

02 Designing a Questionnaire to Gather Carer Input to Pain Assessment for Hospitalised People with Dementia.

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ABSTRACT

We describe development of a questionnaire to elicit pain symptoms and experience, for use by people with dementia or their carers, at hospital admission. The questionnaire provided contextual information to support professionals' use of the Abbey Pain Scale, a validated tool used by nursing staff internationally. Appropriate information and physical design were required in order, not only to create an approachable questionnaire for patients and carers, but also to ensure fit with hospital processes. Fit with hospital process had significant influence on the final form of the questionnaire, compromising some aspects of design for patients and carers, but this compromise was considered essential to ensure pain management procedures were supplemented by wider, contextual information.

Management of pain symptoms in hospitalized, older people can be compromised by communication difficulties, particularly if patients' ability to describe their experience is limited by conditions such as dementia (Horgas, Elliott and Marsiske 2009; Manias 2012). Coe and Miller (2000) have highlighted the importance of both relatives and nursing staff in mediating communication between physicians and older patients. However relatives are rarely able to remain with a patient all the time they are in hospital and so their contribution to such communication can be limited. Manias (op cit.) has described situations where pain symptoms may go untreated because nursing staff mistakenly attribute expressions of pain to delirium or dementia. Such attribution may be more likely if no family carer, with knowledge of the patient, is available to give clarification. Furthermore delirium and dementia symptoms can, themselves, be exacerbated by pain, increasing the difficulty of recognizing and assessing pain symptoms (Herr and Garand 2001).

In this context of potentially limited communication between patient and hospital staff and practical constraints on how much a carer can contribute we describe development of a questionnaire to be used as a communication tool for family carers of people with dementia. The aim of the questionnaire (which might be completed by a family carer on their own or in consultation with a member of hospital staff) was to elicit information from carers about their relative's experience of and response to pain. This information would then be available to hospital staff to help disambiguate pain symptoms in patients who were unable to communicate their experience themselves and, hence, support appropriately targeted pain relief. Note that the purpose of the research described in this paper is the development of a viable questionnaire, the effectiveness of which (on pain relief procedures and outcomes) could then be assessed through subsequent clinical trial.

The setting for this study was a large (800 bed) district general hospital in the UK. The hospital had made effective pain relief for people with dementia a clinical priority, in line with guidance from the UK Department of Health to reduce inappropriate anti-psychotic prescription (Banerjee and Owen 2009, ch. 5). Systematic monitoring of pain symptoms had been newly instigated, using the Abbey Pain Scale (Abbey et al. 2004), a professional monitoring tool, designed for assessment of pain symptoms in people with dementia. The scale is used internationally and, simple and quick to use, is recommended by UK national guidelines for assessment of pain in older people with impaired cognition/communication (Royal College of Physicians 2007). Used at regular intervals, the scale (*Figure 142*) tracks and assigns a score to pain symptoms, along six dimensions, in order to guide prescription of pain relief.

Abbey Pain Scale
For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6

Name of resident:

Name and designation of person completing the scale:

Date: **Time:**

Latest pain relief given was **at** **hrs.**

Q1. Vocalisation
eg: whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3 **Q1**

Q2. Facial expression
eg: looking tense, frowning, grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3 **Q2**

Q3. Change in body language
eg: fidgeting, rocking, guarding part of body, withdrawn
Absent 0 Mild 1 Moderate 2 Severe 3 **Q3**

Q4. Behavioural Change
eg: increased confusion, refusing to eat, alteration in usual patterns
Absent 0 Mild 1 Moderate 2 Severe 3 **Q4**

Q5. Physiological change
eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
Absent 0 Mild 1 Moderate 2 Severe 3 **Q5**

Q6. Physical changes
eg: skin tears, pressure areas, arthritis, contractures, previous injuries.
Absent 0 Mild 1 Moderate 2 Severe 3 **Q6**

