

**The role of the fear-of-loss-of-control marker within the accounts of people affected by
dementia about their illness: implications for psychotherapy**

Richard Cheston

Professor of Mental Health (Dementia) Research

University of the West of England

Bristol

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Abstract

One way research can explore the psychological and social factors underlying the awareness of people affected by dementia about their illness is by intensive examination of the process of psychological change as it occurs both within psychotherapy and in ordinary life. The assimilation model describes a series of stages through which clients' problematic experiences are hypothesized to progress during successful psychotherapy. Markers of assimilation stages are recognizable types of events in psychotherapy discourse that are linked to those stages and which may be useful both clinically and in research. This paper describes how the "*fear-of-losing-control*" marker may operate in the accounts of people affected by dementia. Analysis of examples of the fear-of-loss-of-control marker suggests that it is associated with avoidance of referring to dementia by name (referred to here as the Voldemort phenomena), the experiences of shame and fears of the loss of self, for instance expressed as concerns about becoming mad. Implications for dementia care and for post-diagnostic therapy are considered

Una delle strategie attraverso cui la ricerca può esplorare i fattori sociali e psicologici che sottendono la consapevolezza delle persone affette da demenza circa il loro stato patologico, è l'analisi intensiva del processo di modificazione psicologica nel suo verificarsi, sia nel contesto psicoterapeutico che nella vita quotidiana. Il Modello dell'Assimilazione (Assimilation Model) descrive una serie di passaggi ipotizzati come il percorso di assimilazione delle esperienze problematiche che il/la cliente effettua nel corso di un trattamento psicoterapico efficace. I marcatori degli stadi dell'assimilazione sono quei tipi di eventi, riconoscibili nel discorso psicoterapeutico, che sono associati a quei passaggi, e che possono risultare utili sia nella clinica che nella ricerca. Questo lavoro descrive i modi in cui l'azione del marcatore 'timore-di-perdere-il-controllo' si rende riconoscibile nelle narrative autobiografiche delle persone affette da demenza. L'analisi di esempi del marcatore 'timore-di-perdere-il-controllo' suggerisce che esso possa essere associato all'evitare di far riferimento alla demenza chiamandola con il suo nome (ciò che qui definiamo fenomeni Voldemort), oppure alle esperienze di vergogna, nonché ai timori della perdita del sé, espressi per esempio attraverso la paura di stare impazzendo/ di impazzire. Vengono discusse le implicazioni rispetto alla cura e alla terapia da intraprendere dopo la diagnosi.

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*“Oh God”
“I as good as lost myself”
“I have lost myself”
“I am lost”*

Frau Auguste Deter as recorded by Dr Alois Alzheimer, 25th November, 1901.

Introduction

The term “dementia” refers to a range of conditions, the most common of which is Alzheimer’s Disease. There are estimated to be around 36 million people living with dementia worldwide, with this figure expected to rise to 66 million by 2030 and 115 million by 2050 (Alzheimer’s Disease International, 2012). The increasing prevalence of dementia, with its associated costs, means that it has become a clear priority area for policy makers as well as researchers. Thus in the UK, the 2009 policy document “*National Dementia Strategy: Living well with Dementia*” emphasises the importance of early diagnosis so that people are able to take greater control over their condition, to be involved more actively in planning care and thus to “*live well*” with dementia.

The move towards an early and timely diagnosis of dementia is based, at least in part, on the belief that this will facilitate people who receive a diagnosis being able to plan ahead and to take control over their illness. However, it is likely that the emotional weight of a diagnosis combined with the impact of the neurological impairment and social difficulties in talking about the diagnosis mean that for many people affected by dementia it can be extremely difficult to make this adjustment. This process is likely to be further exacerbated by the lack of specialist support provided to people after they have received a diagnosis (Guss et al, 2014).

Probably the most common form of post-diagnostic support for people affected by dementia is through support or therapy groups (Cheston, 1998). There is an emerging evidence base for these groups, for instance an evaluation of Early Stage Memory Loss Support Groups in the USA by Logsdon et al (2010) found significant improvements in quality of life and depression compared to a

control condition. In the UK, research into the effectiveness of a 10 week group intervention found preliminary evidence that this lowered levels of depression compared either to baseline and follow-up (Cheston, Jones and Gilliard, 2003) or to a psycho-education group (Cheston and Jones, 2009), and that similar groups can be delivered in memory clinics by nurses and others without a formal background in psychotherapy (Marshall et al, 2014) and within primary care (Cheston and Howells, forthcoming).

