help-seeking for the early detection of AD, explaining 9.2% of the variance.
Shinan-Altman and Werner, 2017/Israel <sup>35</sup>	To examine the relationship between help-seeking for early detection of AD and lay persons' beliefs and emotional reactions toward AD	Quantitative	Two hundred thirty-six community-dwelling adults; mean age = 59 years	
Lo Sterzo and Orgeta, 2017/UK <sup>20</sup>	To describe IRs in dementia caregiving and examine the relationship between illness perceptions and caregivers' sense of coherence	Quantitative	One hundred fifty-five family caregivers of people with dementia, age range: 26–82 years	Regression analyses indicated that after controlling for demographic factors, burden, and psychological distress in caregivers, illness coherence and emotional responses to the disease independently contributed toward explaining variance in caregivers' sense of coherence.

**Abbreviations:** AD, Alzheimer disease; IPQ, Illness Perception Questionnaire; IRs, illness representations; MCI, mild cognitive impairment; SMC, subjective memory complain; SRM, Self-Regulation Model.

that people living with dementia are unhygienic, aggressive, and have the same needs as children.<sup>36</sup>

## Methodological aspects of studies assessing dementia IRs

In this section, we will describe the type of population examined, the methodology, and the assessment instruments that were used.

### Research populations

The majority of studies were conducted among people with dementia (n=13) in the early-moderate stages of the disorder. Five studies assessing family caregivers included spouses/partners, children, siblings, and granddaughter/sister/niece.<sup>21,22,24,29,30</sup> Three of the studies examining formal caregivers assessed physicians, social workers, and nurses.<sup>23,31,32</sup> Finally, seven studies were conducted among students or the lay public.<sup>19,33–38</sup>

### Research methodology

Thirteen studies used quantitative methods (using questionnaires) and seven used qualitative methods (including in-depth, semistructured interviews, vignette methodology, and discussion groups). Five studies used mixed methods, namely, both qualitative and quantitative methods.

### Assessment instruments used to examine dementia IRs

As can be seen in Table 2, most quantitative studies used a revised or brief version of the Illness Perception Questionnaire (IPQ)<sup>2</sup> with adaptations. The most common adaptations referred to the cause dimension, which was measured in some studies with an open item asking for “the three most important factors that you believe cause AD,”<sup>37</sup> while in other studies the cause dimension was measured with a multiple item including different causes such as stress, worry, aging, heredity, and abnormal brain changes.<sup>19,22,27,28,31–33,35,38,39</sup> In addition, six studies<sup>19–22,26,37</sup> used dimensions that are not specifically included in the original IPQ and IPQ-Revised (eg, distress, perceived threat).

The assessment instruments used varied in the number of items they included, from eight items<sup>30</sup> up to 97 items.<sup>27,28</sup> In addition, almost all measures adopted similar scoring systems using five-point Likert-type scales. Regarding the scales' psychometric characteristics, almost all studies examined internal consistency (through Cronbach's alpha), but only four examined validity (concurrent validity, discriminant validity, and face validity).<sup>26,33,38,39</sup>

## Relationship between dementia IRs and outcome variables

It should be noted that given the relatively small number of articles and their heterogeneity, we cannot make concrete predictions about dementia IRs. Moreover, only six of the 25 publications included in this review examined factors associated with IRs. Among these publications, four outcome variables were examined: help-seeking, professional burnout, sense of coherence, and willingness to discuss concerns about cognitive changes. Findings showed that students and the lay public were more likely to indicate an intention to seek help if they perceived dementia as having severe symptoms and consequences, such as permanent damage, with higher perceived coherence.<sup>33,35</sup> Among older adults with subjective memory complaints, it was found that IRs including social comparison and causal attributions predicted help-seeking behavior.<sup>26</sup> Among formal caregivers, emotional representations were significantly associated with professional burnout, namely, the higher the negative emotional representations, the higher the professional burnout.<sup>32</sup> Among carers of people with dementia, perceiving dementia as having severe symptoms and consequences with lower coherence and negative emotional representations were associated with a lower sense of coherence.<sup>30</sup> Finally, significant correlations were found between anticipation of beneficial consequences and willingness to discuss concerns about cognitive changes among the lay public.<sup>19</sup>

