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## Caregivers' beliefs about dementia: findings from the IDEAL study

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IDEAL Study Team

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### ABSTRACT

**Objective:** Informal caregivers of people with dementia develop their own beliefs about the condition, referred to as Dementia Representations (DRs), as they try to make sense of the changes they are observing. The first aim of this study was to provide a profile of the types of DRs held by caregivers. The second aim was to examine the impact of caregivers' DRs on their well-being, satisfaction with life (SwL) and caregiving stress.

**Methods:** Participants were 1264 informal caregivers of people in the mild-to-moderate stages of dementia from time-point 1 of the IDEAL cohort study.

**Measures:** DRs were measured using questionnaire items covering: Identity, Cause, Control, and Timeline.

**Results:** Almost half (49.2%) of caregivers used a diagnostic term to describe the person's condition, although 93.4% of caregivers stated they were aware of the diagnosis. Higher well-being, SwL, and lower caregiving stress were associated with the use of an identity term relating to specific symptoms of dementia, attributing the cause to ageing or not knowing the cause, and believing the condition would stay the same. Lower well-being, SwL, and higher caregiving stress were associated with believing there was little that could be done to control the effects of the condition.

**Conclusion:** Healthcare professionals should assess and gain an understanding of caregivers' DRs in order to provide more tailored information and support.

### ARTICLE HISTORY

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### KEYWORDS

Caregiver; Common Sense Model; dementia; diagnosis; illness representation

Informal caregivers have a major role in supporting people with dementia; worldwide 40.4% of the costs of dementia can be attributed to informal care (Prince et al., 2015). The importance of providing support for caregivers has been recognised in both

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policy and practice (e.g. Alzheimer's Association, 2017; National Institute for Health and Care Excellence, 2018). One recommendation is that healthcare professionals offer educational and skills training to caregivers to help them understand dementia and the person's behaviour (National Institute for Health and Care Excellence, 2018). To provide such help, it is important to consider caregivers' underlying beliefs about dementia as these may influence how they process the information. Caregivers are often the first to notice the early signs of dementia and can be instrumental in obtaining a diagnosis (Bunn et al., 2012). During this period, caregivers will be developing their own beliefs about the causes of these changes, which may persist even after diagnosis (Scodellaro & Pin, 2013). These beliefs may have implications for caregivers' own adjustment and well-being. The aim of this study was to explore caregivers' beliefs about dementia and the influence of these beliefs on their well-being, satisfaction with life (SwL), and caregiving stress.

A person's beliefs about illness or disease can be influenced by many factors. The Common Sense Model (CSM) was developed as a means of explaining how people try to make sense of symptoms (Diefenbach & Leventhal, 1996). This explanatory model incorporates cognitive processes, which involve the person attempting to make sense of observed symptoms by assimilating information from a wide range of sources (Diefenbach & Leventhal, 1996). Through this process, the person creates mental representations of the illness, referred to as 'illness representations' (IRs), which consist of five components. The first is 'identity', which is the term the person assigns to the illness. The other components consist of beliefs about cause, cure/control, timeline (duration of the illness), and consequences (Hagger & Orbell, 2003). IRs are not considered to be static and can be influenced by the person receiving new information, such as a diagnosis. In the CSM, how people interpret symptoms will guide their subsequent reactions, influencing coping strategies and help-seeking behaviour (Hagger & Orbell, 2003). The CSM has been utilised in a wide range of health conditions, with studies reporting associations between IRs and outcomes such as well-being and coping responses (Hagger & Orbell, 2003).

The CSM could be a useful model for exploring the beliefs held by caregivers of people with dementia. Studies involving caregivers or spouses of people in other health conditions have reported that IRs can influence caregivers' coping styles and well-being (e.g. Heijmans, de Ridder, & Bensing, 1999; Lobban, Barrowclough, & Jones, 2005; Rexhaj, Python, Morin, Bonsack, & Favrod, 2013). There has been little exploration of IRs in caregivers of people with dementia. Some studies have explored caregivers' beliefs about dementia (Askham, 1995; Hinton, Franz, Yeo, & Levkoff, 2005; Hinton & Levkoff, 1999; Roberts & Connell, 2000). However, these studies did not use the CSM as a conceptual framework and only a few studies have done so. Both Glidewell, Johnston, and Thomas (2012) and Quinn, Jones, and Clare (2017) have qualitatively explored elements of IRs in caregivers of people with dementia. Glidewell (2012) reported a single case study with the person with dementia, the caregiver and the general practitioner, reporting differences in beliefs. The caregivers in Quinn et al. (2017) attributed the observed changes primarily to changes in the brain. Some felt there were things that people with dementia could do to help manage the condition and others thought nothing could

be done. There was considerable uncertainty about how the condition would progress over time.

