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Shared understandings of dementia? An application of the Common Sense Self Regulation Model to a case study

Introduction

Eliciting how people with a diagnosis of dementia talk about their condition

Accumulating research evidence suggests that people with a diagnosis of dementia are capable of talking about their condition in an insightful and meaningful way (Bryden, 2002; Linda Clare, Rowlands, & Quin, 2008; R. Davis, 1989; Friel-McGowin, 1993). Steeman et al (Steeman, de Casterle, Godderis, & Grypdonck, 2006) in a meta-synthesis of qualitative studies that considered personal experiences of living with dementia, concluded that there are many common features of experience, but ultimately it is a “highly individualised experience”. Davis (D. Davis, 2004) notes that whilst dementia is a medical condition, theoretical perspectives can offer another way of looking at the condition and how it affects the person and those involved in their care.

The Common Sense Self-Regulation Model (CS-SRM) Illness Representations (IRs)

The Common Sense Self-Regulation Model (CS-SRM) proposed by Leventhal (H. Leventhal, et al., 1984) provides a framework for understanding how individuals think about health threats such as medical conditions. It is proposed that

individuals think about their condition in terms of five key components that combine to form an Illness Representation (IR): identity (the symptoms they experience and attribute to it, and the label they give them), cause (what they believe caused their condition), cure/control (their belief about the ability to either cure or control their condition), timeline (the expected duration and variability of their condition), and consequences (what they perceive to be the consequences of their condition). How individuals represent their condition (on these five dimensions) and the parallel emotional representation of their condition combine to direct self-regulatory behaviour to manage their condition.

Research evidence suggests that IRs may not correspond to the expected biomedical model. For example, it is accepted in the medical literature that hypertension is asymptomatic. However, a study recruiting such patients (Bauman & Leventhal, 1985) reported that 92% of individuals believed that they experience symptoms which indicated that their blood pressure was elevated. Accumulating research evidence also suggests that individuals with equivalent symptom severity report different IRs (Heijmans, 1999). This has important implications both for the individual and for clinical management, as individuals subsequently behave in different ways e.g. report different levels of symptoms, disability, quality of life etc. that are not predictable from 'objective' measures of severity. Therefore the CS-SRM IRs can be used as a framework to explore how people represent their health condition(s) and subsequently understand why people with similar/equivalent symptoms behave in different ways.

Can Illness Representations further our understanding of people with a diagnosis of dementia?

Lobban (Lobban, Barrowclough, & Jones, 2003) has suggested that the CS-SRM can further our understandings of how people represent different mental health conditions, however this review did not include studies of dementia. Subsequent research by Harman and Clare (Harman & Clare, 2006) and Clare et al (L. Clare, Goater, & Woods, 2006) provided evidence to suggest that IRs can further our understanding of the “highly individualised experience” of dementia. They suggest that the model should also “consider the representations held by carers and professionals alongside those held by individuals with dementia”.

Illness Representations (IRs) of caregivers

Cohen-Mansfield (Cohen-Mansfield, Parpura-Gill, & Golander, 2006) suggests that caregivers can be helped to communicate with the person who has a diagnosis of dementia, if they understand the specifics of the self-identity of that person. A lack of shared understanding may be problematic as Langdon et al (Langdon, Eagle, & Warner, 2007) notes; the person being aware of others either concealing or avoiding open discussion can fuel the notion that dementia is a “taboo subject and stigmatising”. Clare (L. Clare & Shakespeare, 2004) reported that being able to construct shared narratives can support joint coping efforts and allow couples to make decisions for the future.

Research using the CS-SRM IRs has also highlighted the importance of caregivers’ understanding in determining the course of the patients’ illness in various medical conditions: schizophrenia (Barrowclough, Lobban, Hatton, & Quinn, 2001), heart disease (Figueiras & Weinman, 2003; Weinman, Petrie, Sharpe, & Walker, 2000), Huntington ’s disease (Helder, et al., 2002), and chronic

illness (Salewski, 2003; Weinman, Heijmans, Figueiras, Cameron, & Leventhal, 2003). Roberts and Connell (Roberts & Connell, 2000) conducted a study that elicited the IRs of first-degree relatives of people with a diagnosis of Alzheimer's disease and found that there were gaps in participants knowledge. This study did not include the person with the diagnosis so could not explore whether these IRs were shared.

Illness Representations of doctors

Research evidence supporting the use of the CS-SRM with health care professionals remains limited (Howard Leventhal, Weinman, Leventhal, & Phillips, 2008; Weinman, et al., 2003). Fortinsky's (Fortinsky, 2001) summary of research studies on health care triads (primary care physicians, family caregivers and persons with dementia) demonstrated that characteristics such as: the presence of a doctor/white coat can influence patient outcomes and the presence of a caregiver can increase the likelihood of a clinical diagnosis. However, none of these studies utilised the CS-SRM IRs as a theoretical framework to systematically understand individual study findings.

The current study

Current evidence suggests that IRs can improve our understanding of how people talk about their health condition(s). Research findings from other conditions suggests that our understanding of patient behaviour can be further improved by also considering the IRs of informal unpaid caregivers. At present, there is insufficient evidence to indicate whether the IRs of formal paid caregivers i.e. health care professionals can add to our understanding. Therefore there is a need to investigate whether considering the IRs of the person with the diagnosis,

their informal caregiver and their formal caregiver (i.e. their doctor) talk about dementia in terms of CS-SRM IRs. This was explored in an in-depth case study.

Research questions

- 1) Does a person with a diagnosis of dementia, their informal unpaid caregiver, and their formal paid caregiver i.e. their primary care doctor, talk about the person's dementia in terms of Common Sense Self Regulation Model (CS-SRM) Illness Representations (IRs)?
- 2) If prompted how do they talk about dementia in terms of IRs?
- 3) Do the caregiver and the doctor understand how the person represents their dementia?

METHODS

Design

In-depth exploratory case study, involving individual semi-structured interviews with three participants (person with the diagnosis (PWD), their unpaid caregiver (C) and the primary care doctor (GP)) that form a health care triad.

Ethics and NHS permissions

Grampian Local Research Ethics Committee reviewed the "How do people with a memory condition, their informal carers and health care workers involved in their care make sense of and cope with their condition: an exploratory assessment using the Common Sense Model of Self-Regulation" study plus amendments (05/S0802/119). The Research and Development office of NHS Grampian approved the study. Permission to undertake the study in the Old Age Psychiatry Directorate was granted by the Service Manager/Acting Clinical Director.

As the study progressed it became apparent that important lessons could be learned from an in-depth exploration and comparison of linking data from a health care triad (person with a diagnosis of dementia (PWD) their nominated informal caregiver (C) and their doctor (GP)). Therefore ethical permission was sought to re-contact PWD, C and the GP and seek consent to explicitly link their individual interview data for this study and paper. PWD, C and GP were asked to consent to one of three options 1) not to link their data 2) review their data before publishing 3) use their data for publication without contacting them again. This paper therefore reports data collected as part of a larger study (Glidewell, 2008).

Participants

Individuals referred from primary care to the Old Age Psychiatry Department (NHS Grampian) with a clinical diagnosis of any type of dementia ICD 10 (Karjalainen, 1999) were considered eligible. Of these individuals aged over 60 years old with a Mini Mental State Examination (MMSE) score between 20 and 26 (indicating early stage dementia) were invited to take part.