Add scores for 1 – 6 and record here **Total Pain Score**

Now tick the box that matches the Total Pain Score

0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe
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Finally, tick the box which matches the type of pain

Chronic	Acute	Acute on Chronic
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Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

Abbey, J. De Bellis, A. Piller, N. Esierman, A. Giles, L. Parker, D and Lowcay, B.
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- B**
- 1 Vocalization e.g. whimpering, groaning, crying
 - 2 Facial expression e.g. looking tense, frowning, grimacing, looking frightened
 - 3 Change in body language e.g. fidgeting, rocking, guarding part of body, withdrawn
 - 4 Behavioral change e.g. increased confusion, refusing to eat, alteration in usual patterns
 - 5 Physiological change e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
 - 6 Physical changes e.g. skin tears, pressure areas, arthritis, contractures, previous injuries.

FIGURE 1 *The Abbey Pain Scale tool used by hospital nurses for regular pain monitoring (A), shown with listing of scoring criteria used in the tool (B).*

As part of the introduction of the Abbey Scale, the hospital's Pain Team conducted an education programme for care staff who were implementing it and became aware of potential misinterpretation of patients' pain symptoms, similar to that described by Manias (op cit.). Working in collaboration with the hospital's Older People's Mental Health Liaison Team, the Pain Team sought the involvement of patients' relatives or carers in improving identification of patients' pain symptoms. This kind of involvement has been recommended by Herr et al. (2006) and, similarly, in the UK's national guidelines on pain assessment (op cit.), although no specific process for this involvement has been set out.

A precedent for carer involvement in providing contextual information, valuable to the care of hospitalised, older patients, had been set by a tool, *Information About Me* (Figure 2), developed through collaboration between the UK Alzheimer's Society and National Health Service (NHS) hospitals. The tool was already in use at the hospital (similar discursive questionnaires are used widely across the NHS and in other health care systems).

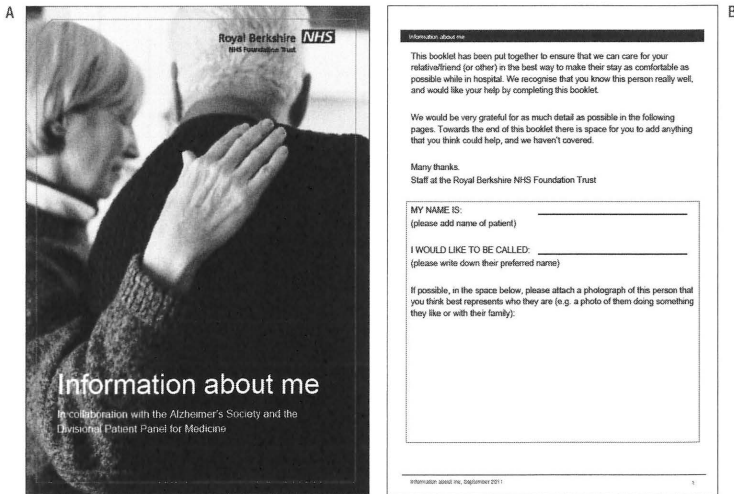


FIGURE 2 Cover (A) and first page (B) of the *Information About Me* questionnaire, developed by the UK Alzheimer's Society and National Health Service hospitals, in order to gather information about hospitalised patients and help build a personalised relationship with care staff.

The hospital Pain Team proposed a questionnaire, designed along similar lines to *Information About Me*, that could be completed by patients or, more likely, their family carers (who might be more able to articulate their relative's history) on hospital admission. The aim of gathering carers' perspective on patients' response to pain and manifestation of pain symptoms was twofold:

- 1 *Firstly, to help disambiguate expression of pain that staff would assess using the Abbey Pain Scale, so reducing potential misattribution of responses to pain to symptoms of dementia or delirium;*
- 2 *Additionally, to provide contextual information about past causes of pain and response to pain relief which would help guide clinical and care staffs' treatment decisions.*

While the Abbey scale was used as the starting point for developing the new, carer-facing tool, we planned to augment questions about expression of pain with questions about interventions that would increase patient comfort (for example, use of heat pads or manipulation) which, if used, could reduce the need for medication.

