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Title Improving professional practice in the disclosure of a diagnosis of dementia: A modeling experiment to evaluate a theory based intervention

Running head: Intervention modeling process dementia

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Abstract

Background

Amongst health professionals there is wide variation in the practice of disclosing a diagnosis of dementia to patients.

Purpose

To evaluate the effect of one theory-based and two pragmatic interventions on intention to perform three behaviours namely [1] finding out what the patient already knows or suspects about their diagnosis; [2] using the actual words 'dementia' or 'Alzheimer's disease' when talking to the patient (i.e. the use of explicit terminology); [3] exploring what the diagnosis means to the patient.

Methods

Within an intervention modeling process members of old age mental health teams in England were sent postal questionnaires measuring psychological variables. Respondents were randomised by team to one of four groups to receive: theory-based intervention; evidence-based communication; patient-based intervention; no intervention (control). Interventions were delivered as pen and paper exercises at the start of a second postal questionnaire that re-measured the same psychological variables. The outcome measures were intention and scenario-based behavioural simulation.

Results

Responses were received from 644/1103 (58%) individuals from 179/205 (87%) mental health teams. There were no significant differences in terms of intention or simulated behaviour between the trial groups. The theory-based intervention significantly increased scores for attitudes to ($p=0.03$) and perceived behavioural control ($p=0.001$) for the behaviour of "finding out what the patient already knows or suspects about their diagnosis".

Conclusions

The intervention had a limited effect. This may be partly explained by clinical or methodological factors. The use of a systematic intervention modeling process allows clearer understanding of the next appropriate steps which should involve further evaluation of the interventions using an interactive delivery method in a less selected group of study participants. [ISRCTN15871014].

Keywords: Intervention modeling, dementia.

Introduction

An international consensus group estimated that in 2001 the global prevalence of dementia was 24.3 million. Modeling what would happen in 2020 and 2040 they predicted that almost 5 million new cases would occur every year (Ferri et al., 2005). These incidence rates coupled with population demographics are predicted to result in a doubling of the number of cases every 20 years. Dementia is associated with major social and economic costs, including those to families and carers. The UK National Service Framework (NSF) for Older People states that the improved care of people with dementia depends on early recognition and management (Department of Health, 2001). A recent national clinical practice guideline in the UK has re-emphasised the need for such care to involve a sensitive and accurate explanation of the diagnosis to individuals and carers, with information about the likely prognosis and possible packages of care (National Collaborating Centre for Mental Health, 2007).

Appropriate disclosure of a diagnosis to individuals with dementia is important for three reasons. First, from an ethical perspective, people with dementia have a right to know their diagnosis. At present, most carers are told the diagnosis (Audit Commission, 2002) but this is not the case for people with dementia themselves (Bamford et al., 2004). Indeed, disclosure is less likely in dementia than in other terminal conditions, such as cancer. Earlier disclosure, supported by advocacy groups, allows the opportunity to plan family, fiscal and long term care arrangements. Second, many people with dementia want to know their diagnosis or receive more information about their illness (Jha, Tabet, & Orrell, 2001; Marzanski, 2000; McWilliams, 1998). Third, disclosure can facilitate decisions about treatment. However, whilst this is increasingly important with the advent of therapies to slow disease progression, anecdotal evidence suggests that patients prescribed anti-dementia medication are not always told their diagnosis. A systematic review of disclosure practice indicates wide variation in the reported practice of disclosure of dementia among health professionals (Bamford et al., 2004). Four main factors appear to influence disclosure: patient characteristics (e.g. age, perceived ability to retain the diagnosis); nature of the dementia (e.g. severity, diagnostic uncertainty, the appropriateness of using disease-slowing therapies); structural factors (e.g. time); and clinician factors (e.g. perceived

value of disclosure) (Bamford, May, Eccles, & Bond, 2001; Downs, Clibbens, Rae, Cook, & Woods, 2002; Fortinsky, Leighton, & Wasson, 1995; Heal, 1998; Johnson, Bouman, & Pinner, 2000; Rice & Warner, 1994; Rice, Warner, Tye, & Bayer, 1997; Vassilas & Donaldson, 1998).

It is a consistent finding that changing clinical practice is unpredictable and can be a slow and haphazard process. There is now a sizeable body of literature suggesting that a range of interventions (e.g. reminder systems, interactive education) can be effective in changing health care professionals' behaviour (Grimshaw et al., 2001). However, substantial heterogeneity in interventions used, targeted behaviours, and study settings means that generalising findings to routine healthcare settings is problematic - there is no underlying generalisable taxonomy for either research or service settings by which to characterise individuals, settings and interventions (Foy, Eccles, Jamtvedt, Grimshaw, & Baker, 2005). To avoid perpetuating this situation systematic, replicable approaches to intervention building are required.