Although these qualitative studies provide rich insights into the content of caregivers' IRs, they do not allow for the exploration of how these beliefs influence the caregivers' well-being. To our knowledge, our two studies have utilised quantitative techniques to explore IRs in caregivers/relatives of people with dementia. Using a measure developed for the study, Roberts and Connell (2000) explored the cause and control dimensions of IRs in first-degree relatives of people with Alzheimer's disease. Using the Brief Illness Perception Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006), Lo Sterzo and Orgeta (2017) reported that components of DRs were related to caregiver mood, physical health, and stress. These findings indicate that the CSM can be applied to explore caregivers' beliefs about dementia and how these beliefs are associated with caregiver well-being. However, the existing evidence base is limited. Roberts and Connell (2000) only focused on the cause and control dimensions, and Lo Sterzo and Orgeta (2017) used generic measure of IRs designed to be employed in a variety of health conditions. There are limitations of using generic measures, which has led to the development of more illness-specific IRs measures (e.g. Lobban et al., 2005).

Dementia is very different from many previously studied health conditions using the CSM, particularly as it is not a single clearly defined disease entity, and the exact causal mechanisms are not always clear. Thus, it has been proposed that instead of examining IRs it may be more appropriate to focus on what can be termed 'dementia representations' (DRs; Clare, Quinn, Jones, & Woods, 2016; Quinn, Morris, & Clare, 2018). For instance, measures of IRs explore 'identity' through the number of symptoms endorsed, yet findings from qualitative research exploring DRs in caregivers and people with dementia indicate that it may be more useful to explore the terms they use to describe the condition (Clare et al., 2016; Quinn et al., 2017). This is particularly the case because Quinn et al. (2017) has identified that caregivers tend to use 'identity' terms interchangeably when talking about dementia in a way that suggests they are aware of the diagnosis but prefer to use non-diagnostic terms to describe the condition. Exploring caregivers' DRs would provide an insight into their understanding of the condition and identify areas in which caregivers may require more support to help them better understand dementia. In addition, given the association between IRs and well-being (Hagger & Orbell, 2003), it is also valuable to explore how these beliefs influence caregivers' well-being. In light of the above, the aims of this study were:

1. To provide a profile of the types of DRs held by caregivers of people with dementia.
2. To examine the impact of caregivers' DRs on their well-being, SwL, and caregiving stress.

## Method

### Design

This was a cross-sectional study which utilised data from informal caregivers taking part in the first wave (time-point 1) of the Improving the experience of Dementia and

Enhancing Active Life (IDEAL) cohort study (Clare et al., 2014). The IDEAL study was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 – 11684). The IDEAL study is registered with UKCRN, registration number 16593.

### **Participants**

For the current study, the participants were informal caregivers of people with mild-to-moderate dementia, typically family members or friends, who provided practical or emotional unpaid support. Caregivers were eligible to take part in the IDEAL study if the person with dementia for whom they provided care consented to take part. In order to take part in the study, the person with dementia had to have a diagnosis of dementia (any type). Details of the inclusion criteria for people with dementia are reported in Clare et al. (2014).

### **Measures**

A sub-set of the measures included in the IDEAL study was used to address the study aims (for full details of the measures included in the first wave of the IDEAL study see Clare et al., 2014).

### **Dementia representations**

Caregivers' DRs were assessed using the RADIX (Quinn et al., 2018). The RADIX was originally developed for people with dementia; in the IDEAL study, the questions were re-phrased for use with caregivers, but the response keys remained the same. This study used the RADIX questions on Identity, Cause, Control, and Timeline. There were two open-ended questions on Identity. Caregivers were asked: 'what do you call the difficulties/condition that your relative/friend has'. In addition, there is also an Identity question about the person's diagnosis: 'are you aware of a specific diagnosis? What does the doctor call it?' To measure Cause, caregivers were provided with six causal categories to choose from: ageing, changes in the brain, illness or disease, hereditary condition, lifestyle/life-events, and don't know. The question on Control 'there is a lot which my relative/friend can do to control the effects of the condition' was rated on a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). Lastly, to measure Timeline, caregivers were asked about the progression of their relative's/friend's condition with responses categorised as 'get better', 'stay the same', 'get worse', and 'unsure'.

### **Background information**

Information was collected about caregiver age, ethnicity, education level, first language, and caregiver kin-relationship to the person with dementia. Information was also collected about the specific diagnosis of the person with dementia, the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) score of the person with dementia, and the time since diagnosis.