A recruitment pack was mailed from the Old Age Psychiatric team. A man (aged 82) who was referred by his primary care doctor to the Old Age Psychiatry Department (NHS Grampian) and subsequently received a clinical diagnosis of Alzheimer's type dementia ICD 10 (Karjalainen, 1999) consented to take part. He had a Mini Mental State Examination (MMSE) score of 22 (indicating early stage dementia).

At their interview the person was asked to nominate the person who knew them best i.e. their informal unpaid caregiver (C) and their formal paid caregiver, the primary care doctor (GP) who referred them to Old Age Psychiatry. The people nominated as C and GP were subsequently invited to participate.

C and GP were recruited in a similar method to PWD using an adapted recruitment pack and both consented to participate. C in this instance was his wife (aged 76) who lived with PWD in their family home, both are retired. His primary care doctor (GP) (male) was also interviewed. At a later date GP consented for his data to be shared. Both PWD and C requested to review their data, before consenting to explicit linkage.

Semi-Structured interviews

In-depth semi-structured interviews were conducted with the three consenting individuals (PWD, C and GP). The interview schedule was designed to elicit Illness Representation's (IRs) with dementia as the target condition (see table 1). Participants were asked a series of open questions to assess if all constructs of the IR were talked about spontaneously without prompting. They were subsequently asked a series of prompted questions to elicit their IRs on individual constructs (identity, case, cure/control, timeline, consequences, coherence and emotion). PWD was also asked about his general health (SF12 (Medical Outcomes) and cognitive function (Mini Mental State Examination (Folstein, Robins, & Helzer, 1975))).

C and GP were asked a similar set of questions to PWD. They were asked to respond on the basis of how they thought that PWD would talk about his condition. The GP was also asked how he represented PWD's condition. During recording the informal caregivers own IRs were also recorded.

The study team decided not to refer to the clinical diagnosis or use the word "dementia" within the interviews, unless any of the participants used such terms.

This decision was taken for a number of reasons. Firstly, an important part of the IR is the label that the individual uses to describe their condition. Secondly, some people choose not to use the clinical diagnoses and/or some may have forgotten (L. Clare, 2002; Pratt & Wilkinson, 2001). We wanted to avoid disclosing clinical information that the participant may not know, or prefers not to talk about. Consequently the recruitment pack referred to the condition that “led to the appointment at the Department of Psychiatry” to avoid talking about other concurrent medical conditions. During the interview the label generated by the respondent was used. To elicit the label that each participant uses to describe PWD’s condition, we asked them to tell us what the appointment with “Doctor’s name” was for.

Unplanned additional data was also collected seven months after the initial interview, when consent to link the data was discussed. All data tables refer to data collected during the first interview.

Analyses

The interviews were recorded and the data were transcribed verbatim by the researcher (LG). QSR NVivo version 7.0.281.0 SP4 was used to facilitate data analysis (<http://www.qsrinternational.com>). Data were coded for Illness Representations (IRs) (see tables 2-8 for a list of theoretical definitions (H. Leventhal, et al., 2007; Moss-Morris, et al., 2002)) by the researcher (LG). Where distinct themes were apparent within constructs they were grouped (e.g. Identity contained sub-categories such as different clinical diagnoses e.g. Alzheimer’s or dementia and different non-medical labels e.g. mixed state of mind). The reliability of coding was explored (between the researcher and two other researchers’ familiar with the CS-SRM (BF & SJ)) on a sample of data. One transcript was

divided into 92 meaning units (sentences/utterances (Lau, Bernard, & Hartman, 1989)) and inter-rater coding reliability was assessed using Krippendorffs Alpha ((Hayes; Hayes & Krippendorff, 2007)).

RESULTS

Inter-rater coding reliability was satisfactory for most constructs (Identity 0.76, Cause 0.80, Cure/control 0.73, Timeline 0.82 & Consequence 0.79), with the exception of emotion ($\alpha=0.59$) and coherence ($\alpha=0.50$).

Summary data elicited from the open questions are presented in table 2.

Subsequently verbatim quotes are presented by theoretical construct in tables 3-9.

Where relevant quotes are cited in the results sections they are annotated with the participant (PWD, C or GP), followed by the construct (e.g. identity) and the relevant quote number. For example *PWDidentity7* refers to Person with the diagnosis quote number 7, on identity. Results for each construct are grouped in separate tables.

Did the PWD C and the GP talk spontaneously about Illness Representations (IRs)? (see table 2)

Spontaneous data coded as identity

PWD talked about having the label Alzheimer's whereas C and GP referred to dementia. The symptom of remembering differently were referred to by PWD. He also referred to a reduction in functional capacity as did the GP. C only referred to symptoms of short-term forgetfulness. Both PWD and the GP noted that PWD was aware that something was wrong.

Spontaneous data coded as cause

None of the participants made any reference to the perceived cause of the condition.

Spontaneous data coded as cure/control

All participants made reference to other's ability to control the condition.

Spontaneous data coded as timeline

Only C spontaneously referred to the onset of the dementia. PWD and the GP referred to the expected duration of the condition.

Spontaneous data coded as consequence

Both PWD and the GP mentioned being aware of consequences. Overall C felt that the condition did not have much effect on PWD's life. However, she noted various consequences e.g. his ability to cope. PWD noted some personal consequences e.g. that other people were aware of his forgetfulness. The GP also noted that there were personal consequences, that his physical/functional ability was affected and that the condition also had social consequences.

Spontaneous data coded as emotion

C and the GP noted that the condition did affect PWD emotionally, and C cited negative emotions. PWD did not spontaneously talk about any aspect of emotion.

Spontaneous data coded as coherence

PWD spontaneously stated that he wanted to understand his condition, as did the GP. Only the GP mentioned that he felt that PWD understood his condition and that he was aware something was wrong. C did not spontaneously talk about coherence.

If questions specifically prompt for Illness Representations (IRs) how do PWD, C and GP represent PWD's condition?

Cued data coded as identity (see table 3)

All participants used the clinical diagnosis of Alzheimer's (*PWDidentity1*, *Cidentity1*, *GPidentity1* and *GPidentity2*). The PWD also used personal labels such as feeling "woofy", "out of sorts" (*PWDidentity2*) and having a mixed state of mind (*PWDidentity3*). Just C (*Cidentity2*) and the GP (*GPidentity3* and *GPidentity4*) used the label dementia and only the GP talked about vascular related dementia (*GPidentity5*).

Each participant talked about symptoms of forgetfulness with regard to short term memory (*PWDidentity4*, *Cidentity3*, *GPidentity7* & *GPidentity8*). The PWD thought that he remembered differently (*PWDidentity5*), was aware that there was "something wrong" (*PWDidentity6*) and that his memory "will change" (*PWDidentity7*). C was uncertain if PWD's condition would progress in a similar way to his mother's and sister's condition (*Cidentity1* & *Cidentity4*). His wife talked about the condition being "not serious" and compared it to cancer "Well it's not serious, and the only thing I say to him, is look it could be worse, you could have a really serious illness that caused you a great deal of pain, and eh, you could be having chemotherapy, you could be having radiotherapy." (*Cidentity5*). The doctor also thought that PWD was "aware" of his condition (*GPidentity9*) and that it would "get worse" (*GPidentity10*). The GP was the only person to refer to a reduction in "functional capacity" (*GPidentity11*).