Although there is some evidence, then, to believe that therapy groups can reduce levels of depression or improve quality of life, it is not clear if these groups also help people to adapt to their illness. This is especially important when working with people affected by dementia, where adjustment to the illness is affected not only by the neurological impairment, but also by the emotional threat that a diagnosis brings with it. Thus, it is only possible for people with dementia to prepare for the future if they can both acknowledge the impact of the illness on them and think ahead to a future of decline. This presents a significant psychological and emotional challenge. In this paper I will explore the contribution that a process model of therapeutic change can make to understanding the emotional impact of dementia.

Assimilation Analysis: the MAPED process. The Assimilation Model of psychotherapeutic change (Honos-Webb & Stiles, 1998; Stiles, 1999; 2001; Stiles *et al*, 1999) is a transtheoretical model of the process of change that occurs in psychotherapy. The Assimilation Model is not a description of how to do therapy, but rather a way of formulating the nature of change that can occur in any form of therapy, or indeed, in everyday life. It has been used to analyse the process of change within psychotherapy sessions not only with clients with a wide variety of mental health needs such as post-traumatic stress (Varvin & Stiles, 1999), but also with people with learning disabilities (Newman & Beail, 2002) and those affected by dementia (Watkins et al, 2006).

The assimilation model represents the self not as a single, unified entity but rather as a community of context-dependent, shifting and multiple selves. This is consistent with post modern or social constructionist theories of the self which describe a “*community of voices*” (Hermans & Kempen, 1992; Mair, 1989; Gergen & Kaye, 1992). Typically, within the Assimilation Model these different

voices are referred to as the Dominant Voice (the voice of continuity, or the preservation of the status quo) and the Problematic Voice (which articulates the existence of threats to the established or dominant community of self-voices). Within the Assimilation Model, most experiences in a person's life are seen to be unproblematic and can be assimilated relatively routinely into that person's existing self. However, some experiences are so traumatic and their implications are so threatening that they represent a profound threat to that person's sense of self. In these cases, conflict arises between the Problematic and Dominant voices which acts to prevent the assimilation of the Problematic, so that the unassimilated material remains unacknowledged or "warded off" (Honos-Webb & Stiles, 1998; Stiles, 2001).

Within this model, the role of therapy is to facilitate a conversation between the Problematic and Dominant Voices (Honos-Webb & Stiles, 1998), leading to the resolution of the differences between the two voices and thus enabling the person to engage with and integrate the otherwise unassimilated material into the community of selves. This therapeutic conversation often takes the form of the client approaching and then retreating from the threatening material - a process that has also been described in psychotherapy with people living with dementia (Betts & Cheston, 2012).

The assimilation model recognises the dynamic nature of how change may occur both in the way in which people talk about their problems and the emotional intensity with which they do so (Varvin & Stiles, 1999). This process of change is represented in terms of eight incremental levels (see Table 1). The emotional quality of the different levels is central to this model of change. As the Problematic Voice begins to be articulated, so the person moves away from a defensive posture of warding off problematic material, towards experiencing the content as painful. In later levels, as the Problematic Voice is increasingly integrated or assimilated into the self, so solutions are tried out, confidence grows and the distressing emotions associated with the material are worked through (Newman & Beail, 2002). Each level is characterised by a number of specific speech markers (Honos-Webb et al, 1998, 1999) which are indicative of the form of dialogue that occurs at the different levels between the Dominant and the Problematic Voice. This process has been formalised through the development of the Markers of Assimilation of Problematic Voices Scale or MAPVS (Honos-Webb, Stiles and

Greenberg, 2003). The MAPVS is primarily a research tool, but it can also be used to help to formulate clinical problems, and as such has high clinical relevance (Stiles, 2001). The assimilation model has been used as a clinical tool in group therapy with people affected by dementia (e.g. Sims and McCrum, 2012) and the MAPVS has recently been adapted for use in analysing the discourse of people affected by dementia (Lishman, Cheston and Smithson, 2014). This adapted scale is the Markers of Assimilation of Problematic Experiences in Dementia or MAPED¹.