That clinical practice is one form of human behaviour and can be described in terms of general theories relating to human behaviour offers the basis for a generalisable classification of methods to change clinical behaviours. These may be influenced by modifiable factors such as health professionals' 'attitudes' or 'perceived control' over their practice – and so interventions to change these factors may change behaviour. Thus generalisable (theory-based) concepts can lead to replicable interventions that can be used across different contexts. Two steps are necessary to design a theory-based intervention for a behaviour change trial (Walker et al., 2003). One is to identify modifiable factors underlying professional behaviour in order to identify which factors to target with an intervention and the second is to understand how interventions might work and be optimised.

As a method of achieving this Collins and colleagues (Collins, Murphy, Nair, & Strecher, 2005) proposed a multiphase optimization strategy (MOST). They describe this as “having three phases: (a) screening, in which randomized experimentation closely guided by theory is used to assess an array of program and/or delivery components and select the components that merit further investigation; (b) refining, in which interactions among the identified set of components and their interrelationships with covariates are investigated in detail, again via randomized

experiments, and optimal dosage levels and combinations of components are identified; and (c) confirming, in which the resulting optimized intervention is evaluated by means of a standard randomized intervention trial.”

We have developed an intervention modeling process within which important constructs are identified and manipulated and their impact on interim measures, such as stated intention, is measured (Bonetti et al., 2005; Bonetti et al., 2003) using an intervention modeling experiment (IME). This corresponds to MOST's phases (a) and (b). Given that a consistent and predictable relationship has been demonstrated between intention and behaviour in studies in general (Armitage & Conner, 2001; Sheeran, 2002; Webb & Sheeran, 2006) as well as in studies of healthcare professionals (Eccles, Hrisos et al., 2006; Godin, Belanger-Gravel, Eccles, & Grimshaw, 2008) an intervention modeling process aimed at changing intention offers the advantages of smaller size and efficiency in developing and testing candidate interventions prior to proceeding to full scale randomised controlled trials (MOST Phase 3).

This paper describes the final phase of a larger study. The aim of the overall study was to use explicit and replicable methods to develop and evaluate a theory-based intervention targeting modifiable factors to increase diagnostic disclosure of dementia by members of old age mental health teams (OAMHTs). The study had a number of discrete steps outlined in the study protocol (Eccles, Foy et al., 2006). First, we identified elements of a model of good clinical practice and from these identified three key behaviours in the disclosure of diagnosis of dementia (Lecouturier et al., 2008). We then measured, within two theoretical frameworks, the factors that predicted the self-reported intention to enact these key behaviours (Foy, Bamford et al., 2007). These two phases of the project are summarised below. On the basis of these results we developed a theory-based intervention (Foy, Francis et al., 2007) the evaluation of which is the subject of this paper.

We identified the potential elements of a model of good clinical practice from: a literature review; 10 face-to-face interviews (four with people with dementia (in two of these the person's informal carer was present), and six with informal carers only); and a stakeholder panel of professionals/advocates from a range of disciplines (two old age psychiatrists, one clinical

psychologist, one social worker, two primary care doctors, one community psychiatric nurse and one carer support worker).. Together these three sources identified over 200 discrete behaviours that were grouped into seven categories: preparing for disclosure; exploring the person with dementia's perspective; negotiating shared understandings; responding to the person with dementia's reactions; focusing on health promotion and quality of life; negotiating management strategy; communicating effectively. This list was reduced using a two-stage Delphi process and the following criteria: the behaviours should cover different facets of the disclosure process; they should be from the stake-holder panels' higher ranked behaviours; they should be important to people with dementia and carers; there should be benefit from performing the behaviour; and there should be the potential for change. Finally three key behaviours were selected: [1] finding out what the patient already knows or suspects about their diagnosis; [2] using the actual words 'dementia' or 'Alzheimer's disease' when talking to the patient (i.e. the use of explicit terminology); [3] exploring what the diagnosis means to the patient (Lecouturier et al., 2008). Then, by postal questionnaire survey, we measured, within two theoretical frameworks, factors that predicted self-reported intention to enact these key behaviours by 399 members of 85 OAMHTs (Foy, Bamford et al., 2007). Overall, the Theory of Planned Behaviour (TPB) (Ajzen, 1991) explained intention better than Social Cognitive Theory (SCT) (Bandura, 1986). For exploring what the patient already knows or suspects, the TPB variables of subjective norm, perceived behavioural control and attitudes explained 29% of the variance in behavioural intention. For the use of explicit terminology, subjective norm, perceived behavioural control and attitudes explained 54% of the variance in intention. For exploring what the diagnosis means to the patient, subjective norm and perceived behavioural control explained 49% of the variance in intention. In a regression model entering all variables (from both theories) modestly improved prediction of intention to perform the three behaviours (to 35%, 63% and 52% respectively). From these results we developed a theory-based intervention (Foy, Francis et al., 2007).

This paper describes the randomised controlled trial evaluating the theory-based intervention alongside two pragmatic interventions. Thus this was a modeling experiment within an overall intervention modeling process. With the primary outcome of intention we included planned

explanatory mediational analyses to assess whether interventions successfully changed targeted mediating factors and whether these factors in turn accounted for any changes in the primary outcome.