## Discussion

As the number of persons with dementia increases because of demographic changes,<sup>40</sup> an increasing number of families, professionals, and laypersons will come into contact with persons with cognitive deterioration. Assessing IRs of these groups may have great importance for understanding their responses to dementia, as has been shown in other diseases.<sup>3,4</sup> The present review intends to advance the current state of knowledge in this area by critically reviewing published literature on the topic. Several conceptual and methodological issues emerged.

## Conceptual issues

### Understanding IRs in the area of dementia

Overall, the study of dementia IRs is still in an early to moderate stage of development, in comparison with other diseases such as cancer, which has been extensively examined among persons with the disease and among other involved parties.<sup>3</sup> However, research attention on the topic has increased over the past several years. This might be the result of two main

Table 2 Assessment instruments of dementia IRs

Assessment	No of items	IR dimensions	Rating scale	Reliability	Validity
Revised IPQ (IPQ-Revised) and the Brief IPQ Anderson et al, 2011 <sup>37</sup>	22	Controllability, controllable causes, uncontrollable causes, controllable risk factors, uncontrollable risk factors	1= strongly disagree to 5= strongly agree	Cronbach's alpha =0.79	–
Revised IPQ (IPQ-Revised) Shinan-Altman and Werner, 2017, <sup>35</sup> Shinan-Altman et al, 2014, 2016 <sup>31,32</sup>	68	Identity, causes, timeline, consequences, control, coherence, cyclical, timeline, and emotional representations	For the identity dimension: 0= no, 1= yes; for the other dimensions: 1= strongly disagree to 5= strongly agree	Cronbach's alpha ranged from 0.65 to 0.90	–
Brief IPQ Lo Sterzo and Orgeta, 2017 <sup>30</sup>	8	Consequences, timeline, personal control, treatment control, identity, concern, emotional representations, and coherence	0–10 varies	–	–
Revised IPQ (IPQ-Revised) Lingler et al, 2016 <sup>11</sup>	32	Timeline chronic, seriousness, personal control, coherence, timeline cyclical, and emotional upset	Five-point Likert scale from strongly disagree to strongly agree	Cronbach's alpha ranged from 0.82 to 0.90	–
IPQ-Memory Hurt et al, 2010, 2012 <sup>20,26</sup>	85	Identity, timeline (acute/chronic), timeline (stability/decline), personal control (blame), personal control (helplessness), consequences, emotional representation, coherence, treatment control, social comparison, and cause	For the identity dimension: 0= no, 1= yes; for the other dimensions: 1= strongly disagree to 5= strongly agree	Cronbach's alpha ranged from 0.68 to 0.89	Concurrent validity; discriminant validity
IPQ-MCI Lin and Heidrich, 2012, <sup>27</sup> Lin et al, 2012 <sup>28</sup>	97	Identity, causes, consequences, chronic timeline, cyclic timeline, personal control, treatment control, and coherence	For the identity and cause dimensions: 0= no, 1= yes; for the other dimensions: 1= strongly disagree to 5= strongly agree	Cronbach's alpha ranged from 0.76 to 0.90	–
IPQ and questions adapted from the Barts Explanatory Model Interview (BEMI) Hamilton-West et al, 2010 <sup>33</sup>	13 items for causes	Causes, timeline, consequence, identity, and Cure-control	Seven-point Likert scale, high scores indicating greater agreement (expect the timeline dimension)	Cronbach's alpha ranged from 0.74 to 0.87	Face validity
Barts Explanatory Model Inventory for dementia (BEMI-D) Giebel et al, 2017 <sup>9</sup>	197 perceptions	Symptoms, causes, consequences, and treatments	Varies	–	Face valid
A description of the MCI diagnosis followed by survey questions Gleason et al, 2016 <sup>19</sup>	54	Causes of MCI; consequences of MCI – potential harm; consequences of MCI – potential benefits; controllability of MCI	Four-point, bidirectional Likert scale, ranging from 1 (definitely no or strong disagreement) to 4 (definitely yes or strong agreement)	Cronbach's alpha ranged from 0.71 to 0.96	–
IPQ with adaptations Roberts and Connell, 2000 <sup>22</sup>	27	Cause, treatment beliefs, distress, and perceived threat	Varies	Cronbach's alpha ranged from 0.63 to 0.88	–
Representations and Adjustment to Dementia Index (RADIX) Quinn et al, 2018 <sup>38</sup>	23	Identity, cause, timeline, control, and consequences	The identity and cause questions were open-ended; timeline, control, and consequences were rated on a four-point Likert scale	Cronbach's alpha $\geq$ 0.70/test-retest	Each subscale was validated separately