### *Well-being*

Well-being was measured using the 5-item World Health Organization-Five Well-Being Index (WHO-5; Bech, 2004), which measures psychological well-being over the previous two weeks. Items are rated on a 6-point scale from 0 (at no time) to 5 (all of the time), the scores of the individual items are summed and transformed into a percentage score. Higher percentage scores indicate better well-being. The scale has demonstrated good internal reliability in a sample of caregivers, with a Cronbach's alpha of .87 (Balducci et al., 2008). In the current study, the Cronbach's alpha was .86.

### *Satisfaction with life*

SwL was measured using the 5-item Satisfaction with Life Scale (SwLS; Diener, Emmons, Larsen, & Griffin, 1985). Items are rated on a 7-point scale from 1 (strongly disagree) to 7 (strongly agree); higher scores indicate better SwL. The scale has demonstrated good internal reliability in a sample of caregivers of people with dementia, with a Cronbach's alpha of .87 (McConaghy & Caltabiano, 2005). In the current study, the Cronbach's alpha was .88.

### *Caregiving stress*

Caregiving stress was measured using the 15-item Relatives' Stress Scale (RSS; Greene, Smith, Gardiner, & Timbury, 1982). Items are rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (always/considerably); higher scores indicate greater stress. The scale has demonstrated good internal reliability in a sample of caregivers of people with dementia, with a Cronbach's alpha of .85 (Greene et al., 1982). In the current study, the Cronbach's alpha was .89.

### *Procedure*

Participant recruitment took place between July 2014 and August 2016. Researchers from UK clinical research networks, based in 29 National Health Service sites within Great Britain, were responsible for participant identification, recruitment, and assessment. People with dementia were identified to take part in the IDEAL study from a variety of sources, including memory services and Join Dementia Research, a UK based registration service that enables people with dementia to register their interest in taking part in research. People with dementia identified from these sources were initially contacted about the study by a researcher via telephone and/or postal contact, and during this initial contact, the researcher also ascertained whether the person with dementia was being supported by an informal caregiver. 'Informal caregiver' was defined as the primary person who provides practical or emotional unpaid support, usually a family member. Those people with dementia who expressed interest in taking part in the study were visited by the researcher. The researcher completed the eligibility checks and took informed consent from the person with dementia. For those people with dementia who had an informal caregiver, the informal caregiver was then approached to take part in the study. Caregivers who consented to take part in the study then self-completed the IDEAL study time-point 1 questionnaires during three visits by the researcher.

Participants were identified from a variety of sources including memory services and Join Dementia Research, a UK based registration service that enables people with dementia to register their interest in taking part in research. Researchers from UK clinical research networks were responsible for participant identification, recruitment, and assessment. Participant recruitment took place between July 2014 and August 2016. Potential participants were contacted about the study and a researcher visited those who expressed an interest to take part. The researcher completed eligibility checks and took informed consent. Participating caregivers self-completed their time-point 1 assessments over three visits during which the participants with dementia were assessed.

### **Analysis**

To provide a profile of the types of DRs held by the caregivers, responses to the open-ended questions on Identity and Cause were analysed using directed content analysis (Hsieh & Shannon, 2005). The data were coded by one person and the coding checked by three other people, with any coding disagreements discussed until consensus was reached. Descriptive statistics were then used to provide a profile of caregivers' DRs. Further analyses were conducted on the Identity question about the person's diagnosis to explore the level of agreement between the diagnosis provided by the caregiver and the person's actual diagnosis. Multivariate modelling was used to investigate differences in well-being, SwL, and caregiving stress. The analysis did not include the Identity question on diagnosis as nearly all caregivers (97.5%) provided a diagnostic term for this question. As two of the categories for Identity and Cause were very small, for the purposes of analysis, it was decided that the responses 'ageing' and 'don't know' should be combined for both Identity and Cause. Unadjusted models were conducted first, followed by models adjusted for caregiver age, gender, education, kin-relationship to the person with dementia, dementia diagnosis, and time since diagnosis. This study used the IDEAL time-point 1 dataset version 2 and all analyses were conducted using IBM SPSS Statistics Version 24.

### **Results**

For the purposes of this paper, we only included those caregivers who completed the RADIX as part of the IDEAL cohort study (20 caregivers had missing data for the entire measure) resulting in a sample of 1264 caregivers. [Table 1](#) provides the details of the caregivers and the people with dementia they were caring for.

#### ***Aim 1: To provide a profile of the DRs held by caregivers of people with dementia***

[Table 2](#) provides details of caregivers' responses to the RADIX questions.