Methods

Design and participants

This was a four-arm randomised controlled trial of the effect of one theory-based and two pragmatic interventions on the intentions of a random sample of members of OAMHTs in England, administered by postal survey (Eccles, Foy et al., 2006). Although disclosure of a diagnosis of dementia might predominantly be the responsibility of consultant old age psychiatrists, we recognised the roles of other professionals in this process (e.g. community psychiatric nurses, clinical psychologists) and therefore invited all the professionals in each OAMHT to participate.

Randomisation

Pre-intervention questionnaires were mailed to all members of OAMHTs. Teams from which responses were received were randomised to one of four groups to receive the study interventions detailed below. Randomisation was by computer generated numbers and was conducted by the study statistician.

Outcome measures

Table 1 summarises the outcome measures. For each of the three disclosure behaviours the primary outcome measure was intention. For each behaviour, intention was measured by two questions of the form “*I intend to ...*” and “*In my practice I expect to ...*”. These were rated on 7-point scales from *Strongly Disagree* to *Strongly Agree*. Responses were averaged and scaled so that a high score indicated a high intention.

A secondary outcome of behavioural simulation was measured post-intervention for two of the behaviours. For *using the actual words “dementia” or “Alzheimer’s disease”*; and *exploring what the diagnosis means to patients* it was possible to write brief clinical scenarios; it was not possible to write a credible scenario for the behaviour of *exploring what the patient already knows or suspects*. Respondents were asked to rate, on a five-point scale from *Definitely* to *Not at all likely*,

whether they would perform the two behaviours for each of 10 clinical scenarios.

Explanatory variables

Table 1 summarises the explanatory measures. The theories (Theory of Planned Behaviour (TPB) (Ajzen, 1991), Social Cognitive Theory (SCT) (Bandura, 1986)) and the theoretical construct of Implementation Intentions (Gollwitzer, 1999) and the reasons for choosing them are described and discussed in the study protocol (Eccles, Foy et al., 2006). Implementation Intentions have been used in the past in the form of an intervention rather than a questionnaire item. As we began to operationalise Implementation Intentions in a questionnaire format we decided there was a real danger of the questions becoming a co-intervention so decided not to proceed with this potentially confounding strategy. Within the Theory of Planned Behaviour, as well as asking questions about instrumental attitudes (perceived costs and benefits), there were also a number of questions asking specifically about affective attitudes (how it would feel to perform each behaviour) (Crites, Fabrigar, & Petty, 1994).

Questionnaire items measuring psychological variables were initially developed from previously recommended scales and items (Ajzen, 1991; Bandura, 2000) as well as from qualitative analysis of interviews with people with dementia and carers.

Unless otherwise stated, all questions were rated on a 7-point scale from *Strongly Disagree* to *Strongly Agree*. In order to reduce the likelihood of response sets, some items were reverse-worded and responses reverse-scored.

The interventions

Intervention content

Three interventions were developed: a theory-based intervention, which incorporated recognised behaviour change techniques matched to targeted theoretical constructs, and two pragmatic interventions included as examples of “commonsense” interventions that a healthcare provider could develop and introduce without theory or prior evaluation with the intent of improving the face validity of the overall experiment for participants. All three interventions were designed to work across all of the behaviours on the basis that, although we had disaggregated behaviours for the purposes of intervention development, when they came to be delivered in a service setting

trial they would be more or less aggregated into a single (though potentially multi-faceted) intervention.

The development of the theory based intervention has been described in detail elsewhere (Foy, Francis et al., 2007); the intervention components are illustrated in Table 2. In summary, the results from a previous questionnaire study (Foy, Bamford et al., 2007) were used to identify constructs that explained the highest proportion of variance in intention: attitudes to the behaviour, subjective norm (i.e. perceived pressure from social sources) and self-efficacy. Using a systematic process (Michie, Johnston, Francis, Hardeman, & Eccles, in press) those behaviour change techniques that were judged most likely to change the constructs were identified. As a result of this process, we used the technique of persuasive communication to target both subjective norms (describing evidence that professional colleagues were in favour of disclosure) and attitudes (describing evidence of positive consequences of disclosure). In addition, we used two techniques to target self-efficacy: behavioural modeling was presented as descriptions of methods used successfully by other professionals; a graded task asked participants to identify methods of tackling disclosure in their next step in a hierarchy of situations of increasing difficulty of disclosure.

The first pragmatic intervention replicated the frequently used technique of offering evidence-based information to healthcare professionals. The evidence-based communication was an A4 size page, formatted as the inside cover of the questionnaire, describing evidence around the following seven issues associated with disclosure of a diagnosis of dementia: many people with dementia want to know their diagnosis; most people with dementia thought it helpful to have been told their diagnosis; people given a diagnosis of dementia develop positive ways to cope with their diagnosis; being given a diagnosis confirms some patients' own suspicions; lack of information can cause distress; there is little evidence of catastrophic reactions to being told the diagnosis; the negative consequences of disclosure are no greater or more persistent than those of other serious diagnoses. There was no specific instruction to read the information.