Cued data coded as cause (see table 4)

PWD questioned what had caused his condition (*PWDcause1*) but felt that he did not know what had caused his condition (*PWDcause2*). C stated that her husband “doesn’t tend to talk about what caused his condition” (*Ccause1* & *Ccause2*) but he “would like to know more” (*Ccause1*). She queried whether PWD’s condition was genetic, as his mother (*Ccause3*) and sister (*Ccause4*) were both diagnosed. Both C (*Ccause5*) and GP (*GPcause1*) referred to old age as a causal factor. The GP also suggested dementia (*GPcause2*) and hypertension (*GPcause3*) as causes. He also stated that PWD would not want to look “into the reasons” or have a “grasp of the underlying process” (*GPcause4*). The GP felt that PWD “would not look into Alzheimer’s” (*GPcause5*).

Cued data coded as cure/control (see table 5)

PWD doubted a cure (*PWDcure/control1*), but hoped for one in the future (*PWDcure/control2*). He acknowledged that he was “not the only one affected” (*PWDcure/control3*).

In terms of PWD’s personal control over his condition he had thought about what he could do to “change it” and wanted to know how to “stem the deterioration” or “bring about an improvement” (*PWDcure/control4*). He wanted to do anything that would help (*PWDcure/control5*) that would be “positive and effective” (*PWDcure/control6*), he wondered about the possibility of medical treatment (*PWDcure/control7*). His wife stated that he was on a course of medication that she hoped would “retard the deterioration” but that was person dependent (*Ccure/control1*). She also expressed concern about the cost of such drugs (*Ccure/control2*). C acknowledged that her husband “tries to treat it now” (*Ccure/control3*).

The GP noted that practice staff had observed PWD deteriorating, but nothing could be done because he had not made a request for assessment (*GPcure/control6*). His wife however said that she had approached the general practice about his forgetting at an earlier date, but nothing was done until he was admitted to hospital for another condition (*Ccure/control5*).

Since presenting PWD had been referred to a consultant in Old Age Psychiatry (*GPcure/control7*). Subsequently he had been prescribed Aricept® (donepezil tablets) which the GP thought would “bring about a period of stability” (*GPcure/control1*) or “at least arrest the process” (*GPcure/control2*). The GP also wanted to monitor the patient’s blood pressure and generally keep him well (*GPcure/control3*). He also spoke about the importance of regular review (*GPcure/control4*). Other members of the clinical team were mentioned by the GP as a source of cure/control, but not felt necessary at this stage in PWD’s condition (*GPcure/control8*).

All participants referred to non-medical controls. PWD noted the helpfulness of his family (*PWDcure/control8*). C acknowledged that she could nudge when it wasn’t obvious to her husband (*Ccure/control6*), and used practical skills like noting both their appointments in her diary to support her husband (*Ccure/control7*). C reported that PWD was continuing to keep-up with his business administration (*Ccure/control4*). The GP stressed the importance of increased stimulation and doing things that PWD might have stopped doing because of his forgetfulness (*GPcure/control5*).

PWD said that he wanted the best advice from medical experts (*PWDcure/control9* & *PWDcure/control10*). PWD (*PWDcure/control11*), C (*Ccure/control8*) and the GP

(*GPcure/control9*) did not think that there was a cure at present, but the GP suggested the psycho-geriatrician as a potential person for controlling PWD's condition.

Cued data coded as consequence (see table 6)

During the interview PWD acknowledged that he was aware of difficulties (*PWDconsequence1*). C and GP also felt that he was aware of the effects of his condition (*Cconsequence1* and *GPconsequence1*). To a certain extent PWD and C felt that his condition had not altered their lives (*PWDconsequence2* and *Cconsequence2*). C felt that it was only his short term memory that was affected, and that he had better recollection of things in the past (*Cconsequence3*). She queried his ability to learn, citing that she still wanted to learn but that PWD didn't want to learn as opposed to not being able to learn (*Cconsequence4*).

Physical or functional consequences

PWD stated that he may feel "totally out of sorts" (*PWDconsequence3*). C felt that he now took longer to think before doing things (*Cconsequence5*). The GP said that PWD had a "functional capacity reduction" (*GPconsequence2*) and that his ability to think and remember had been affected (*GPconsequence3*).

Personal consequences

In terms of how PWD felt he was affected, he noted the effect on his confidence (*PWDconsequence4*), this was also noted by the GP (*GPconsequence4*). C stated that he was affected by pressure (*Cconsequence6*). PWD noted that his life may now be shorter (*PWDconsequence5*). His wife noted that he should stop driving (*Cconsequence7*) and that his condition had affected his independence

(*Cconsequence8*). The GP noted the many effects on PWD's life in terms of his ability to participate (*GPconsequence5*).

Social consequences

Recently PWD had changed his social activities and was unsure how to live his life (*PWDconsequence6*). He now found it hard to "make up his mind as to how he wanted to live his life" (*PWDconsequence7*). PWD stated that he could become confused and felt that he remembered things differently (*PWDconsequence8*). Although he felt that his condition had consequences he also suggested that some of these changes were for other reasons (*PWDconsequence9*).

C acknowledged that other people were aware of his forgetting (*Cconsequence9*). She felt that PWD had restricted his activities and was now unwilling to socialise in large groups (*Cconsequence10*). Some of this restriction she felt was due to another health condition and partly because this was the way he had always been (*Cconsequence11*). She felt that he wanted more support from her (*Cconsequence12*).

The GP also agreed that others were aware of his condition (*GPconsequence6*). He felt that PWD had changed his activities (*GPconsequence7*) and modified his lifestyle (*GPconsequence8*) to compensate. He felt that PWD had changed his role (*GPconsequence9*), and had become more dependent on his wife as she shielded him from stressful situations (*GPconsequence10*).

Economic consequences

None of the participants reported any economic consequences.

Cued data coded as timeline (see table 7)

Timeline onset

In the past two to three years PWD was aware of problems with his memory (*PWDtimeline1*). C felt that the forgetfulness started about five years ago (*Ctimeline1*). This was difficult for her to specify as she felt the condition to be “gradual” and “insidious” (*Ctimeline1*). It was further complicated by the cyclical nature of the condition in that some days her husband would function normally (*Ctimeline2*). The GP felt that PWD had been impaired for “many, many months” (*GPtimeline1*), before he was assessed and diagnosed within the past couple of months (*GPtimeline2*). The GP felt that PWD had “fairly significant dementia for a long time” (*GPtimeline2*).

Timeline duration

It was only recently (past 2-3 months) that PWD had to consider a shorter life span (*PWDtimeline2*). In general he felt that the “future was open” (*PWDtimeline3*). C felt that PWD would eventually get more forgetful (*Ctimeline3*), but she had been told that “at the current rate of deterioration her husband wouldn’t live long enough to reach the difficult stage” (*Ctimeline4*). The GP stated that it was a “chronic problem” (*GPtimeline4*) that would be progressive (*GPtimeline5*), and that PWD would probably deteriorate within the next three to four years (*GPtimeline6*). But there was hope that the drugs could arrest or reverse the condition (*GPtimeline7*).

At the later meeting to discuss consent PWD noted that they had changed their view on a shorter life span, he attributed this to the change in his medication, and now felt that he had a much more positive outlook.

Cued data coded as emotion (see table 8)

PWD stated that he became emotional if he spoke about his condition (*PWDemotion1*), and he did become weepy during the interview. He often felt “surprised” when he realised he had forgotten (*PWDemotion2*) and found these times puzzling (*PWDemotion3*). He acknowledged that he was apprehensive about the “intensity” of socialisation (*PWDemotion4*) and that he may feel “totally out of sorts” because of the “sheer emotion” (*PWDemotion5*). The doctor also felt that he was now frightened to socialise (*GPemotion5*)

He stated that he was thoughtful about his condition (*PWDemotion6*). But that the thoughts he had were not “negative” (*PWDemotion7*). On the whole he wanted to bring about continued enjoyment in life (*PWDemotion11*). However he went on to say that although he was not depressed he was a little disturbed (*PWDemotion9*) and found his condition “unsatisfactory” (*PWDemotion10*) and did not enjoy the fact that something was starting to go wrong (*PWDemotion11*).