**Table 1.** Characteristics of the caregivers and people with dementia.

Demographic information	N (%)
<i>Characteristics of caregivers</i>	
<i>n</i> = 1264	
Gender	
Female	869 (68.8%)
Age	
<65	362 (28.6%)
65–69	204 (16.1%)
70–74	263 (20.8%)
75–79	221 (17.5%)
80+	214 (16.2%)
Kin-relationship	
Spouse/partner	1029 (81.4%)
Other family member/friend	235 (18.6%)
Ethnicity	
White British	1211 (96.3%)
Other	46 (3.7%)
Education	
No qualifications	265 (21.8%)
School leaving certificate at age 16	272 (22.4%)
School leaving certificate at age 18	366 (30.1%)
College-level	313 (25.7%)
Main language	
English	1258 (98.4%)
Other	20 (1.6%)
<i>Characteristics of people with dementia</i>	
<i>n</i> = 1264	
Gender	
Female	528 (41.2%)
Age	
<65	482 (37.6%)
65–69	306 (23.9%)
70–74	232 (18.1%)
75–79	160 (12.5%)
80+	103 (8%)
MMSE score, <i>M</i> ( <i>SD</i> )	23.05 (3.7)
Diagnosis	
Alzheimer's disease	706 (55.9%)
Mixed Alzheimer's and vascular dementia	258 (20.4%)
Vascular dementia	140 (11.1%)
Frontotemporal dementia	44 (3.5%)
Parkinson's disease dementia	43 (3.4%)
Dementia with Lewy bodies	42 (3.3%)
Unspecified/other dementia	31 (2.5%)
Time since diagnosis	
Less than 1 year	413 (35.3%)
1–2 years	549 (47%)
3–5 years	183 (15.7%)
6–10 years	24 (2.1%)

### Identity

Of the 1264 caregivers who completed the RADIX, 1184 caregivers (93.7%) responded to the Identity question. Just under half ( $n = 583$ , 49.2%) of caregivers used a 'diagnostic' term (e.g. dementia), whilst 424 (35.8%) used a descriptive term relating to 'specific symptoms' of dementia (e.g. memory loss). The other categories related to 'general changes' in the person or an 'emotional response', with only a small number of caregivers using a term relating to 'ageing'. Twenty (1.7%) responses were considered 'unclassifiable' and thus excluded from further analyses.

In terms of the Identity question on diagnosis, 1181 (93.4%) caregivers stated they were aware of the diagnosis, and of those, 1163 (92%) provided details of the

**Table 2.** Descriptive information on caregivers' responses to RADIX items.

Variables	N	M (SD)
Identity	1184	
Diagnostic term	583 (49.2%)	
Descriptive: term describing specific symptoms	424 (35.8%)	
Descriptive: term describing general changes	82 (6.9%)	
Descriptive: term describing emotional response	48 (4.1%)	
Ageing	17 (1.4%)	
Unclassifiable	20 (1.7%)	
Don't know	10 (0.8%)	
Diagnosis	1163	
Diagnostic term	1134 (97.5%)	
Descriptive: term describing specific symptoms	19 (1.6%)	
Unclassifiable	8 (0.7%)	
Don't know	2 (0.2%)	
Cause	1256	
Changes in the brain	941 (74.9%)	
Illness/disease	120 (9.6%)	
Ageing	109 (8.7%)	
Hereditary	39 (3.1%)	
Lifestyle/life events	34 (2.7%)	
Don't know	13 (1%)	
Control	1238	
Strongly disagree	161 (13%)	
Disagree	472 (38.1%)	
Agree	539 (43.5%)	
Strongly agree	66 (5.3%)	
Timeline	1252	
Worse	1075 (85.9%)	
Unsure	133 (10.4%)	
Stay the same	31 (2.5%)	
Better	13 (1%)	
WHO-5	1247	55.26 (19.78)
SwLS	1240	23.77 (6.5)
Stress	1198	19.16 (9.83)

Notes. Unclassifiable refers to responses that did not fit under one of the identified categories and for which a suitable category could not be identified. WHO-5, World Health Organization-Five Well-Being Index; SwLS, Satisfaction with Life Scale

diagnosis. Nearly, all provided a 'diagnostic' term ( $n = 1134$ , 97.5%), and for 731 cases (62.9%), this response exactly matched the person's actual diagnosis. In 165 (14.2%) cases, the responses were partially consistent; for example, some caregivers used the term 'vascular dementia' when the diagnosis was actually 'mixed Alzheimer's and vascular dementia'. In 192 (16.5%) cases, the responses did not match as the caregivers used the term 'dementia' instead of the person's specific diagnosis. Only for 46 (4%) cases did the term provided and the diagnostic term not match at all.

### Cause

Most caregivers believed that the person's condition was due to 'changes in the brain' ( $n = 941$ , 74.9%) or to an 'illness/disease' ( $n = 120$ ; 9.6%).

### Control

The responses were fairly evenly split between those who 'agreed' ( $n = 539$ , 43.5%) and those who 'disagreed' ( $n = 472$ , 38.1%) that there were things the person could do to control the effects of his/her condition.