The second pragmatic intervention took the form of a patient leaflet that could be sent in advance of an initial outpatient appointment and that contained prompts about the nature and content of

questions that the person might like to ask. Designed as a three panel patient leaflet, formatted onto a single side of A4, it had three sections. The first offered brief information on possible causes of memory problems (including Alzheimer's disease/dementia). The second provided space where the person was invited to write down their ideas about the causes of their memory problems. The final section offered examples of questions that they might ask during their consultation and provided space for them to write down additional questions of their own. Respondents were asked to "imagine that all patients being assessed for a diagnosis of dementia have received [this leaflet] in advance of their appointment or meeting with you".

Intervention targets

The target variables for the theory-based intervention were attitudes, subjective norm and self-efficacy. For the two pragmatic interventions, we used a consensus process within the research team to specify which predictor variables the interventions might target. Before any experimental results were available two researchers (CB and JF) used a grid to independently categorise which constructs and behaviours were targeted by each aspect of the interventions. A third researcher (RF) arbitrated during a second round of rating to resolve any disagreement. The evidence-based information intervention was judged to mainly target the behaviour of '*using the actual words*' and to strongly target attitudes and weakly target subjective norm. The patient leaflet intervention addressed all three behaviours and mainly targeted subjective norm, perceived behavioural control and self-efficacy.

Intervention delivery

All the interventions were presented as 'pen-and-paper' exercises that were formatted as the front pages of the follow-up questionnaire. We assumed that respondents would read and perform the activities within the interventions and then move on to answer the subsequent cognitions questions. Questionnaires incorporating the three interventions are available from the corresponding author.

Sample size and analysis plan

The sample size for a four armed trial, powered to detect a difference between any two arms, was based upon the following assumptions: OAMHT as the unit of analysis; the outcome variable

(intention or simulation) in the form of a score for the team; 80% power; and a type 1 error rate of 2.5% (rather than 5% to allow for multiple comparisons). Furthermore, we aimed to detect a relatively large effect size of 0.8 on the basis that the modeling experiment eliminates some of the sources of variability associated with a 'service based trial' (e.g. patient characteristics) and any smaller modeling effect size is unlikely to translate into a worthwhile effect in a subsequent service based trial. Therefore, we required four groups of 30 teams (120 teams in total). We surveyed 240 teams to allow for a 50% response rate in order to achieve the required sample size.

The primary outcome of interest was the intention to perform each of the three behaviours. Secondary outcomes included a measure of behavioural simulation for two of the behaviours and, for all three behaviours, each of the psychological constructs described in Table 1.

Each variable was analysed using multilevel modelling with health care professionals nested within mental health care teams. The dependent variable was the score at follow up and where available the score at baseline was included as a covariate. Variation between health care professionals and variation between health care teams were modelled as random effects with normal distributions. Differences between the four arms of the study were fitted using three dummy variables corresponding to each of the active interventions. Models were fitted using the statistical package MLwiN version 2.02 using an iterative generalised least squares estimation procedure. For each outcome the following two step procedure was adopted. First an omnibus test of overall variation between the four study groups was undertaken using a likelihood ratio test (the change in -2 log likelihood was compared against the percentage points of a chi-squared distribution). Secondly, when this variation was significant at the 5% level, the differences between the four groups were explored further.

Postal Questionnaire administration

We ascertained the general composition of mental health teams from contacts, usually service managers, local to the teams.. We then wrote an open letter to all professionals, which was delivered via these contacts, and asked those who agreed to participate to complete and return an 'opt-in' form. All potential participants were offered an incentive (£20 (approximately \$40) gift

voucher) enclosed with the initial questionnaire. We asked respondents to complete questionnaires independently (i.e. not together in teams). We posted up to three reminders to non-respondents.

Respondents to the initial questionnaire were sent the second questionnaire which contained their allocated intervention and the second set of questions. Data on simulated practice was collected only in the second postal questionnaire. All other variables were collected in both questionnaires.

Ethics approval.

The study was approved by the Multi-Centre Research Ethics Committee for Scotland and by the Research and Development offices of the participating NHS Trusts.

Results

Participation and response rates

Initial invitation letters were posted out to 2843 individuals in 258 teams. A total of 948 individuals from 199 teams returned pre-intervention questionnaires and 644 individuals from 179 teams returned post-intervention questionnaires (mean 3.6 respondents per team; range 1-17). Based on baseline responses, the overall mean response rate was 87% for teams and 58% for individuals (Table 3).

There was some evidence that response rates varied by trial arm ($\chi^2_3 = 10.1$, $p = 0.02$) and by professional group ($\chi^2_5 = 14.5$, $p = 0.01$). These effects were independent (the difference between trial arms could not be attributed to variation in response rates by professional group).