C agreed that sometimes his condition affected him emotionally in that he would become weepy (*Cemotion1*), and that he found his condition “distressing” (*Cemotion2*). She felt that he tried to “treat it with humour” (*Cemotion1*) but that he could get angry (*Cemotion3*) and frustrated (*Cemotion4*) by his forgetfulness. The GP thought that the condition was beginning to “get to him” and affect PWD’s confidence (*GPemotion1*). He felt that he was “obviously emotionally labile” (*GPemotion2*) and that stressful events made him emotional (*GPemotion3*). However he felt that medication had brought about emotional stability (*GPemotion4*) which was a “dramatic improvement”.

Cued data coded as coherence (see table 9)

PWD knew that something was “wrong” (*PWDcoherence1*) and was “willing to learn more” (*PWDcoherence2*) and wanted to know more (*PWDcoherence3*) about the condition. He felt that he was now in a position to think more about “why did it happen” (*PWDcoherence4*), but currently had “no clear picture” (*PWDcoherence5*) of his condition. C stated that he was “fully aware” (*Ccoherence1*), and that he had accepted his condition (*Ccoherence2*). She felt that she didn’t know enough about his condition (*Ccoherence3*). The GP also felt that PWD was aware of almost no short term memory (*GPcoherence1*). He felt he understood why he was being referred to the clinic (*GPcoherence2*), but that he wouldn’t look beyond the label or be “curious” or “able to...assimilate the information...to give him a much more detailed explanation” (*GPcoherence3*). The GP also felt that his wife would “accept the label” and “not really look for much more than that” (*GPcoherence4*).

Discussion

We conducted an in-depth study of how one individual conceptualises their dementia a few months after receiving a confirmed clinical diagnosis.

Did PWD C and GP spontaneously talk about Illness Representations (IRs)?

All participants spontaneously talked about dementia in terms of Illness Representations (IRs) (identity, cure/control, timeline, and consequences). However, none of the participants spontaneously talked about the cause of dementia. The PWD did not spontaneously talk about emotion and the caregiver did not spontaneously talk about coherence. However, they did talk about these

constructs when prompted. This may be because the open questions were at the beginning of the interview schedule, as Leventhal (H. Leventhal, Meyer, Nerenz, & Rachman, 1980) notes “The patient’s symptoms, his beliefs about their determinants, and his beliefs about treatment form an organized and more or less coherent theory of illness. The degree of organization will vary from person to person as will the ability to verbalize the organization”.

A number of individual themes within constructs were not elicited in response to open questions but were elicited in response to questions prompting for IRs. These included the labels: memory, vascular dementia and personal labels, behavioural symptoms and progressive symptoms. They did not spontaneously suggest any non-medical interventions to control the condition e.g. lifestyle, routine, stimulation, other people and writing things down. None of the participants made reference to there being a cure for dementia, nor to wanting to be able to control the condition. In terms of consequences, the effect of the condition on the person’s ability to manage was not elicited. Nor was the possibility that the condition did not affect them emotionally; that there is hope for the future; and that the family are affected emotionally. It may be possible that the cued questions prompting for IRs allowed the person to talk about what is not normally talked about.

Data were also found in support of work by Harman and Clare (Harman & Clare, 2006) and Clare et al (L. Clare, et al., 2006) that people with a diagnosis do spontaneously talk about their condition in terms of Illness Representations (IRs). Data from this case study suggests that caregivers and health care professionals spontaneously talk about dementia in terms of IRs. We are conducting an ongoing study that will explore if these results are applicable to a larger representative sample (Glidewell, 2008).

If questions specifically prompt for Illness Representations (IRs) how do PWD, C and GP represent PWD's condition?

Specifically prompting for IRs elicited a range of responses. PWD labelled their condition as a memory problem, and noted various symptoms related to their condition. C expressed a similar set of symptoms but also used the diagnostic label dementia. In comparison, GP used more clinical labels (dementia and vascular related dementia, and early stage Alzheimer's. GP also referred to more global symptoms for example 'level of functioning'.

In terms of what caused the condition all three participants stated that they did not know what caused the condition. Differences of opinion were expressed as to potential causes e.g. PWD "doesn't know" but "wanted to know more", C thought it ran in the family whereas GP personally thought that it was vascular and age related. The GP thought that PWD would not look further than the clinical label. However, data elicited from questions on coherence contradicted this view point, as both PWD and C expressed a desire to know more.

Importantly a discrepancy was observed in terms of how PWD, C and GP viewed the timeline of PWD's condition. In terms of onset PWD referred to a period of two or three years. C felt that symptoms had been apparent for approximately five years. However the GP noted that he had been impaired for "many, many months". With regard to duration PWD talked about a shorter life span. C was unsure about the timeline. However, the GP expressed a more positive timeframe in terms of speed of deterioration, estimating years (not months).

A range of emotions were expressed during each interview. References to negative emotions were made e.g. anger, frustration and annoyance by the caregiver. These references were made in relation to behaviour e.g. forgetting things that you are aware that you should know. Only the PWD talked about positive emotions such as hope and the effect of limiting negative emotions once medication had been prescribed. He also used milder words such as puzzlement. In contrast the GP referred to emotional behaviour such as he “broke down”.

Are their shared understandings?

Data suggest that there are many areas where understandings are shared. Importantly throughout the interview all participants acknowledged the clinical diagnosis of dementia. This is an area that is often difficult for a doctor to disclose to their patient and caregiver (Bamford, et al., 2004).

However there were areas where understandings were not shared. For example, whereas the GP thought that PWD and C were not curious in knowing more about the clinical label because they had not asked. PWD said that he wanted to know what he could do to repair and C also stated that she wanted to know what she could do and wanted information on how to aid her husband’s memory.

Study strengths

Key strengths of this study are that it explored the perspectives of three individuals in a health care triad. Compared with other studies that do not use a theoretical framework (Steeman, et al., 2006) this particular triad systematically explored areas of shared understanding. Unlike some doctors (Bamford, et al., 2004) the doctor in this study used the word dementia and had disclosed the diagnosis to his patient and their caregiver. Using Illness Representations (IRs) provides a

framework for knowing both how to ask and what to ask to identify what patients and their caregivers are thinking, to identify areas where IRs are not shared.

An additional strength of this project was the use of psychological theory. Applying a theoretical framework has the advantage of exploring understandings in a systematic and objective manner. The participants validated this approach. At the later interview (to obtain consent to link participants' data) the person with the diagnosis and the caregiver agreed with how the data were coded. However they also noted that their IRs had not remained static, supporting Leventhal's (H. Leventhal, et al., 1984) idea that IRs are formed through active processing on a moment by moment basis. This finding also supports the work of Langdon (Langdon, et al., 2007) who suggests that how individuals think about health conditions is not static, but involves an ongoing process of adjustment.