INSERT TABLE 1 ABOUT HERE

The fear-of-loss-of-control marker. Markers are identifiable events in discourse that recur throughout the transcripts and which indicate important clinical phenomena. Within the markers of assimilation framework, the transition from warding off knowledge of a Problematic Voice, towards the expression of this experience is significant. Not only is the emergence of problematic material often associated with intense feelings, but the person is, in effect, faced with a choice to either engage with this previously unrecognised material, or to continue to avoid exploring those experiences. One marker that has been identified is the “*fear-of- loss-of-control*” marker (Honos-Webb, Lani and Stiles, 1999). This marker can be identified in transcripts of psychotherapy sessions when a client contends that he or she needs to avoid an issue because it will lead to a loss of control or will be disruptive either to daily life or to his or her long held beliefs about themselves and others (Honos-Webb, Surko and Stiles, 1998). The client may describe being frightened of allowing further expression of the problematic material because of a fear of losing control in some way for instance by going mad, being excluded or rejected or being defeated. The client recognises that they have a choice to make: to continue to engage with the material and risk this loss of control, or to avoid further engagement. The latter course of action may be seen by the client changing the conversation abruptly, seeking reassurance or by leaving therapy.

Examples of the fear-of-loss-of-control marker in the accounts of people affected by dementia.

Dementia represents a significant, potential threat to self not only because it is an incurable illness that involves a progressive decline ending ultimately in death, but also because it is characterised by

¹ See accompanying document.

increasing dependency, the potential loss of identity and challenges to meaning and purpose. For these reasons, worries about developing dementia are one of the most significant fears of growing old (Kessler et al, 2012).

This paper presents a series of examples of the fear-of-loss-of-control marker identified in the accounts of people affected by dementia. These accounts are taken from research in two contexts: group psychotherapy process studies (Watkins et al, 2006); and qualitative research based on semi-structured interviews with people affected by dementia around the time of their diagnosis. Lishman, Cheston and Smithson (2014) interviewed people affected by dementia before and after they received a diagnosis, while Snow, Cheston and Smart (2014) interviewed couples shortly after one of them had received a diagnosis and asked them to discuss their experiences of dementia together.

Following Honos-Webb, Lani and Stiles (1999) I have presented extracts from interviews and therapy sessions in the form of lines and stanzas, following principles suggested by Gee (1986, 1991) in order to better convey my understanding of emphasis and psychologically important thought units. All clients' names are pseudonyms, and the use of different forms (e.g. Mr B or Ken) reflects that used in the original published material. Ellipses (...) indicate material omitted to save space. The use of two diagonal lines (/ /) indicates one person interrupting or talking over the speech of another. Italics and underlining have been used to indicate those parts of the passage that express the defining feature of a loss-of-control marker – that is the recognition of a fear of disequilibrium and the choice to avoid further confrontation with the problematic experience.

The first extract occurred in the initial few minutes of the first session of a group within the Dementia Voice project described by Watkins et al (2006). During individual therapy, Mr E had recognised that his memory was deteriorating, which he found upsetting. He was then offered group therapy. In trying to articulate his dilemma about whether or not to be in the group, so Mr E struggled to put the conflict between the DV (not to think) and the PV (awareness of something being wrong) into words:

[1] Mr E: I find what we're doing now, it brings all memories to me
so and being around listening to you all
talking

I find I just want to be

Facilitator: Normal?

Mr E: Well not normal no

[1.1] I don't think a memory loss and I don't talking, and being around each other

I'm not being funny about that

I'm trying to make a point that I'd rather be at home doing what I need to do and want to do

[1.2] And this is why I really don't want to talk about that you know,

I mean I'm sure it's being selfish but, it's just the way I feel about it

[1.3] I don't really want to be here.

Facilitator: Sometimes the things you remember that are the most painful and you do want to forget about it all.

Mr E: Yes, that's exactly, yes that's exactly what it is

Mrs A: Does it disturb you, that you can't or does it//

Mr B: //depress you?

[1.4] Mr E: Well I just don't want to be here.

I just want to be.

I've got lots of things I'd like to do, and er.

[1.5] Well, I can't think about coming here, it just brings it all back.

Shortly after this Mr E left the group session, and returned to individual work with one of the group facilitators. For Mr E. thinking about memory loss seems to have risked destabilising his psychological equilibrium (1.2, 1.5). He articulates a clear choice of either staying in the group and risking the emotional consequences of engaging with his dementia, or to leave (1.3, 1.4) and continue to ward off the distress associated with the illness. It is important to note that part of Mr E's avoidance of distress is achieved by avoiding using the terms "dementia" or "Alzheimer's disease" (despite the fact that the session was held within the local branch of the Alzheimer Society, and had the name of the charity in large letters written over the front door). Instead, Mr E restricted himself to using the more neutral term "memory loss" (1.1). In this regard, referring to more threatening terms would directly articulate the Problematic Voice, and thus risk destabilising his internal world. Thus the Dominant Voice prevents the problematic threat to the self from being articulated not only by resisting talk about dementia, but also by avoiding the use of this term.