The breakdown of post-intervention respondents by job category is shown in Table 3. As we were not allowed (by the Ethics Committee) to have access to details of individuals prior to their opting into the study we cannot report an analysis of initial non-responders. There were no significant differences in gender, years experience of working with people with dementia or baseline intention scores between responders and non-responders to the post-intervention questionnaires.

Effect of the interventions

The results are shown in Table 4. There were no significant differences in intention or simulated

behaviour between the four randomised groups. The theory-based intervention significantly increased scores for instrumental attitudes ($p=0.03$) and perceived behavioural control ($p=0.001$) for the behaviour of “finding out what the patient already knows or suspects about their diagnosis”.

As the theory-based intervention relied on respondents engaging with the various steps in the intervention we analysed responses to identify the number of sections of the intervention that were fully completed, partially completed or not completed. Fifty-four percent of respondents completed all of the intervention sections as intended. A further 21% attempted all sections but only partially completed some sections; 25% left some sections uncompleted. The other two interventions were presented in a format that just required them to be read by participants so we had no way of quantifying the level of engagement with these interventions.

Discussion

Within an explicit and replicable intervention modeling process three interventions each failed to change intention or behavioural simulation scores in relation to performing three important behaviours in the process of disclosing a diagnosis of dementia to patients. The theory-based intervention was designed to change attitudes, subjective norms and self-efficacy. For one of the three behaviours of interest, it significantly increased scores for instrumental attitudes and perceived behavioral control, a construct that is conceptually very close to the targeted construct of self-efficacy and which is theorized to have a direct effect on behaviour. Nevertheless it failed to shift the theoretically predicted dependent variable of intention.

Given that we comfortably exceeded our required sample size, possible explanations for the lack of effect are: (a) study participants not engaging with the interventions; (b) the method of delivery within the modeling experiment and (c) ceiling effects from intention already being relatively high and the linked issue that therefore the factors influencing behaviour may be “post-intentional” (i.e. relating to difficulties translating intentions into action). Each of these has implications for future work with these interventions and how an intervention modeling process might be used in the future.

Given our analysis of engagement with the theory-based intervention it is unlikely that lack of

engagement was a major factor, at least for this intervention. With 75% engaging totally or partially with all steps in the intervention we can be confident that respondents went through the processes we planned. However, the theory-based intervention group had a significantly lower response rate to the second questionnaire than the other three trial groups suggesting that some subjects found it difficult to, or did not wish to, engage with the greater complexity of the theory based intervention delivered in this paper-based format. As indicated in the results, it is possible that lack of engagement was a factor for the other two interventions.

Intention scores were relatively high with two of the key behaviours having mean intention scores across all four groups within (or almost within) one standard deviation of the top of the scale. This suggests that the potential for any of the interventions to increase intention in this population may have been limited. The position with the targeted constructs (with the exception of self-efficacy) was similar. However, across all the trial groups there was a substantial non-response at the two stages of the postal survey. It is possible that we were working with more motivated individuals who had higher intention scores and the interventions may have a different effect with a group whose intention scores were lower. Within evaluations non-response will always be an issue and having taken all reasonable steps to reduce it the final step would be to characterize non-responders and compare them with responders. A particular feature of this study was the recruitment method constraints imposed by the ethics committee because of which we are unfortunately unable to say much about the attributes of our non-responders.

Finally, for the theory-based intervention, it is possible that, despite getting respondents to engage with the steps in the intervention, the postal, paper-based self-administered nature of the intervention was not "potent" enough. Whilst it took them through the various stages of the three behaviour change techniques that we used (Table 2) the techniques are more commonly used in interactive contexts. Based on the results of this paper-based experiment a logical next step would be to deliver the same intervention components in a small group format to members of the same mental healthcare team.

The Theory of Planned Behaviour proposes that intention and perceived behavioural control are the immediate precursors of behaviour. For one of our behaviours we did significantly increase

perceived behavioural control and it is possible that this could result in a change in behaviour by virtue of its theorized direct effect on behaviour. However, in the face of a less than perfect relationship between intention and behaviour it is recognized that there are other factors that influence behaviour that can operate in the gap between intention and behaviour (Sheeran, 2002). Knowing that the behaviours are not being routinely enacted, the relatively high intention scores for at least two of the behaviours raise the possibility that the way to increase rates of performing the behaviours is to intervene on factors operating in the gap between intention and behaviour. Such factors include situation-behaviour associations that become salient as a result of planning interventions. For example, a plan in the form, "When I first discuss a diagnosis of dementia with a patient [situation] I will suggest a follow up appointment to explore what the diagnosis means to the patient [behaviour]" would strengthen the situation-behaviour association and make it more likely the situation would act as a prompt for the associated action. There is evidence that other relevant modifiers of the intention-behaviour relationship are intention certainty, past behaviour, self-schema and anticipated regret. In addition, whether the behaviour is more likely to be influenced by internal factors (e.g., attitudes) or by external factors (e.g., perceived normative constraints) is important and, finally, temporal stability of intention appears to be key (Sheeran & Abraham, 2003). The fact that we did not include explicit measurement of such factors nor aim any of the interventions at them may have limited the experiment. However, there is a limit to how many theories can be included and operationalised within a single instrument and we already had problems with response rates. One future possibility to consider is a hypothesized theoretical framework for the study of healthcare professionals' behaviour and intention that was described on the basis of a systematic review of studies of healthcare professionals (Godin et al., 2008). The two social cognitive models that we used claim to be able to account for non-volitional factors. They posit that such effects are mediated through their effect on the included theoretical constructs such as attitudes within TPB or self efficacy within SCT. Therefore with no effect on intention or behavioural simulation, but with an effect on perceived behavioural control for one behaviour we conclude that, for this study's participants it is unlikely that the interventions as delivered in the experiment would be effective in the real world.