We agreed on a user-centred development process, involving informants typical of those who would use the developed questionnaire, both professionals involved in pain assessment and end-users i.e. family carers of people with dementia. Note that the project team comprised clinical and care staff (an old age mental health liaison psychiatrist, a pain nurse and a mental health liaison nurse) and that two of the designers had experience of family members with dementia. However we wished to broaden consultation beyond the design team and consideration was given early on to confidentiality and the ethics of involving consenting carers in the design process. The project was designed in the manner of a clinical survey or technology appraisal with anonymisation and no patient identifiable information.

FIRST DESIGN ITERATION

DESIGN DEVELOPMENT

CONTENT

The first four and sixth questions of the Abbey Pain Scale were taken as the core of the new questionnaire.¹ These five questions focused on the behavioural responses to pain (vocalisation, facial expression, body language, behaviour) and physical changes (cuts, bruising etc.) that hospital staff would need to interpret and assess when using the Abbey scale. No attempt was made to replicate the numeric rating of the Abbey scale (the numeric ratings on the scale are used to aid professionals' decisions about pain relief intervention) but, instead, the questions were refocused to gather family carers' descriptions of patients' typical pain responses and known physical symptoms. The fifth question from the Abbey scale, relating to physiological changes as a result of pain (temperature, blood pressure etc.) was excluded as it was thought inappropriate for people without clinical experience to respond to. The project team, through team discussion, generated further questions they considered relevant to pain management, based on their experience of caring for people with dementia, resulting in a list of fifteen questions. An additional question, to gather feedback on the questionnaire itself, was included in this trial version. See *Figure 3* for a listing of questions in the first design iteration.

IS YOUR FRIEND OR RELATIVE IN PAIN? HELP US TO LOOK AFTER THE PEOPLE YOU CARE ABOUT

1. Does..... ever complain of pain?
2. What words have they used to describe their pain? For example, burning, shooting, stabbing, pinching, stretching, aching. Are there other things they say when in pain?
3. How often do they feel pain? For example, is it constant, does it come and go, is it very sudden and short, or is it only during specific activities?
4. Have they complained of pain in the past but stopped telling you about it recently?
5. Where does it hurt them? [body map image]
6. Do they cry out with pain?
7. Does their face ever show pain? For example, by looking tense or frightened or by frowning? Can you describe how?
8. Has their body language changed recently? For example fidgeting, rocking, guarding part of the body, or hunching. Can you describe how?
9. Has their behavior changed recently?
For example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behavior, increase in swearing, wanting to be left alone? Can you describe how?
10. Are there specific activities that they find painful and resist doing?
For example washing, getting out of bed, climbing stairs.
11. Have you noticed any possible causes of pain?
For example, cuts, bruises, arthritis or recent falls.
12. Have they been on painkillers in the past? If yes, do you know what kind and why?
Were there any side effects as a result of the painkillers?
13. Are there things that seem to help to soothe their pain?
For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.
14. Is there anything else you think is relevant or could help us to help them?

FIGURE 3 List of questions, brainstormed by the project team, for inclusion in the first iteration of the carer-facing questionnaire.

Since the questions were verbal, the clinical team suggested inclusion of a body map, recommended by UK national guidelines on pain assessment (op cit.), to provide a graphic parallel to the questions. Gender neutral outlines of front and back body views were drawn. The design team discussed whether to ask carers to use the body map both to describe pain experience as well as show pain locations but decided this would duplicate other questions on the questionnaire and that there could be benefit to hospital staff using carers' input in maintaining a set of questions that, as far as possible, paralleled those in the Abbey scale. Hence the body map was shown with a simple request to show pain location.