Study limitations

The main limitation of this study is that results relate to one health care triad. Ongoing work is exploring shared understandings in a larger population (Glidewell, 2008). Inclusion criteria are based on diagnostic criteria from the UK that were applied by clinicians. It is therefore not possible to determine whether clinicians applied the inclusion criteria as intended or excluded participants that they felt should not be contacted. This study was conducted in one region of Scotland, so may be subject to cultural biases. There is therefore an opportunity to replicate this work in other areas.

This study approached individuals who had been referred to secondary care. It is possible that IRs of patients who do not present to the doctor may differ. There

may also be some patients who are not referred to secondary care, and again their IRs may differ from those in this study.

A decision was made to focus on what was talked about by PWD, C and GP. Data about other variables (e.g. other clinical conditions, current medication etc.) that may influence how people perceive their condition were not collected in this study.

Further work is needed to ensure that coding is valid as well as reliable. Work is ongoing to improve the coding of emotion as there is a need to clarify what is considered an emotion for instance: lack of enjoyment, being silly, surprise, lack of satisfaction. In addition we need to tighten the definition of coherence e.g. wanting to learn more and questioning why it happened.

Conclusions

This in-depth case study of a health care triad found that the person with the diagnosis of dementia, their caregiver and their doctor did talk spontaneously about dementia in terms of Illness Representations (IRs). However, questions specifically prompting for individual components of the IR elicited more specific data from all participants in the triad. These data taken together could be used to highlight where inappropriate information and/or missing clinical information is required by people with a diagnosis and their caregivers. The Common Sense Self Regulation (CS-SRM) Illness Representations (IRs) provides a theoretical framework for knowing what to ask people with a diagnosis to explore their condition from their perspective.

Table 1 Interview questions for person with the diagnosis

<p>Open questions (This section generated the “LABEL” used in subsequent sections.)</p>	<ul style="list-style-type: none"> •You had an appointment with doctor INSERT NAME is that right? •What was it for? •Can you tell me about what made you go to the clinic? •How has it affected your life?
<p>Identity</p>	<p>How do you describe your INSERT LABEL in your own words?</p> <p>How does it affect you?</p> <p>What do you think are the symptoms associated with INSERT LABEL?</p>
<p>Cause</p>	<p>People often have ideas about what caused their INSERT LABEL – do you have any ideas about what caused your INSERT LABEL?</p>
<p>Cure/control</p>	<p>Are there things that can be done to manage or treat your INSERT LABEL?</p> <p>Are there things that you can do?</p> <p>Are there things other people can do?</p> <p>Are there things that can cure INSERT LABEL?</p> <p>Are there things that can control INSERT LABEL?</p>
<p>Consequence</p>	<p>How does INSERT LABEL affect you – what are the consequences of having INSERT LABEL?</p>
<p>Timeline</p>	<p>How does INSERT LABEL change with time?</p> <p>How do you think it will change in the future?</p> <p>How long do you think that INSERT LABEL will last?</p>
<p>Emotion</p>	<p>How does INSERT LABEL affect you emotionally?</p>
<p>Coherence</p>	<p>How well do you feel you understand INSERT LABEL?</p>

Table 2 Illness Representations spontaneously elicited across the triad

Identity: labels	P	C	GP	Cause	P	C	GP	Cure/control	P	C	GP	Timeline	P	C	GP	Consequence	P	C	GP	Emotion	P	C	GP	Coherence	P	C	GP
	WD				WD				WD				WD				WD				WD				WD		
Alzheimer's	x			Want to know more				Control – unsure				Onset		x		Aware	x		x	Does			x	Aware something wrong			x
Dementia		x	x	Do not know				Personal control				Expected duration	x		x	No effect		x		Does not				Understands condition			x
Vascular related dementia				Genetic				Others control	x	x	x					Physical/functional		x	x	Did				Want to understand	x		x
Out of sorts				Old age				No cure								Personal	x		x	Positive emotions				Puzzled			
Mixed state of mind				Dementia												Social			x	Negative emotions		x		Not able to understand			
Identity: Symptoms				Vascular related dementia												Economic							Limited information				
Short-term symptoms			x	Hypertension																							
Remember differently	x			No grasp underlying process																							
Aware something wrong	x		x	Not looking further																							
Progressive symptoms																											
Not serious																											
Functional capacity	x		x																								

PWD person with dementia
 C caregiver
 GP doctor

Table 3 Illness Representations of Identity across the triad

Identity	Identity refers to the category, name or label of the illness, and the experience of symptoms, changes in function and visible signs that are identified with the illness. The combination of abstract and concrete experiential features 'define' or identify a disease/condition. (H. Leventhal, Forster, & Leventhal, 2007)		
Identity: Labels	Person with diagnosis	Caregiver	Doctor
Alzheimer's	Now I know that the visit was for, because of the fact that I have perhaps the early or there is evidence of the early stages of Alzheimer's. PWDidentity1	So whether his dementia or Alzheimer's will go that way I don't know. Cidentity1	Beyond the fact that we've labelled it as being Alzheimer's GPidentity1 I think he would just say oh I've got early Alzheimer's GPidentity2
Dementia		So whether his dementia or Alzheimer's will go that way I don't know. Cidentity2	he'd obviously been assessed by me, I was fairly sure he had dementia, and I wanted a second opinion GPidentity3 Erm I'm not sure he, I mean, I think he would probably answer dementia GPidentity4
Vascular related dementia			I would imagine he's got vascular related dementia GPidentity5
Out of sorts	Ah, I would say that some of the time erm I have been affected by feeling just a little bit, sort of, I would say woofy, just a feeling that I have on the odd occasion during the day. When I feel gently out of sorts. But eh it doesn't really affect me in any extreme way. PWDidentity2		
Mixed state of mind	in my mixed state of mind PWDidentity3		So I think it was fairly obvious for him, GPidentity6
Identity: Symptoms			
Short-term symptoms	and you speak about the past and that's been, that's been no difficulty but there are a few things that I've forgotten about what happened over the years. But it is this making silly little thing about forgetting that I've said something or did something erm two or three days before, and I've forgotten clearly that I had done it, PWDidentity4	Well the symptoms are just immediate things he forgets, erm... Cidentity3	very dramatically impaired short term memory, GPidentity7 What would he think the symptoms were, I think he thought the main symptom was that he erm had a very diminished short term memory. GPidentity8
Remember differently	Pretty good apart from having to sort of, occasionally eh be faced by the fact somewhere along the line small detail does seem to change. It doesn't, it hasn't changed, I've forgotten eh briefly how something transpired, or something took place, PWDidentity5		

Identity: Symptoms	Person with diagnosis	Caregiver	Doctor
Aware something wrong	and I know that there's something wrong, PWDidentity6		But he is aware that there is the potential for him to get worse with time. GPidentity9
Progressive symptoms	My memory will change PWDidentity7	his mother lived with us for ten years. I looked after her until she died, and eh it was obvious then the type of memory loss she had. But she could be very lucid some days. And some days not so lucid, it just went in spells. Cidentity4	eventually he will get worse, but eh I mean, GPidentity10
Not serious		Well it's not serious, and the only thing I say to him, is look it could be worse, you could have a really serious illness that caused you a great deal of pain, and eh, you could be having chemotherapy, you could be having radiotherapy. Cidentity5	
Functional capacity			memory loss is the main one but also a functional capacity reduction from where he was usually able to manage. GPidentity11