The intervention modeling process, of which this experiment formed one part, has the major advantage of transparency. In this stage of the process we were able to examine the effects on the targeted constructs as well as the chosen outcome measures. In addition, the use of a modeling experiment, with proxy outcomes, was less resource-intensive than a full trial. In the light of the null result this study suggests that these interventions should not be taken forward into a service level trial (MOST's phase c (Collins et al., 2005)) at this point. Rather, they should be further examined addressing the shortcomings of recruitment and method of delivery. Even with the advantages of the intervention modeling process there are still a range of methodological developments that need to occur before it can be regarded as a stable method and as an effective and efficient 'filter' to decide which are the most promising interventions to take through to a full-scale, real-world trial.

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References

Table 1. Theoretical constructs and example questions for the three behaviours (A) finding out what the patient already knows or suspects (B) using the actual words “dementia” or “Alzheimer’s disease” (C) exploring what the diagnosis means to the patient.

<i>Constructs (number of questions)</i>	<i>Example Question(s)</i>
Theory of Planned Behaviour (Ajzen, 1991)	
Behavioural intention (two for each of the three behaviours)	I intend to <behaviour>
Attitudes: instrumental: (first 4 for behaviour A; all 7 for behaviours B & C);	In my practice I expect to <behaviour> I think that, overall <behaviour> is: harmful/beneficial; wrong/right thing to do; distressing/not distressing; poor/good use of time; stigmatising/not stigmatising; hinders/helps understanding; discourages/encourages planning.
Attitudes: affective (three for each of the three behaviours)	I would feel uncomfortable whilst <behaviour> I feel out of my depth whilst <behaviour> I would find it upsetting to <behaviour>
Subjective Norm (Normative beliefs 4 for each of the three behaviours x motivation to comply 3 for each of the three behaviours). The fourth normative belief item contained the dimension of motivation to comply within it)	Normative beliefs Generally, patients with dementia think that I should <behaviour> Generally, carers and relatives of patients with dementia think that I should <behaviour> Members of my Mental Health team would approve of <behaviour> Other people who are important to me professionally would approve of <behaviour>
Perceived Behavioural Control (three for each of the three behaviours)	Motivation to comply What patients with dementia think I should do is very important to me What carers and relatives of patients with dementia think that I should do is very important to me What members of my Mental Health team think that I should do is very important to me The decision whether or not to <behaviour> is beyond my control I feel that I have the skills that I need to <behaviour> It is easy for me to <behaviour>
Social Cognitive Theory (Bandura,1998)	
Outcome Expectancies	Measured using the same items as Attitudes: instrumental for TPB.
Self-Efficacy (first 4 questions for behaviours A and C, all 8 questions for behaviour B)	I am confident that I can <behaviour> when: I am short of time; a carer/relative is absent; a carer is present and is interfering with communication with the patient; the patient has little insight; the patient thinks that their problems are just dues to old age; when the patient does not want to know the diagnosis; the carer has requested that the diagnosis be withheld; appropriate support is not available for the patient shortly afterwards.

Table 2. Illustrative contents of the theory based intervention: the three behaviour change techniques with illustrations of the items designed to encourage active engagement