The Voldemort phenomenon –dementia is too frightening to name. In the Harry Potter novels, a recurring device that JK Rowling uses to indicate the terror caused by the central villain, is that even his name is too frightening for almost all of the characters to use. Their fear of Lord Voldemort is so extreme that they believe that even naming him risks terrible, largely unspecified, consequences.

Thus, he is referred to indirectly, either as “*he-who-must-not-be-named*” (by his opponents) or as “*the Dark Lord*” (by his supporters). Only Harry himself and his mentor Dumbledore, are brave enough to consistently refer to Lord Voldemort directly.

Just as Voldemort is too frightening to be named directly, so too for some people are the syndrome of dementia and the illness of Alzheimer’s disease. To name dementia (and thus to articulate the Problematic Voice) is to acknowledge its existence and thus I would argue to risk a loss of emotional equilibrium. Part of the process by which an emotional balance is maintained, therefore, lies in the use of alternative methods of describing dementia: this may take the form of euphemisms (such as memory loss) or figurative language. Snow, Cheston and Smart (2014) describe an instance of this conflict which suggests the presence of a Dominant Voice seeking to suppress a stronger articulation of a threatening Problematic Voice. This material came from a couple named Sue and Peter, where Sue had received a diagnosis of dementia.

[2] Sue: [2.1] *It’s like being given a ticking time bomb*

and you never know when the next alarm’s gonna go off and

So you got that in your mind all the time

yea I’, good now I don’t think I’ve forgotten anything today and all that sort of thing

[2.2] *And in the back of your mind you know that*

you’re not right

it’s happened once, could it happen again?

and uhhh so you’re always alert

and an and when I meet people now

cause Peter’s told them

they always ask how I am and ya know and I know what (...)

I was obviously

you know when people tell you

you keep forgetting things

you start to think to yourself well maybe there is a problem

but then you want to bury that because you don’t want to know about it

[2.3] just like you dread getting cancer don’t you

and those things *something your mind just doesn’t want to know*

The choice that Sue describes is between (2.2) “*knowing that you’re not right*” and (2.3) how “*your mind just doesn’t want to know*”. Thus while the Problematic Voice threat of dementia is not directly

named, nevertheless the emotions around this threat are described here as (2.1) “*a ticking time bomb waiting to go off*” and elsewhere in the interview as “*a sword of Damocles*”.

This process of avoiding the use of the term of dementia is further illustrated by the example of Henry, which is drawn from Lishman, Cheston and Smithson (2014). In this study, people who had been referred to a memory clinic were interviewed after their original assessment (but before they received a diagnosis) and again after they had received the diagnosis. Throughout both interviews, Henry did not directly address the reasons why he had been referred to a memory clinic. During the second interview he is asked by the interviewer whether he is ever concerned about a poor memory:

[3] Henry - It [memory loss] has been in my mind yes,
 erm , because in a way it’s almost writing you off
 and I don’t think that is right at all
 [3.1] but you are suddenly becoming somebody totally different to what you used to be
 and mentally you don’t want that
 mentally you don’t want to accept that
 and I think that’s a good thing
 [3.2] because once you start waving the white flag, you pack up and I don’t want that
 (...)
 Well I think, you have got to have a positive attitude in life
 [3.3] if you don’t you just wave the white flag and you pack it all in,
 and I don’t want that, no
 (...)
 I mean once you have reached the age of 80 [3.4] it’s ever so easy to wave the white flag
 and say oh I can’t do this I can’t do that
 but you have got to have a positive attitude, which I think I have got

While Henry does not directly use the term dementia, he does describe the threatening enemy as one in which “*you are suddenly becoming somebody totally different*” (3.1). The recurrent use of the phrase “*white flag*” to describe this internal struggle (3.2, 3.3 and 3.4) suggests that while the Dominant Voice experiences the emergence of the threat of dementia as potentially overwhelming it remains determined to continue to resist further acknowledgement. Although the Problematic elements of dementia have been muted and are not voiced, they remain powerful and the person experiences their life as being poised precariously on the edge of losing control: Henry’s choice is either to fight on, or to surrender. For the Dominant Voice, even to acknowledge the possibility of dementia would be to surrender to it, and to “*raise the white flag*”.