## Timeline

Most caregivers felt the person's condition would get 'worse' ( $n = 1075$ , 85.9%), followed by those who were 'unsure' about the progression of the person's condition ( $n = 133$ , 10.4%).

## Aim 2. To examine the impact of caregivers' DRs on their well-being, SwL, and caregiving stress

### Identity

In the unadjusted model (reported in Table 3), those using terms relating to 'specific symptoms' had higher well-being (6.15; 95% CI 3.71, 8.58), SwL (1.94; 95% CI 1.14, 2.74), and lower caregiving stress (-2.93; -4.15, -1.71) than those using 'diagnostic' terms (the reference group). Although some differences in scores on the outcome measures were found in those using terms relating to 'emotional response' or 'ageing/don't know', the confidence intervals were wide, likely due to small numbers of caregivers in these groups. There was little difference in scores on the outcome measures between those using terms relating to 'general changes' and those using 'diagnostic' terms. Adjusting for co-variates did result in a slight reduction in the effect sizes but the observed differences remained apparent; those using terms related to 'specific symptoms' continued to have higher well-being, SwL, and lower caregiving stress than the reference group.

**Table 3.** Unadjusted and adjusted models showing associations of identity and cause with well-being, SwL and caregiving stress.

	WHO-5 Coefficient (95% CI)	SwLS Coefficient (95% CI)	Caregiving stress Coefficient (95% CI)
<i>Identity</i>			
Diagnostic	Ref	Ref	Ref
Descriptive: specific symptoms	6.15 (3.71, 8.58)**	1.94 (1.14, 2.74)**	-2.93 (-4.15, -1.71)**
Descriptive: general changes	0.04 (-4.56, 4.64)	1.09 (-0.42, 2.61)	-0.05 (-2.35, 2.25)
Descriptive: emotional response	-5.32 (-11.26, 0.62)	-0.65 (-2.61, 1.31)	2.56 (-0.42, 5.53)
Ageing/don't know	5.79 (-1.98, 13.56)	3.35 (0.79, 5.91)*	-4.69 (-8.57, -0.80)*
<i>Adjusted for caregiver age, caregiver gender, caregiver education level, dementia diagnosis, and time since diagnosis</i>			
Diagnostic	Ref	Ref	Ref
Descriptive: specific symptoms	5.82 (3.39, 8.24)**	1.43 (0.63, 2.23)**	-2.30 (-3.52, -1.08)**
Descriptive: general changes	1.29 (-3.21, 5.79)	1.24 (-0.25, 2.73)	-0.21 (-2.48, 2.06)
Descriptive: emotional response	-4.46 (-10.65, 0.92)	-0.93 (-2.84, 0.98)	3.06 (0.15, 5.97)*
Ageing/don't know	5.21 (-2.39, 12.81)	2.57 (0.06, 5.08)*	-3.74 (-7.56, 0.09)
<i>Cause</i>			
Changes in the brain	Ref	Ref	Ref
Illness/disease	-3.55 (-7.39, 0.29)	-0.66 (-1.92, 0.60)	0.94 (-0.98, 2.85)
Ageing/don't know	7.76 (3.86, 11.66)**	3.11 (1.84, 4.39)**	-4.21 (-6.16, -2.26)**
Hereditary	-2.95 (-9.29, 3.40)	-1.92 (-4.00, 0.15)	3.12 (-0.05, 6.28)
Lifestyle/life-events	3.32 (-3.57, 10.21)	0.74 (-1.52, 2.99)	-1.33 (-4.77, 2.11)
<i>Adjusted for caregiver age, caregiver gender, caregiver education level, dementia diagnosis, and time since diagnosis</i>			
Changes in the brain	Ref	Ref	Ref
Illness/disease	-2.21 (-6.05, 1.63)	-0.31 (-1.57, 0.95)	0.22 (-1.71, 2.15)
Ageing/don't know	6.52 (2.68, 10.36)**	2.28 (1.02, 3.54)**	-3.27 (-5.20, -1.34)**
Hereditary	-1.77 (-8.00, 4.46)	-1.67 (-3.71, 0.38)	2.39 (-0.72, 5.51)
Lifestyle/life-events	3.46 (-3.30, 10.22)	0.27 (-1.95, 2.50)	-0.87 (-4.27, 2.53)

Note. WHO-5, World Health Organization-Five Well-being Index; SwLS, Satisfaction with Life Scale.

\* $p \leq .05$ .

\*\* $p \leq .01$ .