Table 4 Illness Representations of Cause across the triad

Cause	Cause reflects the perception of the single or complex set of events that are perceived to be responsible for disease/condition onset. (H. Leventhal et al., 2007)		
Cause	Person with diagnosis	Caregiver	Doctor
Want to know more	I've given more, I've been in a position where I have to think more about, erm why did it happen, PWDcause1	But eh he would never really say what causes it, he would like to know, I think. Ccause1	
Do not know	No, I've no ideas whatsoever, I've never even considered it. PWDcause2	I don't think he ever see's what causes it, Ccause2	
Genetic		but of course his mother had dementia. So he accepts the fact that it can run in the family. Whether it is completely hereditary, I don't know. I haven't that medical information. I haven't that knowledge I should say. Ccause3 And then HUSBAND'S NAME has had a, one sister died two years ago, and she did have dementia but her also problem with her was she had cancer, lung cancer and she had to go into a home, she was a widow. Now his other sister who's had a very serious op three years ago almost died, suddenly lost her husband, he on the 18th September, he died in the house, and she was on her own with him. And erm, she's now living with her daughter, but I don't think that she's forgetful she's very acute, HUSBAND'S NAME thinks that she's beginning to forget things and she's two years older than he is ha ha Ccause4	
Old age		Well he just says well I'm getting old, Ccause5	he probably had been putting up with and thinking it was just part of getting old. GPcause1
Dementia			Erm I'm not sure he, I mean, I think he would probably answer dementia GPcause2
Vascular related dementia			
Hypertension			Well he's got hypertension, he's had that for a number of years. GPcause3
No grasp underlying process			without really looking into the reasons about the pathogenesis of, of dementia, I don't think he actually has got any really grasp of the underlying process, GPcause4
Not looking further			I've got Alzheimer's, without looking into what is Alzheimer's. GPcause5

Table 5 Illness Representations of Cure/control across the triad

Cure/control	Control refers to the expectation that a specific disease can be cured or controlled by the body's own defences and/or in conjunction with expert intervention, and the actual experience of the effects of these interventions on specific features (symptoms and/or test results) of disease/condition. (H. Leventhal et al., 2007)
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Cure/control	Person with diagnosis	Caregiver	Doctor
Control – unsure	<p>I don't know, and I doubt that there is totally, but, even to stabilise it or eh, bring about an improvement, or at least stem the deterioration eh a little, PWDcure/control1</p> <p>So on that basis I'm hoping that, assistance will arrive on the scene and perhaps prolong stability. PWDcure/control2</p> <p>I hope there is. I sincerely hope there is but I will not condemn, because I'm not the first. PWDcure/control3</p>	<p>he started a course of remenate XLA and they are hoping that will retard the deterioration. But of course it depends on the person doesn't it. So. Ccure/control1</p> <p>Well I do think they are trying. I think they are trying with modern drugs, but of course they are bound to be expensive and as you know the National Health are cutting back on their expenses, so if he is fortunate enough to be given these drugs, and I have a friend, or he has a friend who's got the same problem and his wife advised me last year to see about it, and to get help for him, because it did help her husband for a spell until it became obvious that he'd reached a level where they couldn't do anymore. And she said look stop the drugs, because they are expensive and give someone else the benefit of them. Ccure/control2</p>	<p>I think eventually he will get worse, but eh I mean, it's relatively early days of these drugs, in the sense that I have got patients who have been on them for a couple of years who haven't, who have maintained a level of cognitive function, without any obvious deterioration so hopefully he'll get a period of stability but it often, at the moment one would expect that his dementing process would get worse. GPcure/control1</p> <p>Because I wanted him to have Aricept or something similar. I mean my explanation to him was that there were drugs that could at least arrest the process of dementia, if not reverse it. GPcure/control2</p> <p>Prescribe the drugs, I think. I don't think, I think, well he, he is aware that we are monitoring his blood pressure, and that various other bits and pieces, and obviously keeping himself well in general he thinks I can help him do that, I think also he's, he expects me to continue to prescribe a drug for as long as it is working, erm and that would be the thing that is probably made more difference than anything else. GPcure/control3</p> <p>I can continue to see him to reinforce all of the positive influences and maintaining his wellbeing. Make sure he complies with his medication, do a review regularly, keep an eye his MSQ and obviously maintain links with Dr Athawes. GPcure/control4</p>

Cure/control	Person with diagnosis	Caregiver	Doctor
Personal control	<p>So on that basis you do think more deeply, about what's happening and eh what can be done to change it. PWDCure/control4</p> <p>If there are some things I can do, I will do them. Especially on good advice, well on advice from someone who has this wider knowledge. I will do them. PWDCure/control5</p> <p>I wish I knew more about it, and I knew sort of how to do something about it positively and effectively, PWDCure/control6</p> <p>Well you know I'm hoping that in some way, eh some combination of erm treatment, or medication or something, can give me, I've no desire. I enjoy my life. (Respondent cries) people have given me a lot, and I want to give it back... PWDCure/control7</p> <p>To help me? I don't know. Most people are very helpful, I've got a very helpful family, so no problem. PWDCure/control8</p>	<p>but he tries to treat it now, now he has accepted it, he said right I've got mild Alzheimer's so I've just got to go on, the way I go. Ccure/control3</p> <p>he's doing all his admin. Ccure/control4</p>	<p>I think he can, he can practice and push himself and do the things he had previously been stopping doing and try and continue living as active a life as he can, and challenging it intellectually and doing the things that would keep the brain active and also look after himself keep his blood pressure healthy, take a good diet and exercise, all the usual things plus carry on with his medications. GPcure/control5</p>
Others control	<p>But on this basis, on the basis of memory difficulty then, I really am in the hands, of the doctors, of the specialists, and whatever they advise and guide I should imagine that I will follow. PWDCure/control9</p> <p>So, I really don't give it much thought apart from listening to good advice from my doctors and eh on that basis, and their experience, believing in what they are saying, and following what they advice, otherwise I, you know it's very difficult for me as a, an individual to make up my mind as and how I want to live my life. Although I live a very straight forward life. I just want, their best advice and I will follow that. PWDCure/control10</p>	<p>I had mentioned to his doctor that, he was forgetful but nothing was done Ccure/control5</p> <p>No, I think eh, if you can give him, nudge him gently in the way of remembering without making it obvious, Ccure/control6</p> <p>but then I started making sure that I note in my diary his appointments alongside mine, or of that sort, so that if I looked what I'm doing for the next few days in my diary eh, I have his appointments in as well. Ccure/control7</p>	<p>I think what brought him to our attention was the fact that something else happened acutely cause, the kind of, the word in the practice, because I'm not his doctor, normally the word in the practice was that he had been deteriorating, well he was coming up to ask for scripts or to come for his check-ups, the staff were aware he was deteriorating before their eyes, and, he wasn't making any requests for any assessments and I am, in retrospect, now that we are there, so the staff obvious, they were obviously aware that he was becoming frail elderly. GPcure/control6</p> <p>who's been the gatekeeper to him getting this drug that has definitely made a major difference so I think he sees Dr Athawes as being a kind of specialist person for him to go to with that particular problem for more detailed eh assessment or whatever it is he recommends you. GPcure/control7</p> <p>I would assess them, find out whether there is any contributing things I can see to, and if I felt appropriate refer them to Dr Athawes if I wanted therapeutic intervention, or if I felt it was more basically to do with dementia and the care and everything and the environment I would get the care, the dementia care manager involved. GPcure/control8</p>

Cure/control	Person with diagnosis	Caregiver	Doctor
No cure	It hasn't erm, it wasn't planned, I didn't organise it, and I doubt if I can reverse it. PWDCure/control11	Well I hope that in the future they can, but I don't think just now they can. Ccure/control8	if you were going to use the words cure and control I think really that the psycho-geriatrician and the doctor would at the moment be the best people placed to do that. GPcure/control9