The questionnaire title 'Is your friend or relative in pain? Help us to look after the people you care about' was proposed in order to orient the reader to the questionnaire purpose. An explanatory introduction reinforced the role of relatives or carers in providing information that was useful to hospital staff.

LANGUAGE

The language of the questionnaire was direct and non-technical. Where questions were thought likely to require interpretation, example answers were given. For instance:

Has their body language changed recently?

For example fidgeting, rocking, guarding part of the body or hunching.

For questions drawn from the Abbey Pain Scale, the examples given were based on those used by Abbey. They were then modified to exclude any examples that could be difficult to interpret by non-professionals and to include additional examples that might help support broad responses from family carers. So, for example, where the Abbey scale exemplified changes in behaviour as:

Increased confusion, refusal to eat, alteration in usual patterns
the carer questionnaire gave more examples, particularly to clarify what might be meant by the Abbey scale's reference to 'alteration in usual patterns':

Increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing, wanting to be left alone

Similar ranges of examples were given for questions that had been generated by the project team, for instance:

Are there things that help to soothe their pain?

For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink

Note that smoking and alcohol were included to help elicit as realistic a picture of the patient's experience and needs as possible.

There was a possibility that examples would constrain, rather than encourage, responses; see Rose (1981) and Schwartz (1999) for discussion of the interpretation of the intentions of questions that respondents must make. However, given the wide range of potential users and circumstances of use (in some cases a carer may not feel confident enough to ask for clarification), supporting interpretation of the question seemed appropriate.

GIVING FORM

A combination of practical and emotional factors influenced initial decisions regarding document format. The precedent set by *Information About Me* suggested an A5 format (close to American half sheet). Within the project team, it was perceived as 'friendlier' in format than the larger A4 (close to American letter), associated with office use (a perception also noted by Perez et al. 2012). A5 format might also be easier to complete in a setting where a table or other surface might not be available to support the document as a respondent wrote on it. Our initial aim was to produce a single sheet (A4) that could be folded to a four page, A5 booklet. This document format could be

printed on demand within the hospital (in many NHS hospital settings, on-demand printing and photocopying are currently preferred over other forms of document reproduction).² However, early attempts to use a single sheet, with typeface Bliss, at 14pt, the upper end of size recommendations for legibility (RNIB 2011), delivered a layout that was too cramped to allow the kind of discursive response to questions that was anticipated (Figure 4).

Is your friend or relative in pain?

People who have difficulty understanding and communicating may feel pain but may not be able to tell us about it. In many cases, simple pain medication can make them more comfortable and prevent distress and suffering.

This leaflet is to help plan care for your friend or relative. We recognise that you know this person really well, and would like your help completing their pain assessment.

Name of patient: _____ Date: _____
 Questionnaire completed by: _____
 Relationship to patient: _____

Does _____ ever complain of pain? YES NO

What words would they use to describe their pain? For example, burning, shooting, stabbing, pinching, stretching, aching.

Talking about pain...

How often do they feel pain? For example, is it constant, does it come and go, is it very sudden and short, or is it only during specific activities?

Have they complained of pain in the past but stopped telling you about it recently? (4-7)

Where does it hurt them? Please describe

Does he/she cry out with pain? Please circle

Never Sometimes Frequently A lot of the time

Does their face ever show pain, for example by looking tense or frightened or by frowning? Please circle and describe how

Never Sometimes Frequently A lot of the time

Showing pain...

Has their body language changed recently, for example fidgeting, rocking, guarding part of the body, or hunching? Please circle and describe how

Not at all Hardy A bit A lot

Has their behaviour changed recently, for example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing? Please circle and describe how

Not at all Hardy A bit A lot

Are there specific activities that he/she finds painful, for example washing, getting out of bed, climbing stairs?

Have you noticed any possible causes of pain, for example cuts, bruises, arthritis or recent falls?