**Abbreviations:** IPQ, Illness Perception Questionnaire; IRs, illness representations; MCI, mild cognitive impairment.

reasons: one is related to the concept of IRs and the other to changes in the dementia discourse.

### The concept of IRs

IRs were traditionally conceptualized to examine illness perceptions among persons with a disease.<sup>1</sup> As such, their implementation with persons with dementia was limited, especially among those in the advanced stages, when cognitive deterioration affects the individual's ability to accurately communicate his/her experiences of the disease. Lately, the contribution of IRs has expanded to include healthy populations.<sup>41–43</sup> Thus, 12 of the 25 publications included in this review were conducted among nonaffected samples. This is an important development, as it enables a deeper understanding of the disease among lay persons. Moreover, this information might provide the necessary foundation and guidance for the development of educational programs to raise awareness and knowledge about dementia, to reduce misconceptions, and to increase timely help-seeking.

### The dementia discourse

For many years, the popular understanding of dementia was based primarily on a medical model, which almost exclusively addressed the clinical aspects of cognitive deterioration.<sup>44</sup> Lately, however, dementia discourse has been undergoing changes, and the implementation of a social model, which enables hearing the voices of the persons with the disease,<sup>45</sup> is now encouraged. Thus, in recent years, literature has emerged, which acknowledges the individual's experience, rights, and perspective. This literature expands our sense of dementia beyond neurobiology and neuropsychology and includes the person's experience.<sup>46,47</sup> This shift is reflected in the development of the literature reviewed here. Indeed, starting in 2006, we observed an increase in the number of studies examining IRs of persons with dementia in the early stages of the disease, using mostly qualitative methods, which voiced participants' personal perceptions and experiences.

### IRs' dimensions in the area of dementia

Overall, similar to other diseases,<sup>48</sup> previous studies in the area of dementia have concentrated on assessing the most traditional dimensions of IRs, with the most consistent findings emerging for identity, causes, timeline, consequences, and control. Regardless of the population examined, dementia is mostly described in the reviewed papers as a chronic condition, presenting more cognitive than behavioral symptoms, and as being caused mainly by age, heredity, abnormal brain changes, and stress or worry.

Examination of the studies in this review showed that, regardless of the type of participants included, memory decline and confusion with time and place were correctly identified as dementia symptoms. Similarly, beliefs of dementia as a chronic condition were consistent across studies. The most frequently endorsed causes of dementia were aging, heredity, abnormal brain changes, and stress or worry.