### Cause

In the unadjusted model (reported in Table 3), providing 'ageing/don't know' as the cause was associated with higher well-being (7.76; 95% CI 3.86, 11.66), SwL (3.11; 95% CI 1.84, 4.39), and lower caregiving stress (-4.21; 95% CI -6.16, -2.26) than those providing 'changes in the brain' as the cause (the reference group). There was little difference in scores on the outcome measures for 'illness/disease' and 'lifestyle/life-events'. Although some differences in scores on the outcome measures were found in those reporting 'hereditary' factors as a cause, the confidence intervals were wide, likely due to small numbers of caregivers in this group. Adjusting for co-variables did result in a slight reduction in the effect sizes but the observed difference remained apparent; those providing 'ageing/don't know' as the Cause had higher well-being, SwL, and lower caregiving stress than the reference group.

### Control

In the unadjusted model (reported in Table 4), those who responded 'disagree' to the condition being controllable had lower well-being (-4.40; 95%CI -6.87, -1.93), SwL (-1.19; 95% CI -2.00, -0.38), and higher caregiving stress (2.24; 95% CI 1.02, 3.46) than those who responded 'agree' (the reference group). Similarly, those who responded 'strongly disagree' had lower well-being (-8.58; 95% CI -12.09, -5.07), SwL (-3.21; 95% CI -4.37, -2.06), and higher caregiving stress (6.61; 95% CI 4.87, 8.34) than those who responded 'agree'. There was little difference in scores on the outcome measures for those responding 'strongly agree'. Adjusting for co-variables did result in a slight reduction in the effect sizes but the differences remained apparent; those who responded

**Table 4.** Unadjusted and adjusted models showing associations of control and timeline with well-being, SwL and caregiving stress.

	WHO-5 Coefficient (95% CI)	SwLS Coefficient (95% CI)	Caregiving stress Coefficient (95% CI)
<i>Control</i>			
Strongly agree	-3.34 (-8.51, 1.83)	-0.51 (-2.21, 1.18)	1.34 (-1.21, 3.89)
Agree	Ref	Ref	Ref
Disagree	-4.40 (-6.87, -1.93)**	-1.19 (-2.00, -0.38)*	2.24 (1.02, 3.46)**
Strongly disagree	-8.58 (-12.09, -5.07)**	-3.21 (-4.37, -2.06)**	6.61 (4.87, 8.34)**
<i>Adjusted for caregiver age, caregiver gender, caregiver education level, dementia diagnosis, and time since diagnosis</i>			
Strongly agree	-2.72 (-7.72, 2.29)	-0.28 (1.94, 1.37)	1.16 (-1.34, 3.66)
Agree	Ref	Ref	Ref
Disagree	-3.88 (-6.29, -1.47)*	-1.02 (-1.81, -0.22)*	1.95 (0.75, 3.16)*
Strongly disagree	-7.61 (-11.04, -4.18)**	-2.67 (-3.81, -1.54)**	5.89 (4.17, 7.60)**
<i>Timeline</i>			
Worse	Ref	Ref	Ref
Stay the same	11.01 (3.36, 18.65)*	4.04 (1.53, 6.55)*	-8.36 (-12.16, -4.55)**
Better	2.79 (-10.10, 15.67)	-1.69 (-5.91, 2.54)	-1.36 (-7.77, 5.05)
Unsure	1.59 (-2.08, 5.27)	1.31 (0.11, 2.52)*	-1.45 (-3.28, 0.38)
<i>Adjusted for caregiver age, caregiver gender, caregiver education level, dementia diagnosis, and time since diagnosis</i>			
Worse	Ref	Ref	Ref
Stay the same	10.14 (2.66, 17.63)*	2.95 (0.46, 5.38)*	-6.95 (-10.70, -3.20)**
Better	-0.29 (-14.02, 11.01)	-2.74 (-6.87, 1.40)	-0.69 (-6.99, 5.61)
Unsure	1.53 (-2.09, 5.15)	0.83 (-0.36, 2.02)	-0.79 (-2.60, 1.02)

Note. WHO-5, World Health Organization-Five Well-being Index; SwLS, Satisfaction with Life Scale.

\* $p \leq .05$ .

\*\* $p \leq .01$ .

'disagree' or 'strongly disagree' had lower well-being, SwL, and higher caregiving stress than the references group.

### **Timeline**

In the unadjusted model (reported in Table 4), those who felt the person's condition would 'stay the same' had higher well-being (11.01; 95% CI 3.36, 18.65), SwL (4.04; 95% CI 1.53, 6.55), and lower caregiving stress (-8.36; 95% CI -12.16, -4.55) than those who felt the condition would 'get worse' (the reference group). There is little difference on the scores of the outcome measures for those who felt the person's condition would get 'better' or were 'unsure'. Adjusting for co-variables did result in a reduction in effect sizes but the difference remained apparent; those who felt the person's condition would 'stay the same' had higher well-being, SwL, and lower caregiving stress than the reference group.