Shame and avoidance. As we have seen in the example of Mr T from extract 1, the avoidance of problematic material associated with dementia involves both intra-psychic and inter-personal behaviour – people avoid thinking about dementia by avoiding situations which may trigger such thoughts. Thus many people affected by dementia withdraw into a more secure environment and seek to control where they go and who they meet. In many cases this may reflect a behavioural strategy motivated by a fear that to engage with the external world may be psychologically de-stabilising. Just as Mr E withdrew from the group, so there are accounts of other people also withdrawing from a wider social world because they wish to hide their altered state. The next extract is taken from the Dementia Voice study reported by Watkins et al (2006) and illustrates how shame and avoidance of the name (of dementia) can be associated with a wider social avoidance:

[4] Mrs A: I've met a lot of people who are rather ashamed of not being like everybody else
but I mean none of us are like everybody else//

Mr F: //I was like that

I was just saying I didn't want anybody to know anything about it

Not going out the front door

being ashamed of the name

The experience of shame is fundamentally social: shame involves a comparison with others in which people may be paralysed by a self-conscious sense of being judged as inferior and, to an extent, morally deficient. The possibility of dementia may be problematic for the self because it involves the loss of many highly valued competencies and the consequent emergence of socially devalued dependency. Thus the Dominant Voice may not only resist the articulation or naming of this Problematic, dementia-related part of the self, but also avoids situations in which it may be exposed (Gilbert, 1988, 1997 and 2000; Gilbert and Andrews, 1988).

Fear of loss of self. In the next extract, again taken from the *Dementia Voice* group therapy study, Mrs H was one of seven participants. This extract occurs immediately after one participant, Mr B, has twice asserted that nobody in the group had dementia or Alzheimer's disease. In response the group had begun to articulate concerns about dementia, and especially feelings of embarrassment and shame. Mrs H who had previously been relatively quiet within the group spoke about her fears of the future:

[5] Mrs H: And I just wonder where it's going to end, that's my fear
you know where am I going to end up, just before the end you know
Facilitator: So what is the frightening, when you say about the future?

[5.1] Mrs H: Being, being useless, you know.

Mrs A: yes

[5.2] Mrs H: not having all my faculties, I dread that, I dread that,
it's as if I'm going to sort of come to it one morning, perhaps, you know

[5.3] and think oh my godfathers, what's left
you know I really worry about that.

(...)

So I'm quite happy in a situation unless I chose to sort of sit there and think.

[5.4] And then I come down, the curtain comes down

Mrs A: What do you think about? Negative?

Mrs H: How it was,

well yes, in the beginning it all seemed negative

Facilitator: And that's when the curtain comes down?

Mrs H: Yes, yes

In this extract, Mrs H was able to articulate both the Problematic Voice (5.1 and 5.2) that the dementia will amount to a negation of herself (5.3). In this regard, this extract reflects a more nuanced, assimilated understanding of the threat of dementia than has been described before in this paper. However, this extract was still rated as a fear-of-loss-of-control marker because Mrs H acknowledged a choice: to continue to explore the Problematic Voice (and risk a loss of psychological equilibrium); or to allow the Dominant Voice to assert control and have the “*curtain come down*” (5.4). The next extract also reflects the Dominant Voice's fear about a future negation of self. Here Sue talks about her memory of her father-in-law (Snow, Cheston and Smart, 2014).

[6] Sue: but I mean, physically could I mean ah,

I think that's the biggest worry

I think anybody with mental health has that physically your body could go on longer than
your brain

and then you cease to be

you, you're just a function, like your Daddy was in the end, just a function

and that's what I don't want,

I think my problem is we nursed Peter's father through Alzheimer's didn't we?

so you know how that particular disease progresses

and you

you don't really want to be reminded that's maybe the way I go

Resolution and Assimilation. The final two extracts differ from the others that I have used in this paper as they do not involve a fear-of-loss of control marker. Instead, these extracts were rated as

markers of a more assimilated form (level 6: problem solution) which is characterised by the person noticing that they have changed. The significance of these two extracts, lies in the way in which both Mr B (from the *Dementia Voice* project) and Len (from Lishman, Cheston and Smithson) were both able to reflect on how their initial fears at a potential loss of control had previously prevented them from acknowledging the existence of their dementia.

The next extract is taken from the ninth of ten sessions in the group, during which participants reflected on what they had gained from attending the group. For Mr B, his dementia seems to have been problematic because he associated memory loss with being stupid and resenting his reliance on other people. However, this extract also suggests that his initial reluctance to address his dementia openly had been associated with fears of madness.

[7] Mr B: I find I've, I've got a great deal of moral uplift by coming here

Meeting you, listening to the way you do it

And I don't see the problem now

it frightened me, the problem of declining memory,

until I came here

and now I'm not frightened

(...)

It frightened me

because I thought, well, I'm going mad, I'm going crazy

What am I going to be like in another five years?