While overall, these perceptions are congruent with the clinical characteristics of dementia,<sup>49</sup> it should be noted that perceiving dementia as a terminal illness may have a major impact on expectations, treatments, attitudes, and help-seeking. Furthermore, concentrating mostly on cognitive symptoms might suggest that there is not enough available knowledge,<sup>50</sup> underscoring the importance of the latest efforts invested worldwide to increase knowledge and awareness about dementia.<sup>51</sup>

### Assessing correlates of IRs

It should be noted that research in the area of dementia and IRs is mostly descriptive, and only few studies have examined correlates of IRs. Three studies found an association between IRs and help-seeking.<sup>26,33,35</sup> This is a significant finding for two reasons. First, the association between IRs and help-seeking is at the core of the commonsense model<sup>52</sup> and demonstrates the suitability of this model in the area of dementia. Second, it suggests that subjective perceptions of dementia, together with the objective nature of symptoms, are important factors in the help-seeking process.<sup>53</sup>

However, a closer examination of the findings about IRs and help-seeking showed that the worse the disease is perceived, the more people seek help. This finding is worrisome, since it indicates that people seek help only when cognitive deterioration is perceived as reaching the more advanced stages. Several possible explanations have been offered for this delay, such as that the symptoms of dementia can be difficult to recognize in their early stages,<sup>54</sup> attribution of memory problems to normal aging,<sup>55</sup> stigma, and embarrassment.<sup>56</sup> Yet, it should be noted that therapeutic interventions are increasingly recognized as being most efficient in the early stages and that seeking help in the early stages of dementia allows optimal medical management to delay progression.<sup>57</sup> Therefore, educational programs should take into consideration the connections between IRs and help-seeking, in order to advance help-seeking in an appropriate and timely manner.

### Methodological issues

As stated, research about IRs and dementia is gradually conceptually evolving. However, our review of the literature

shows that, methodologically, it is characterized by design, sample, and data collection weaknesses, which need to be addressed.

### Sample issues

Regardless of the type of population examined, the majority of the studies in the review were based on nonrepresentative and small samples.<sup>15–17,19,20,24,25,28,31–35,37</sup>

To advance the existing knowledge and be able to generalize and draw conclusions, there is a need to start conducting large-scale studies based on representative samples, which will allow the examination of IRs among different populations, as has been done in regard to other diseases.<sup>58</sup>

### Design issues

According to the current review, all studies examining dementia IRs until today were cross-sectional, therefore limiting the possibility of assessing changes in dementia IRs across time, as has been done with regard to other diseases.<sup>4,59</sup> This is an important limitation, especially since, as noted by Leventhal et al,<sup>1</sup> IRs do not remain static but are rather dynamic – formed and changed through active processing. In the case of dementia, a progressive disease involving cognitive deterioration<sup>6</sup> examining changes across time might be especially important.

### Data collection issues

Two main issues associated with data collection arise from examining the body of knowledge on dementia IRs accumulated until today: the first relates to the type of data collection used, and the second to the instruments used.

The current understanding of dementia IRs is based mainly on quantitative methodology. Indeed, only eight studies included in this review were qualitative, while another four used a mixed methods methodology. Two reasons might explain this tendency: first, as mentioned above, the use of qualitative methods to assess IRs of persons with dementia has increased lately, as a result of the change in the dementia discourse.<sup>45</sup> Second, the availability of a valid structured instrument, such as the IPQ, facilitates the use of quantitative methodologies. And indeed, overall, most previous studies exploring dementia IRs were based on detailed descriptions of modifications of the IPQ and the IPQ-Revised. Thus, these modifications are consistent with the recommendations of Weinman et al<sup>60</sup> and Moss-Morris et al,<sup>2</sup> who argued that users can adapt the IPQ and IPQ-Revised to be illness specific. However, it should be noted that the IPQ is limited, given that people with moderate to severe dementia may be unable to complete it.