Table 6 Illness Representations of Consequences across the triad

Consequences	Consequences are the set of expected and perceived physical/functional, personal and social and economic factors that are impacted by the illness/condition. (H. Leventhal et al., 2007)		
Consequences	Person with diagnosis	Caregiver	Doctor
Aware	and eh I do have difficulty now, I do have difficulty. PWDconsequence1	but of course he's so acute he knows. He's not, not a stupid man, and he can see if you're guiding him in certain ways. Cconsequence1	So I think it was fairly obvious for him, a level that he was trying to function at that he was struggling, many people who have maybe led a quieter life, less demanding life, would maybe not be aware as early as he was, so he was, so he had typical symptoms, GPconsequence1
No effect	because, when it comes down to brass tacks, I live a pretty, sort of normal life with the issue, disturbances in it, look after it, eat well and sleep well. PWDconsequence2	No, no we just have to deal with it. Cconsequence2 it is only immediate things, he remembers things far back that I don't remember, he remembers details I would never remember, so in some respects he's far luckier than I am because I have, I haven't recollection, of things far back. Cconsequence3 I feel that he knows he isn't capable of learning, or he doesn't want to learn new skills. Now that's the difference I would like to learn new skills, but this must be the mind set, you know the level that his mind is at now. He is probably incapable of learning new skills. Because he doesn't want to. Cconsequence4	
Physical/functional	Because I may feel totally out of sorts by the end of day, just because of the sheer emotion of the whole situation (respondent cries) so on that basis I may have to. PWDconsequence3	Well the symptoms are just immediate things he forgets, erm... he takes longer to do things. He's not, he always has been a thinker before he would act, but he's definitely slowing down slightly. Cconsequence5	And also a diminished ability to work out what he, where he was and what he was supposed to be doing. Almost at the basic level of oh right, sometimes you would actually ask his wife, why are we here or whatever so, memory loss is the main one but also a functional capacity reduction from where he was usually able to manage. GPconsequence2 he would describe it as that he was no longer able to do many of the things that he used to take for granted. He wasn't able to, he wasn't as good at thinking, he wasn't good at remembering, he wasn't as good at joining in in some of the things that were happening like going on holiday, going out for a meal, so he just, he, he didn't have the same confidence in his ability to actually handle these things, these new or challenging situations. GPconsequence3

Consequences	Person with diagnosis	Caregiver	Doctor
Personal	<p>so that erm, it becomes more, becomes more difficult to be confident that when you do give an answer, the answer that you sometimes giving, may be correct, but it may not be correct, eh and that as an individual I don't particularly enjoy, PWDconsequence4</p> <p>So that I do realise that going from a point where, life had no termination, possibly there's going to be a shorter life span than I'd considered just a matter of two months ago. PWDconsequence5</p>	<p>Put him under pressure and he can't answer you as well as he would if he wasn't under pressure, that sounds Irish but, it's obvious, if he feels under pressure he can't react normally. Cconsequence6</p> <p>Though the doctor says no, at this present instance he's quite capable of driving, but we know it will come, but he'll be told at, at 82 he should be stopped driving you know. Cconsequence7</p> <p>that's giving up a little independence. And that would be sad. Cconsequence8</p>	<p>progressively erm affected by short term memory loss. Eh loss of confidence, GPconsequence4</p> <p>he couldn't tell you what he had for his breakfast, he sometimes put on this pseudo of oh dear a kind of dispractic type thing where he wasn't functioning, he used to be, he used to go out and play bridge or whatever and he wouldn't do that, erm, you know he kind of , he wasn't able to function eh interactively with other people, who he would normally feel comfortable with, he was becoming less able to be erm, an active part of, with his family, community, the work, they had the shop, when they were, he was just withdrawing into himself because he felt less able and he was being protected by his wife, he was patently aware of his limited, limitations. GPconsequence5</p>
Social	<p>Because there are sometimes and some things that we like doing, that I am thoughtful now about whether or not we should actually do them, not necessarily from the point of view of, it would be wrong and counterproductive, but just the fact that, during the time that I was doing them, would I then have a slight change and in some degree of pleasure or enjoyment of what we've, we've, planned to do, so rather than, PWDconsequence6</p> <p>believing in what they are saying, and following what they advice, otherwise I, you know it's very difficult for me as a, an individual to make up my mind as and how I want to live my life. PWDconsequence7</p> <p>I had another three quarters of an hour when WIFES NAME said, don't forget you know, 11 o'clock is appointment time. I said no, it's 11.30 so I went and got my diary immediately and sure enough it was 11 o'clock ha ha. So there it is. PWDconsequence8</p> <p>Well I haven't bowled this year. Now that was a, that, that's got nothing to do with my health. It had to do with circumstances within the bowling club erm PWDconsequence9</p>	<p>You can see he was getting forgetful, our family did too, but eh they just used to laugh about it. I told dad that they would say to me, and I would say well, he didn't remember, but now he is eh, getting, as he is more conscious of it, it makes him worse. If that sounds sensible. Cconsequence9</p> <p>Now that, this is one thing that he seems to be unwilling to participate in, social events. All right small gatherings, but larger gatherings no. Now that is definitely a consequence of eh the inability to cope under stress I would say. Cconsequence10</p> <p>And not so able to... he never was a very social person he's very good in single one to one conversations, he's not good in a large company a) because he's totally deaf in his left ear through war service, and he likes to have a serious conversation with someone, he's not a chit chat person in a social scene. Cconsequence11</p> <p>he always says, well you come with me because you'll absorb what is being said, and can remind me later. Cconsequence12</p>	<p>the word in the practice was that he had been deteriorating, GPconsequence6</p> <p>loss of erm ability to do things he would normally be quite comfortable to do. Including during the day and socially, playing cards, whist or whatever with his friends and he was deteriorating in his mental capacity to an extent where it was fairly obvious that he had early dementia. GPconsequence7</p> <p>they as a couple their lifestyle is modified, in that, they would be away from home a lot abroad particularly, out for meals, very much a social dynamic couple I think. He's aware that the consequences are at least in part erm that that lifestyle would be to some extent curtailed and he may not go quite as far a field, and may not go for quite as long at a time as he would previously have done. GPconsequence8</p> <p>he had stopped doing many things that he used to love doing, was frightened of going on holiday etc. Lost many of the, of the hobbies and activities that he loved doing, sort of lost his sort of place in the, kind of heart of his family and the business, GPconsequence9</p> <p>she would deal with things that are troublesome, and he would be kept probably away from that. Difficult decisions or, or, or major issues in the family, illness in his grandchildren or whatever, I think that she would probably deal with most of these things and keep him out of any, any, stressful situations where possible. GPconsequence10</p>
Economic			