But now I realize that everybody is getting this problem

Watkins et al argued that a pivotal point in therapy for Mr B occurred when the Problematic Voice (a fear of madness) was assimilated into the community of voices. They argued that this resolution of the PV was facilitated by the sequence of dialogue that included extract 5 (in which Mrs H spoke of her fears about losing her faculties) and extract 4 (in which Mr F spoke about being ashamed). This enabled Mr B. in the following session to articulate the Problematic Voice for the first time (he acknowledged his own dementia) and angrily asserted that having a poor memory was not the same being stupid (which indicated a shifting dialogue between the PV and the DV).

If Mr B's movement from warding off his dementia to assimilating the PV into his self-concept had been facilitated by therapy, there is also evidence that a similar process can occur away from therapy.

The final extract is taken from Lishman, Cheston and Smithson in their study of accounts of people before and after they had received a diagnosis of dementia. One of these people was Len:

[8] Len: I think that if people know, they understand

[8.1] *but if you hide it as I did*, first going, they get frustrated with you
so if I was advising someone

if they found themselves in the situation I found myself in

I think you've got to be open with people

and they may understand instead of thinking [8.2] 'oh that silly old fool is losing his marbles''

(...)

[8.3] *I mean I tried to cover up*

which I suppose is a natural thing to do

[8.4] yeah, *you try to cover up and swear blind that you haven't been told*,

you know, what you have been told

and eventually you accept the reality that you're not right

and I think that took a long time for me to recognise it

but I'm glad that it happened

you know I'm glad that it was brought to people's attention

For Len, his dementia was initially experienced as a Problematic threat which could not be articulated.

Indeed, Len's assertion that he hid his dementia (8.1) and covered it up (8.3 and 8.4) echoes Gilbert's description of these two strategies as the behavioural consequences of shame (Gilbert, 1988). Just as for Mr. B, so Len's description is of a Dominant Voice experiencing the Problematic elements of dementia around concerns of madness (8.2).

Discussion

It has been argued that an apparent lack of awareness amongst people affected by Alzheimer's disease may act as a form of emotional regulation (e.g. Clare et al, 2011; Clare, 2002). Thus warding off awareness may allow people to retain a psychological balance in the face of the significant emotional threat that dementia may represent (Seiffer, Clare and Harvey, 2005). At the same time, lower levels of awareness have been consistently linked to a range of problems including psychiatric disturbances such as psychosis and a deterioration in global functioning (Aalten et al, 2005), and is associated with higher levels of care-giver strain (Nelis et al, 2011; Rymer et al, 2002). Thus, while knowing less about dementia may protect people against distress, it may also increase the risk both of psychological dysfunction and also of tension within families. If we are to help people to balance knowing about

their illness while not being emotionally overwhelmed by this knowledge, then it is important to understand more about the psychosocial processes underlying awareness (Seiffer, Clare and Harvey, 2005).

This paper has argued that a fear of internal loss of control may be one of the reasons why some people who are affected by dementia choose not to engage with their illness. The person affected by dementia is faced with a choice: to attempt to control the high level of affect around material associated with problematic aspects of dementia through suppressing painful emotional material or to explore these issues and risk having their psychological equilibrium overturned. People affected by dementia may describe talking or thinking about their dementia as being too disruptive or threatening to be tolerated—it is as if being required to think about the changes that have occurred is too frightening to put into words. Just as is the case with clients in psychotherapy, the person affected by dementia chooses not to “*explore or symbolize it because they fear this would be intrapsychically destabilizing and disruptive to their adaptation in everyday life*” (Honos-Webb, Lani and Stiles, 1999). The movement across these initial levels of the Assimilation Model (warding off, unwanted thoughts and vague awareness) involves not only talking about dementia in a different way, but also engaging with the significant increase in affect that this brings, and is represented in Figure 1.

INSERT FIGURE 1 ABOUT HERE

The fear-of-loss-of-control marker, along with other Level 1 and 2 markers occur at a critical point within the therapeutic process. Just as some of the people affected by dementia that we have described have chosen **not** to engage with their dementia, so others made a choice to acknowledge their dementia. Both Mr. B in extract 7 and Len in extract 8 felt that they had gained therapeutically from doing this, even if it had been a difficult process for them. However, for therapists, working with people who are ambivalent about engaging with their diagnosis of dementia brings a series of ethical concerns.