In addition, the qualitative components of the mixed methods studies offered an opportunity for a deeper examination of IRs. Information from the qualitative interviews was also utilized to adapt the IPQ-R specific population (eg, patients with subjective memory complain).<sup>20</sup> Furthermore, the qualitative research findings revealed that participants nurtured additional perceptions and feelings regarding dementia that they could not express through the structured questionnaires. Therefore, one of the conclusions of the mixed methods studies was to expand the IPQ by adding some open questions in order to receive more information about IRs, which cannot be expressed by the closed questionnaire.<sup>24,32</sup>

### Limitations of the review

The present review has two main limitations. First, despite making every attempt to include the relevant literature, we cannot disregard the possibility that some studies may not have been identified. This is an inherent limitation of a review paper which, in an effort to be specific, is prone to not including all studies of importance. Second, information was synthesized and reported in summary tables, but no statistical techniques were used to assess methodological issues, such as sample size. However, it should be noted that this review was not intended to be an exhaustive review of the literature in the area, but rather to focus readers' attention on conceptual and methodological developments and their impact for future research and for clinical interventions.

### Future research

Our examination of the current body of knowledge in the area of dementia IRs revealed several promising lines of inquiry for future investigations. Some relate to conceptual aspects and others to methodological aspects.

Conceptually, one of the areas in need of further attention is the examination of dementia IRs among different ethnic groups. This is especially important since, according to Leventhal and Ian,<sup>61</sup> cultural factors influence individuals' IRs. Furthermore, recent studies recognize ethno-racial differences in the prevalence and incidence of dementia,<sup>62</sup> stressing the importance of developing this direction. In addition, it is suggested that future studies would examine IRs among young people with dementia and their surrounding (eg, family members, formal caregivers). This is especially important as alertness for dementia in young patients (before the age of 65 years) is increasing.<sup>63</sup>

Methodologically, additional research with more representative samples and more fully validated measures are necessary in order to further explore and detail racial and

ethnic differences in dementia IRs. In addition, this review revealed that the majority of studies were cross-sectional, which may hinder the ability to understand the dynamic nature of dementia IRs. Therefore, as suggested in the area of IRs and mental health,<sup>48</sup> longitudinal and intervention studies are required to show the influence of interventions aimed at challenging negative illness perceptions and exploring how this impacts upon clinical outcomes. These designs will also allow exploration of how illness perceptions may change over time. For example, a study following individuals throughout a lifetime would be an interesting one. Moreover, the development and validation of standardized measures to examining dementia IRs are imperative.

## Clinical implications

Advancing these conceptual and methodological issues will promote the development of more effective clinical interventions. Indeed, the study of IRs in other areas has suggested that to improve health and psychosocial outcomes, it may be beneficial for interventions to target individuals' maladaptive or unrealistic IRs, while at the same time forming alternative representations.<sup>3,48</sup> The time has come to advance this knowledge in the area of dementia as well.

Special attention should be paid to perceptions of personal control, which might be useful to increase the use of adaptive coping strategies such as cognitive reappraisal and reduce maladaptive coping strategies such as avoidance or denial.<sup>3</sup> In the same vein, a systematic review of the literature exploring IRs in mental health utilizing the SRM has found that perceptions of personal control over one's illness and beliefs that treatment can help control symptoms were associated with greater engagement with services, treatment adherence, a reduction in symptoms, and less emotional distress.<sup>48</sup>

In addition, interventions that aim to decrease the perceived emotional impact of AD may reduce psychological distress and may improve one's quality of life. However, it should be noted that in interventions targeting IRs, it is important to hold in mind that some IRs about poor illness outcomes may be realistic; for a family member of a relative with advanced AD, representations of a chronic timeline and severe consequences may be justified. In these cases, interventions could better target IRs such as emotional representations in order to allow ventilation of the emotional distress.

To sum up, this review indicates that despite important advances, gaps in the theoretical and methodological issues of dementia IRs remain. We have tried to identify these gaps and provide suggestions for further advancing this area of knowledge. Nevertheless, the 25 reviewed studies have provided valuable insight into the significant meaning of

IRs in the area of dementia, offering valuable implications for clinical practice.

## Disclosure

The authors report no conflicts of interest in this work.

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