FIGURE 4 Initial attempts to create a single sheet questionnaire incorporating all the desired questions were thought by the project team to be too cramped to take forward to trial.

Instead we agreed on a more generously-spaced, eight-page, A5 leaflet, at least for initial feedback. We were aware that this format reduced the options for local, on-demand printing.

END USER INPUT

INFORMAL FEEDBACK

A draft questionnaire leaflet was prepared and distributed to four informants for informal feedback on its content and design. The informants (ages ranging from their 50s to their 80s) were currently caring for or had cared for relatives (parents or spouses) with dementia. Informants were asked to fill out the questionnaire as if it applied to their relative and to note any comments about the questionnaire itself that occurred to them while they were completing it (see, for example, *Figure 5*). They were then interviewed about the experience of filling out the form and comments they had made. Additional input was gathered from dementia care support staff (care assistants trained specifically to support nursing of people with dementia, who would be implementing the questionnaire) and one of the hospital's consultant geriatricians, who were asked to review and comment on the draft questionnaire.

5 Where does it hurt them? Please show us on this drawing.

So often it is a generalised pain - can this be indicated?

Page 4

6 Do they cry out with pain? Please circle

0 Never 1 Sometimes 2 Frequently 3 Constantly

7 Does their face ever show pain? For example by looking tense or frightened or by frowning?

0 Never 1 Sometimes 2 Frequently 3 Constantly

Can you describe how?

(MORE HELP WITH WORDING)

Page 5

8 Has their body language changed recently? ^{NOT CLEAR WHAT SHOULD BE CIRCLED?} For example fidgeting/jockeying, guarding part of the body, or hunching. Please circle

0 Not at all 1 Hardly 2 A bit 3 A lot

Can you describe how?

IT IS MORE "RESTLESS" - I WOULD LIKE THIS WORD SHOULD BE INCLUDED

9 Has their behaviour changed recently? For example increased (confusion) refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing? Please circle

0 Not at all 1 Hardly 2 A bit 3 A lot

Can you describe how?

SHE DOESN'T ALWAYS RECOGNISE ME, AS IS WHERE SHE IS

Page 6

10 Are there specific activities that they find painful and resist doing? For example washing, getting out of bed, climbing stairs

SHE RESISTS THIS, BUT IT MAY NOT BE BECAUSE OF PAIN

11 Have you noticed any possible causes of pain? For example cuts (rough) arthritis or recent falls

THESE GIVE SOME CAUSE FOR CONCERN AS SHE CANNOT EXPLAIN - HE MIGHT BE DUE TO NEURALGIC PAIN OR CAR?

12 Have they been on painkillers in the past? YES NO

If yes, do you know what kind and why? Were there any side effects as a result of the painkillers?

PROBABLY ONLY PARACETAMOL SIDE EFFECTS DIFFICULT TO DETERMINE

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Figure 5 Examples of feedback from one of the informants who reviewed drafts of the questionnaire during its development.

Across carer informants and staff the response to the use of such a questionnaire on hospital admission was positive. After project team discussion, some of the proposals that informants and carers had made for amendments to the detailed presentation of the questionnaire were fed into a subsequent editorial and design iteration before the next stage of trialling the questionnaire on hospital wards.

QUESTIONNAIRE TRIAL

A three month trial was arranged to assess the questionnaire's intrinsic effectiveness, i.e. whether it elicited appropriate responses from its intended users. We had some specific questions about its design:

Was the questionnaire too long – would carers flag before completing it?

Were individual questions relevant and comprehensible?

*Did use of example responses constrain carers' own responses?
Could carers use the body map effectively?*

What were carers' and staff members' views of the questionnaire's usefulness?

We were also concerned to establish the questionnaire's extrinsic effectiveness, i.e. its fit into hospital routine and potential for impact on prescription of analgesic and antipsychotic medication.

As mentioned in Section 1, this trial was a precursor to a study of the questionnaire's actual impact on pain treatment, and particularly medication prescription, which would need to be assessed through a larger-scale, controlled trial.