Behaviour change technique	Instruction for engaging in task	Number of items/responses and example response options and items
Persuasive communication	Here are some reasons that other mental health professionals have suggested for appropriately disclosing the diagnosis to patients with dementia. Please tick each box to show which statements you generally agree with.	8 items. The patient has a right to know (or not to know). It helps to avoid later confusion and ambiguity.
	A recent national survey asked a sample of UK mental health teams for older people about key aspects of disclosing a diagnosis of dementia. There were 368 respondents. Please tick each box if you agree with the views expressed by the mental health teams surveyed	3 items 91% agreed that exploring the meaning of the diagnosis with the patient was a good use of professionals' time
	Here are some statements, supported by research evidence, about the disclosure of dementia. Please tick the THREE statements which you find most persuasive.	7 items Most people with dementia thought it helpful to have been told their diagnosis. Following disclosure, the majority of people with dementia thought it was helpful to have been told their diagnosis (75%)
Behavioural modelling	Disclosing the diagnosis of dementia can be relatively straightforward or very difficult, depending on circumstances and the individual patient. Here, we would like you to focus on a relatively straightforward situation where you are certain of the diagnosis, a helpful carer is present, the patient has insight and you have sufficient time . Below are some approaches and examples of phrases which other professionals find useful. Please tick the boxes for those that you already use or think you might want to use. They also don't need to be the <u>exact</u> approaches or words you would use. Tick as many boxes as you like.	9 items. Response boxes: <i>Already use, Might want to use</i> Finding out what the patient already knows or suspects <i>Examples of specific phrases or actions</i> "Do you have any concerns about what has been happening to you recently?" "What do you think could possibly be causing your memory problems?" "What is your biggest fear about what might be causing your problems?"
	Other mental health professionals have suggested that the following approaches – often around the ways that local teams or services are organised - might help improve the process of disclosing a diagnosis of dementia. Out of this list, there are some approaches that you might already use, you might think are useful and could use. You may tick more than one box for each approach.	9 items. Response boxes: Please tick if you ... use this already ... think this is useful ... (and your team) could do this. Offering written information following consultations
Graded Task	This section is about using the actual words 'dementia' or 'Alzheimer's Disease' when talking to patients. Depending on your own role within your team, this might take place after first making a diagnosis or during subsequent appointments or visits Five situations now follow. These have been ranked from easiest to most difficult based upon the experience of other mental health professionals. Starting with number 1, consider each situation in turn and place a tick in the box to indicate how confident you are that – when you are certain of the diagnosis - you could use the actual words 'dementia' or 'Alzheimer's Disease' when talking to the patient.	5 items. Could you confidently use the actual words 'dementia' or 'Alzheimer's Disease' when talking to the patient if ... 2. ... the carer or relative is absent, the patient has insight and you have sufficient time? 5. ... a carer or relative is present but is interfering with communication, e.g. interrupting the patient, the patient has insight and you have sufficient time?

	<p>If <u>ALL</u> your responses are YES... Can you think of a situation in which you would find it difficult to use the words 'dementia' or 'Alzheimer's Disease' when talking to the patient? Briefly describe the situation</p> <p>If you have responded NO or MAYBE for <u>any</u> of the situations above ... Imagine yourself with a patient in the situation you have selected or described.</p>	<p>Firstly, record a list of up to five possible alternative approaches that would help you in that situation.</p> <p>Secondly, now try to visualise your chosen situation. Based on your responses immediately above, which approach do you plan to use?</p>
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Table 3. Response rates (overall and by intervention type and professional group) and distribution of professional type across intervention type.

	Number of teams	Mean team size ¹	Range of team size	Number of team members			
Identified by participating trusts	258	11.96	1-50	2843			
Sent baseline questionnaire	205	5.38	1-22	1103			
Returning baseline questionnaire	199	4.76	1-21	948			
Returned intervention questionnaire	179	3.60	1-17	644			
Response rate	179/205 (87%)			644/1103 (58%)			
Theory-based intervention							
- sent	51	4.63	1-15	235			
- returned	41 (80%)	3.41	1-12	140 (60%)			
Evidence-based information							
- sent	49	5.47	1-21	267			
- returned	45 (92%)	4.38	1-17	197 (74%)			
Patient leaflet							
- sent	49	4.43	1-14	217			
- returned	47 (96%)	3.26	1-9	153 (71%)			
No intervention control							
- sent	50	4.54	1-17	225			
- returned	46 (92%)	3.35	1-9	154 (68%)			
Doctors							
sent	92						
returned	65 (71%)						
Nurses							
sent	445						
returned	304 (68%)						
Profession Allied to Medicine							
sent	160						
returned	123 (77%)						
Social worker or Care Manager							
sent	96						
returned	58 (60%)						
Manager or Team Leader							
sent	20						
returned	14 (70%)						
Support worker							
sent	130						
returned	80 (62%)						
¹ Information on team size was available for only 238 teams							
	Professional group (n(%))						
Study Group	Doctor	Nurse	PAM	Social worker or Care Manager	Manager or Team Leader	Support worker	Total
Theory-based intervention	14 (10)	64 (46)	25 (18)	13 (9)	4 (3)	20 (14)	140
Evidence-based information	24 (12)	82 (42)	36 (18)	18 (9)	4 (2)	33 (17)	197
Patient leaflet	12 (8)	82 (54)	29 (19)	16 (11)	2 (1)	12 (8)	153
Control	15 (10)	76 (49)	33 (21)	11 (7)	4 (3)	15 (10)	154
Overall	65 (10)	304 (47)	123 (19)	58 (9)	14 (2)	80 (12)	644

Table 4. Pre-post construct scores by behaviour and randomised group.