Ethical issues. Due to the difficulties that people have in articulating the thing that it is that they are frightened about, it is important for psychologists, therapists and others to be especially clear about a number of ethical issues that talking to people about their dementia may provoke. There is a delicate

balance to be struck here: if clinicians do not use terms such as “*dementia*”, then although they avoid distressing the person, they disallow him or her from having the opportunity to adjust to reality and to assimilate knowledge of their illness. At the same time, disclosing information that is too threatening at too great a pace may risk clients warding off this difficult material as a way of regaining equilibrium. Thus, Cheston and Jones (2009) speculated that increased levels of depression in two psycho-education groups may have resulted from too much information being disclosed to participants with dementia at too fast a pace. This dilemma will be especially acute when working with psychologically frail or vulnerable people. Therapists, then, must continually assess the capacity of people to engage with Problematic material, and not persist in exposing clients to unnecessary distress.

One way to engage the person with dementia in a discussion about the nature of those changes that have taken place, is by initially approaching dementia indirectly, by talking, for instance, more widely about the changes that accompany growing old. After this, the topic of dementia can be brought into the room, for instance by noticing the slips and attempts at covering up that someone makes, or through third party descriptions. Just as Sue (extract 2) and Henry (extract 3) used figurative language to articulate the existential loss of control, so the key therapeutic task is to enable the person to find words with which to acknowledge change, but without then feeling overwhelmed by naming the dementia directly. One way to do this is through using stories or narratives within therapy. Narratives (stories about real or imagined events outside of therapy) may play a variety of roles in psychotherapy, including allowing the person to approach threatening material indirectly or symbolically. The use of narratives as a way of metaphorical sense-making by people affected by dementia has been reported elsewhere. Thus, Cheston (1996) described a group therapy participant who talked about his fears about dementia indirectly through a story about being lost when flying over a jungle, while Cheston, Jones and Gilliard (2004) described a story told by Martin about a tidal wave which seemed to have a similar therapeutic significance. In this way whilst direct confrontation with dementia is ‘*warded off*’, nevertheless some parts of this Problematic Voice can be experienced, processed and assimilated into the community of selves.

A further dilemma, however, concerns how to ensure that the person affected by dementia provides informed consent to enter into a therapeutic relationship which has, as its aim of facilitating their adjustment to a diagnosis that they may not at that time acknowledge. Naming dementia outright at this point risks alienating the very people who may stand to benefit the most from such an intervention. However, without informed consent, covert psychotherapy is no more ethical than covert medication.

Final thoughts. I began this paper by quoting the words of Frau Auguste Deter that were carefully noted down by Alois Alzheimer, the admitting doctor at the Frankfurt am Main Irrenschloß. They show how dementia needs to be understood not only as an illness that reduces cognitive function, and as a social disability, but also as a condition that inevitably evokes powerful emotional forces. I have then gone on to argue that for some people affected by dementia, engaging with the threat of dementia involves engaging with concerns about the loss of psychological equilibrium that may result from engaging with fears about future dependency, madness or the loss of self. These fears of loss of internal control present the person with an apparent choice – to continue to engage with the material (and risk future distress) or to disengage with dementia, avoid reminders of their illness, and to find other ways to assert control. This dilemma is further compromised by difficulties that participants experience in naming the problem. To use the terms Alzheimer’s disease or dementia is sometimes resisted because to do so would be to articulate the Problematic Voice.

However, the choice around “*thinking*” or “*not thinking*” about dementia is only one of a number of methods that people with dementia can use to emotionally regulate their internal world. Many of the individuals who were identified as expressing this fear-of-loss-of-control marker, also used other strategies to regulate their emotions including the avoidance of threatening situations where their deficits may be exposed, the projection of deficits onto others and attempts to regain mental control through thoughts of suicide. Ironically, the retreat away from dementia which for some people seems to represent an assertion of control and an avoidance of distress tends to result in neither of these things: failure to engage in the problems of living caused by dementia forces others to step in and make decisions for the person. This typically becomes part of a cycle in which warding off awareness

about dementia leads to others taking control, while the externalising of problems tends to lead to confrontation and greater distress.

Understanding more about the psychological mechanisms that contribute to the difficulties some people affected by dementia have in acknowledging their illness, may enable us to develop more effective ways of providing support. Moreover, given that higher levels of awareness are associated with higher quality of life, and with enabling a person to make choices about how they live, increasing awareness will benefit the person with dementia directly. If we are able to identify and validate markers of the extent to which knowledge of dementia has been assimilated, then this may be of general benefit. It will assist clinicians by providing a better understanding of the mechanisms underlying awareness, help researchers to identify what facilitates or acts as an obstacle to greater awareness and enable people affected by dementia to engage with the existential threat of their illness. Just as the psychological needs of people who are diagnosed with cancer or who suffer other life changing events are recognised, so people affected by dementia deserve to have access to psychological therapy. If society is to become “dementia aware”, then it must address the worries and fears that people affected by dementia express. Just as Frau Auguste Deter told Dr Alois Alzheimer that she had lost herself in 1901, so we must be aware that fears of being lost, and of losing control still permeate the discourse of people who receive a diagnosis of Alzheimer’s Disease over 110 years later. Now, however, we may be able to listen, to hear and to respond. As Terry Pratchett, the British author who recently died, after a long struggle with dementia, has written before we can slay the demon, we must be able to speak its name.