### **Discussion**

This is the first study to specifically explore DRs in a large cohort of caregivers of people with dementia. Overall the findings indicate that the caregivers held varying beliefs about the person's condition and that certain viewpoints were associated with better outcomes for the caregivers. In particular, higher well-being, SwL, and lower caregiving stress were associated with the use of an identity term relating to specific symptoms of dementia, attributing the cause to 'ageing/don't know', and believing the condition would stay the same. Lower well-being, SwL, and higher caregiving stress were associated with believing there was little that could be done to control the effects of the condition.

The findings indicate that most caregivers were aware of the person's diagnosis, but some preferred to use a different term to describe the person's condition. There are varied explanations for this. It is possible that the caregivers did not agree with the diagnosis and thus chose not to use that term (e.g. Pucci, Belardinelli, Borsetti, & Giuliani, 2003). The term used may have reflected the caregiver's own attempts to understand the condition (Askham, 1995). Terms such as 'dementia' and 'Alzheimer's' can be associated with stigma and may not have been used because of the negative associations (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). Certainly, there is some evidence that caregivers prefer to use less medicalised terms when talking about the condition to the person with dementia (Quinn et al., 2017), which may reflect the observation that people with dementia tend to use non-diagnostic terms when describing their condition (Clare et al., 2016; Quinn et al., 2018).

Compared to those using a 'diagnostic' term, those using a term relating to the 'specific symptoms' of dementia had higher well-being, SwL, and lower caregiving stress. This mirrors the finding of Clare et al. (2016) whereby people with dementia who used diagnostic terms and identified the cause as biological, psychosocial, or environmental reported lower quality of life. Similarly, studies which measure identity through the number of symptoms endorsed have also reported that a stronger illness identity (endorsing more symptoms) is linked to lower well-being, higher stress, and higher distress (e.g. Evans & Norman, 2009; Hagger & Orbell, 2003; Lo Sterzo & Orgeta,

2017). In the current study, those using 'diagnostic' terms may have been more aware or accepting of the person's condition and thus, this awareness was linked to more negative outcomes for the caregiver. Given this association, these findings do raise the question about how important it is for caregivers to use an accurate diagnostic term when referring to the person's condition. What may be more important is that caregivers have an understanding of what is happening to the person.

The majority of caregivers identified that the person's condition was due to changes in the brain or illness/disease. This differs from the findings of studies with people with dementia whereby they are less certain about the cause (e.g. Matchwick, Domone, Leroi, & Simpson, 2014). Caregivers who believed the cause was 'ageing' or 'didn't know' the cause had higher well-being, SwL, and lower caregiving stress than those who believed the cause was due to 'changes in the brain'. This finding may relate to theories on illness causation and locus of control, whereby judgements are made as to whether changes are linked to uncontrollable external factors or more controllable internal factors (e.g. Pagel, Becker, & Coppel, 1985). In the current study, those attributing observed changes to ageing may have been normalising these changes and thus less at risk of blaming themselves or the person for the effects of the dementia. It is possible that this normalisation lessened the perceived seriousness of the changes and thus less impact on outcomes for the caregiver.

Caregivers were split in their opinion as to whether there were things the person could do to control the effects of the condition. These beliefs may have been influenced by information given during the diagnosis. Healthcare professionals may also be reluctant to discuss dementia symptoms with patients because of a belief that 'nothing can be done' (Batsch, Mittleman, & Alzheimer's Disease International, 2012). However, there have been public campaigns to challenge traditional perspectives about dementia, including the controllability of the condition (e.g. Limb, 2011). As nearly half of the sample felt that there were things the person could do suggests that some caregivers were aware of strategies to help manage the effects of dementia. In terms of caregiver outcomes, those caregivers who did not feel that anything could be done had lower well-being, SwL, and higher caregiving stress. This finding is similar to that found in other health conditions; for instance, low feelings of personal control have been linked to higher distress in people with Parkinson's disease (Evans & Norman, 2009) and poorer mental health in people with schizophrenia (Lobban, Barrowclough, & Jones, 2004). This may relate to theories of 'learned helplessness', whereby feelings of loss of control have been linked to depression in caregivers (Pagel et al., 1985).

Most caregivers' view of the timeline was that the person's condition would get worse. Again, this may reflect greater public awareness about dementia and the degenerative nature of the condition. Those caregivers who felt the condition would 'stay the same' had higher well-being, SwL, and lower caregiving stress than those who felt the condition would 'get worse'. Studies in other health conditions have found links between beliefs about timeline and well-being, with those with perceptions of a more chronic timeline having worse well-being (Hagger & Orbell, 2003). Dementia is a degenerative condition, but the nature of the condition means that the symptoms may stabilise for a time. Thus, the findings of the current study may reflect

different coping techniques; those who believed the condition would remain stable may have been more hopeful about the future and thus this may explain why these caregivers had better outcomes. For instance, studies have found that hope is associated with better caregiver well-being (Irvin & Acton, 1997).