Table 7 Illness Representations of Timeline across the triad

Timeline	Time-line is the duration that is expected and/or perceived with respect to the onset and duration of an illness/condition both with and without effective treatment. Time-lines are represented abstractly as clock and calendar time and concretely as experienced or felt time. (H. Leventhal et al., 2007)		
Timeline	Person with diagnosis	Caregiver	Doctor
Onset	<p>No problems at all until just past the last two or three years erm PWDtimeline1</p>	<p>Yes. So that is one definite I would say effect, and that is as long as five years ago I noticed that. It's just such a gradual, insidious thing you don't, you just, you know yourself you can forget something. Ctimeline1</p> <p>He can function quite normally, some days. Ctimeline2</p>	<p>erm in particular his short term memory and just general cognitive function had been significantly impaired, for many, many months, GPtimeline1</p> <p>Something like that but I haven't got the notes so it's difficult, but certainly it would be a couple of months between A and B but in that, in that couple of months he'd obviously been assessed by me, I was fairly sure he had dementia, and I wanted a second opinion just so that I could then go ahead and use the drug and, and in the way that we are supposed to do regarding the local guidelines. GPtimeline2</p> <p>he had fairly significant dementia for a long time GPtimeline3</p>
Expected duration	<p>And I, no, I'm willing to look ahead, although I realise that, the last erm, sort of couple of months have totally changed any real thoughts I have, on erm, prolonged life, it might, might be shorter than I thought it would be, because er, prior to my, having my little turn eh when I was on my break, I gave no thought to ill health because I have been so well, for so many years. That's about it really. PWDtimeline2</p> <p>I think that the future is open. PWDtimeline3</p> <p>So that I do realise that going from a point where, life had no termination, possibly there's going to be a shorter life span than I'd considered just a matter of two months ago. PWDtimeline4</p> <p>but I suppose there may be a time in the future when it would be, it will just become a welcome release, PWDtimeline5</p>	<p>Well I think he'll definitely get more forgetful. And erm, definitely unable to cope with everyday things I know that will happen eventually. But until then we just have to keep going. Ctimeline3</p> <p>And as he was told I won't mention names, erm at 82 he's not going to live long enough to reach the very difficult stage, that would be, unless he progresses very rapidly, but at the rate that he has shown the deterioration of memory, it is only immediate things, he remembers things far back that I don't remember, he remembers details I would never remember, so in some respects he's far luckier than I am because I have, I haven't recollection, of things far back. Ctimeline4</p>	<p>it turned out to be more of an ongoing chronic problem. GPtimeline4</p> <p>I think he has regained many of the things that are involved in that by taking the medication but I think that will be temporary, I think he will gradually lose them again. GPtimeline5</p> <p>It's difficult to be objectively confident of saying things but I would have thought that he would probably deteriorate in the next three or four years. GPtimeline6</p> <p>Erm well I've told him that this can be a progressive condition and that the drugs are intended to at least stop and if not, I mean to some extent reverse it. But he is aware that there is the potential for him to get worse with time. GPtimeline7</p>

Table 8 Illness Representations of Emotion across the triad

Emotion*	An emotional response generated by the illness/condition. (Moss-Morris et al., 2002)		
Emotion	Person with diagnosis	Caregiver	Doctor
Does	<p>Only when I speak about it ha ha only when I speak about it. No it doesn't affect me at all. I don't worry about it really, PWDemotion1</p> <p>those particular circumstances tend to surprise me, still surprise me, ha ha and I still feel that on the odd occasion that eh like this morning. PWDemotion2</p> <p>and that er, something that I've been very puzzled about really was not exactly what had happened at the time. PWDemotion3</p> <p>Now this year I am a little apprehensive, that if I do, if we do go, just the intensity of the, of the friendship and the conversation and the general sort of day to day build up of, of erm activity. PWDemotion4</p> <p>Because I may feel totally out of sorts by the end of day, just because of the sheer emotion of the whole situation (respondent cries) so on that basis I may have to. PWDemotion5</p>	<p>And he tries to treat it with humour. But it must get upsetting, he does occasionally go and weep about something. Cemotion1</p> <p>He is emotionally affected he, he can eh, weep about certain things, you know he has to stop himself and compose himself because he finds it distressing I think and it's difficult to say what really distresses him emotionally erm, can't just put it in instantly. Cemotion2</p>	<p>eh it was beginning to get to him as regards to he was beginning to lose confidence as a result of it. GPemotion1</p> <p>obviously emotionally labile GPemotion2</p> <p>his wife would be the first to say that he isn't the same. He is, less able to deal with things that are stressful emotionally and therefore would, would kind of accede to whatever she felt. GPemotion3</p>
Does not	<p>Well I don't feel downhearted and low, I'm very thoughtful, and I know that there's something wrong, but I don't feel downhearted and low. It wouldn't do me any good. PWDemotion6</p> <p>but I, I don't think that way at all, I've no negative thoughts at all on this. PWDemotion7</p>		
Did			<p>often broke down into tears, he, since he has been on the medication, has dramatically improved in that context and he's now, I would have said fairly back to normal regards to his emotional stability, he is no longer nearly as tearful as he was. GPemotion4</p>
Positive emotions	<p>and have said previously, all I want to do, find out what I can do to stabilize it and if possible erm re-divert it and bring about a continuation of something I enjoy. PWDemotion8</p>		

Emotion	Person with diagnosis	Caregiver	Doctor
Negative emotions	<p>But it doesn't frighten me, I don't, it doesn't depress me to, it disturbs me a little, it doesn't frighten me because I thought I was in good shape, and well looked after, I've led a very good life. PWDemotion9</p> <p>not satisfactory, in no way satisfying, PWDemotion10</p> <p>although it doesn't really upset me awfully terribly I don't enjoy the fact that somewhere along the lines, something is starting to go wrong. PWDemotion11</p>	<p>But he would, forget that I had told him something, when I say to him, well I've told you that, he gets angry. Cemotion3</p> <p>In that he gets frustrated, definitely frustrated, Cemotion4</p>	<p>was frightened of going GPemotion5</p>

Table 9 Illness Representations of Coherence across the triad

Coherence*	How much patients understand or comprehend their illness/condition. (Moss-Morris et al., 2002)		
	Person with diagnosis	Caregiver	Doctor
Aware something wrong	and I know that there's something wrong, PWDcoherence1	Oh I think that he's fully aware of it. But eh, understanding the reason, I don't know. I've never really discussed with him, I've always tried to be upbeat and say look alright so you forget things, but that doesn't alter our lives. Ccoherence1	However also was particularly aware of having almost no short term memory, GPcoherence1
Understands condition		he's just accepted it, and since he's accepted it I think he's beginning to come to terms with the fact that he has to be reminded to do certain things. Ccoherence2	Erm and the way to access to that had to be through a consultant psycho geriatrician so that was, that was his understanding of why he was going to the clinic. GPcoherence2
Want to understand	I'd be willing to learn more. PWDcoherence2 I'm thoughtful about it, I wish I knew more about it, PWDcoherence3	I don't think I know enough about it. Ccoherence3	
Puzzled	It's something that I haven't really given a great deal of thought too, because only recently have I had to face, suddenly I've had to face the fact that because of the collapse in, in, due to pneumonia in the lung um, I've given more, I've been in a position where I have to think more about, erm why did it happen, what can I do to get over it, and how can I repair any damage that was done at that particular moment urm. PWDcoherence4 No clear picture. PWDcoherence5		
Not able to understand			Beyond the fact that we've labelled it as being Alzheimer's I don't think that he is either that curious or that able to actually assimilate all the information that would be necessary to give him a much more detailed explanation. His wife would be different on the other hand, if she was to ask more searching questions I'm sure we could reveal all the relevant facts but she, they would be typical of many of the patients with dementia and their families, in that they would accept the label, accept the treatment but not really look for much more than that.¶ GPcoherence3
Limited information			he understands it to the level whereby we've used a label if I said oh i.e. Alzheimer's and we've explained that the drug is proven to be of benefit to many people with Alzheimer's and that he certainly would fit that criteria at the moment. But I, we haven't gone into anymore greater detail than that. GPcoherence4

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