*It occurred to me that at one point it was like I had two diseases – one was Alzheimer’s and the other was knowing that I had Alzheimer’s. There were times when I thought I’d have been much happier not knowing, just accepting that I’d lost brain cells and one day they’d probably grown back or whatever. It is better to know, though, and better for it to be known ...
The first step is to talk openly about dementia because it’s a fact, well enshrined in folklore, that if we are to kill the demon, then first we have to speak its name. Once we have recognised the demon, without secrecy or shame, we can find its weaknesses.*

(Terry Pratchett, *The Observer*, 15.03.15)

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Table One: Markers of Assimilation of Problematic Experiences of Dementia Scale (MAPED)

Assimilation level	Content and affect	Markers
0. Warded off	Content is un-formed and features avoidance. Minimal affect, reflecting successful avoidance	
1. Unwanted thoughts	Emergence of thoughts associated with dementia or memory loss. Further discussion may be avoided and dementia is likely to be talked around rather than named directly. Unfocused strong emotions (e.g. anxiety, fear, anger sadness) are more salient than the content	<ul style="list-style-type: none"> a) Changing the conversation b) Telling a contradictory story c) Fear-of- loss-of- control (e.g. being mad or abnormal) d) dementia is located elsewhere or referred to indirectly (e.g. as "it") e) the significance of dementia is otherwise minimised
2. Vague awareness	The problematic experience of dementia is acknowledged and uncomfortable associated thoughts are described. The person is in distress, and this seems to come from some internal conflict relating to dementia, so that in talking they seem to be caught up in the moment of the emotion. Affect focused on acute psychological pain or panic	<p>Expressions of</p> <ul style="list-style-type: none"> a) Feelings of sadness, depression, worry or anxiety. b) Anger or irritation about some aspect of dementia c) Puzzlement or confusion about what is happening to them. d) Feeling overwhelmed or that things are getting worse. e) Stories that point to the problem but are not clearly described. f) Use of metaphors to talk about the problem
3. Problem statement or clarification	The person acknowledges the existence of dementia as a problem and attributes this to an illness such as dementia. Affect is negative but manageable	<ul style="list-style-type: none"> a) Describing their reaction to dementia, which may include mixed feelings (e.g. "yes But") b) The person appears 'stuck' and sees no way out. c) Developing a clearer understanding of dementia (e.g. asking questions or being curious) d) Describing contradictions in the illness e) Describing that previous difficulties in recognising the problem
4. Understanding/insight	The person acknowledges the existence of dementia and is able to describe how this makes them feel, or how they react to this. They are able to stand back from their feelings. Curiosity of affect, with mixed pleasant and unpleasant recognitions	<ul style="list-style-type: none"> a) Describing situations where their feelings differ in intensity b) Emotional distance from the dementia (e.g. through use of humour) c) Making links between dementia and others areas of their life d) Making links between the past and the present e) Comparing themselves with

		others in a worse position
5. Application/working through	The person both acknowledges the existence of a dementia and can also point out what needs to get worked on. Business-like positive affect that is optimistic or hopeful and linked to strategies	<ul style="list-style-type: none"> a) Weighing up attempts at a partial solution to the problem (e.g. taking medication). b) Acknowledging deterioration and explicitly describing some acceptance.
6. Problem solution	The person acknowledges that they have a dementia, and have achieved a successful solution for a specific problem. They recognise change in their lives. Affect includes positive satisfaction or pride linked to accomplishments	<ul style="list-style-type: none"> a) Achieving a change in their life in living with the dementia that they feel positive about. b) Change in their understanding of what is happening to them or their relationships with others c) Comments on how others have noticed that they have changed
7. Mastery	The person is able to integrate dementia into the whole of their life. Dementia is acknowledged and recognised but no longer defines them as a person. Affect is neutral (i.e. this is no longer something to get excited about)	<ul style="list-style-type: none"> a) The person successfully uses their new solutions in new situations

Figure 1: the relationship between levels of assimilation and affect, illustrating the impact of fear of losing control markers