In considering the findings of this study, it is important to reflect on the strengths and limitations. This study utilised a large cohort of caregivers of people with mild-to-moderate dementia; however, the nature of data collection does place some limitations on our findings. Primarily, whilst this study has information about caregivers' DRs, we do not have information about how the diagnosis was conveyed to the caregivers. This information may have influenced their DRs; for instance, healthcare professionals may use terms such as 'memory problems' during diagnostic meetings or highlight the uncertainty of the diagnosis (Dooley, Bass, & McCabe, 2018). This study used a quantitative approach; had the study incorporated qualitative data collection, this would have allowed further exploration of the caregivers' responses. However, it has been recognised that the quantity and quality of information elicited about IRs using qualitative techniques with large samples can be variable (Quinn et al., 2018; Weinman, Petrie, Moss-Morris, & Horne, 1996). Caregivers in this study were predominantly white British and it would be interesting to explore DRs in a culturally diverse sample to investigate differences in caregivers' beliefs (e.g. Hinton et al., 2005). This study only explored four components of DRs, and we did not have a measure of consequences. However, it is likely that such a measure would have overlapped with items in the measure of caregiving stress. Finally, as this was a cross-sectional study it can only explore associations between DRs and caregiver outcomes; however, as IDEAL is a longitudinal study, it will be possible in the future to explore the longitudinal influences of caregivers' DRs.

Holding certain DRs can have implications for caregiver well-being. With the exception of beliefs about controllability, there was a trend in the findings for more realistic beliefs about the person's condition being linked to poorer outcomes. This is in contrast to findings from other studies whereby caregivers with higher knowledge about dementia have better well-being (e.g. Graham, Ballard, & Sham, 1997). The current study raises the question of how important it is for caregivers to hold accurate beliefs about dementia, particularly as these beliefs can be linked to worse outcomes in the caregivers. Rather than focusing on the accuracy of beliefs, it may be more important for healthcare professionals to assess and gain an understanding of caregivers' DRs, which would help to improve communication between them and caregivers. For example, many caregivers in the current study were aware of the diagnosis but used a different term to talk about the condition. By checking caregivers' understanding of the condition this would help healthcare professionals to appropriately tailor how they talk to the caregiver about the condition and offer support. In terms of support, the current study highlights one area where caregivers would benefit from more information. Caregivers who held more negative beliefs about the controllability of the condition had worse outcomes; thus, this suggests that these caregivers would benefit from being provided with information about ways to help manage the effects of the condition. This would be in line with recent guidelines that have emphasised the role that interventions can have in promoting

independence and well-being in people with dementia (e.g. National Institute for Health and Care Excellence, 2018).

The findings of the current study also have implications for the development of interventions and psychological therapies for caregivers. Interventions that are designed to provide education and support to caregivers need to explore caregivers' existing DRs, particularly as these beliefs may in themselves be a barrier to implementing interventions (Donovan & Ward, 2001). Interventions could follow the 'representative approach' which is a process whereby a person's pre-existing IRs are identified before the person is provided with new information (Donovan & Ward, 2001). It has also been recommended that 'significant others' are involved in such interventions as their beliefs may influence those of the patient (Broadbent, 2010). Thus, this suggests that the beliefs of the caregiver may be influenced by the person with dementia and vice versa. Therefore, interventions for both caregivers and person with dementia need to take into account the DRs of the other member of the dyad and the influence of this on the uptake of support. For example, caregivers who believe that nothing can be done to control the effects of dementia may be less willing for the person to take part in interventions aimed at improving cognition or functioning. This highlights the importance of understanding the DRs held by both members of the dyad.

In conclusion, this is the first study to explore DRs in a large cohort of caregivers of people with mild-to-moderate dementia. The findings identify that caregivers held different beliefs about dementia and that some of these beliefs were linked with worse outcomes for the caregivers. These findings highlight the importance of understanding caregivers' DRs, to help healthcare professionals provide more tailored support to caregivers. An understanding of DRs is also important for the development of psychological therapies or interventions.

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## Author contributions

Authors Quinn, Rees Jones, Martyr, Nelis, Morris, and Clare were involved in the original conception and design of the project. The lead author Quinn is responsible for the data analysis and interpretation, and for drafting the article. All authors have contributed to the critical revision of the article, and provided final approval of the version to be published.

## Disclosure statement

No potential conflict of interest was reported by the authors.

## Data deposition

The IDEAL data will be deposited with the UK Data Archive upon completion of the study. Details on how the data can be accessed after this date will be made available on the project website [www.idealproject.org.uk](http://www.idealproject.org.uk).

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