Construct	Behaviour [#]	Group								Likelihood ratio test χ^2
		Theory based		Evidence based		Patient leaflet		Control		
		Baseline Mean (SD)	Follow up Mean (SD)	Baseline Mean (SD)	Follow up Mean (SD)	Baseline Mean (SD)	Follow up Mean (SD)	Baseline Mean (SD)	Follow up Mean (SD)	
Outcome Measures Intention	A	5.7 (1.3)	5.9 (1.1)	5.7 (1.3)	5.7 (1.3)	5.7 (1.2)	5.9 (1.1)	5.8 (1.1)	5.7 (1.3)	6.64
	B	4.4 (1.6)	4.8 (1.4)	4.6 (1.7)	4.9 (1.5)	4.3 (1.7)	4.5 (1.5)	4.7 (1.4)	4.9 (1.3)	1.58
	C	5.4 (1.4)	5.6 (1.3)	5.5 (1.4)	5.5 (1.3)	5.5 (1.3)	5.5 (1.4)	5.7 (1.1)	5.6 (0.9)	2.82
Simulated Behaviour	B		0.1 (0.7)		-0.1 (0.7)		0.1 (0.8)		-0.1 (0.6)	5.76
	C		0.1 (0.8)		-0.02 (0.7)		0.01 (0.7)		-0.1 (0.6)	5.13
Explanatory measures Attitudes: instrumental	A	5.6 (1.0)	6.0 (1.0)	5.7 (0.9)	5.8 (0.8)	5.8 (0.9)	5.8 (0.8)	5.8 (0.9)	5.8 (0.8)	9.00*
	B	4.6 (1.2)	4.9 (1.0)	4.6 (1.0)	4.9 (1.0)	4.7 (1.0)	4.7 (1.1)	4.8 (0.9)	4.8 (0.9)	5.59
	C	5.3 (1.1)	5.4 (1.1)	5.3 (1.0)	5.4 (1.0)	5.5 (1.0)	5.4 (1.1)	5.4 (0.9)	5.4 (1.0)	2.38
Attitudes: affective	A	5.5 (1.2)	5.6 (1.3)	5.4 (1.4)	5.4 (1.2)	5.6 (1.2)	5.7 (1.2)	5.4 (1.4)	5.4 (1.3)	6.56
	B	5.1 (1.3)	5.3 (1.2)	5.2 (1.2)	5.3 (1.2)	5.2 (1.2)	5.2 (1.3)	5.3 (1.3)	5.3 (1.2)	0.58
	C	5.2 (1.4)	5.4 (1.3)	5.3 (1.3)	5.3 (1.2)	5.3 (1.4)	5.4 (1.3)	5.2 (1.3)	5.3 (1.3)	2.49
Perceived Behavioural Control	A	5.3 (1.0)	5.6 (0.9)	5.3 (1.0)	5.3 (1.0)	5.3 (0.9)	5.4 (1.1)	5.5 (1.0)	5.3 (0.9)	17.22***
	B	5.0 (1.2)	5.2 (1.1)	5.0 (1.0)	5.0 (1.1)	4.9 (1.1)	4.9 (1.2)	5.1 (1.1)	5.2 (1.1)	5.35
	C	5.3 (1.0)	5.4 (1.1)	5.1 (1.1)	5.2 (1.1)	5.5 (1.0)	5.3 (1.2)	5.4 (1.0)	5.4 (0.9)	2.16
Subjective Norm (standardised)	A	-0.1 (3.3)	0.4 (3.2)	0.03 (3.1)	0.4 (3.3)	-0.1 (3.2)	-0.2 (2.9)	0.2 (2.8)	0.3 (3.1)	2.31
	B	-0.4 (3.6)	0.7 (3.3)	-0.01 (3.7)	0.6 (3.2)	-0.7 (3.5)	-0.1 (3.1)	0.6 (2.9)	0.8 (3.1)	1.80
	C	-0.2 (3.4)	0.3 (3.4)	0.02 (3.0)	0.03 (3.4)	-0.1 (3.5)	-0.2 (3.3)	0.4 (3.3)	0.2 (3.1)	5.14
Self-Efficacy	A	3.7 (1.3)	3.6 (1.2)	3.5 (1.1)	3.7 (1.2)	3.6 (1.3)	3.7 (1.2)	3.7 (1.2)	3.7 (1.1)	4.02
	B	3.1 (1.2)	3.2 (1.0)	3.3 (1.1)	3.5 (1.1)	3.1 (1.2)	3.1 (1.1)	3.4 (1.1)	3.4 (1.1)	6.89
	C	3.2 (1.2)	3.2 (1.2)	3.2 (1.2)	3.2 (1.3)	3.0 (1.2)	3.0 (1.3)	3.3 (1.2)	3.3 (1.1)	1.77

Behaviours: A Finding out what the patient already knows or suspects about their diagnosis; B, Using the actual words 'dementia' or 'Alzheimer's disease' when talking to the patient; C, Exploring what the diagnosis means to the patient.

* $p < 0.05$, *** $p < 0.001$.

Cells with borders represent the constructs targeted by the intervention.

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