Two hundred finalized questionnaires (see thumbnails in *Figure 6*) were distributed to the dementia care team at the hospital, for use in two pilot patient areas. Distribution was preceded by presentations to care staff introducing the questionnaire and the thinking behind it. Staff were asked either (according to circumstances) to give the questionnaire to relatives of newly admitted patients to complete independently or to support relatives in completing the questionnaire. Staff were asked to return completed questionnaires to the research team after the patient had been discharged. A collection box was placed at the nursing stations of the pilot wards and completed questionnaires were collected by members of the project team. We were aware of the potential pitfall of this method of gathering data, since returning questionnaires could be forgotten, but we had the commitment of care staff to the project. As is reported in the results section, returns were limited even though staff were prompted throughout the trial to ensure that questionnaires were used and returned for analysis. A further 50 questionnaires were presented to family carers of people with dementia at a local carer education meeting, where some attendees consented to complete trial questionnaires.

Royal Berkshire NHS Foundation Trust

Is your friend or relative in pain?

Help us to look after the people you care about

13 Are there things that seem to help to soothe their pain?
For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.

14 Is there anything else you think is relevant or could help us to help them?

This is a trial leaflet. Your comments on filling it out would be helpful.

Thank you very much for your time.

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FIGURE 6
Thumbnails showing structure of the first iteration questionnaire.

Name of patient _____

Today's date ____/____/____

Questionnaire completed by _____

Relationship to patient _____

People who have difficulty understanding and communicating may feel pain but may not be able to tell us about it. In many cases, simple pain medication can make them more comfortable and prevent distress and suffering.

This leaflet is to help plan care for your friend or relative. We recognise that you might know this person really well, and would like your help completing their pain assessment.

1 Does _____ ever complain of pain? YES NO

2 What words have they used to describe their pain?
For example burning, shooting, stabbing, pinching, scratching, aching

3 How often do they feel pain?
For example, it is constant, once a day, once a week, it is very sudden and short or it is only during specific activities?

4 How they complained of pain in the past but stopped telling you about it recently? YES NO

Page 2

5 Where does it hurt them?
Please show us on the drawing.

6 Do they cry out with pain? Please circle:
Never Sometimes Frequently Constantly

7 Does their face ever show pain?
For example by looking tense or tightened or by frowning?

Never Sometimes Frequently Constantly

Can you describe how?

Page 4

8 Has their body language changed recently?
For example fidgeting, moaning, grinding teeth of the body or hunching. Please circle:
Not at all Fairly Often A lot

9 Has their behaviour changed recently?
For example increased confusion, refusing to eat, problems sleeping, irritability or aggressive behaviour, increase in sweating, sweating to the left, drowsy? Please circle:
Not at all Fairly Often A lot

10 Are there specific activities that they find painful and more than?
For example walking, getting out of bed, drinking water.

11 Have you noticed any possible causes of pain?
For example cuts, bruises, infections or sprain falls.

12 Have they been on painkillers in the past? YES NO
If yes, do you know what kind and why? What other side effects as a result of the painkillers?

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RESULTS

NUMBER OF RETURNS: Pooling the returns from hospital wards and the carer education meeting, of the 250 questionnaires distributed, only 25 were returned. Even taking into account concern about relying on staff to return the questionnaire, this poor return was a strong indicator of the questionnaire's limited potential impact.

QUALITY OF RETURN: Despite low return numbers the quality of returns was instructive. They were fully filled out, suggesting that those who consented to complete the questionnaire did not find it too long. Some respondents provided expansive answers to questions, through to the last page (see *Figure 7*), although others gave answers of one or two words. We did not find any questions that were misunderstood. Answers to questions with example responses (discussed in section 2.1) showed sufficient variation to convince us that the examples did not constrain respondents.

A

8 Has their body language changed recently?
For example fidgeting, rocking, guarding part of the body, or hunching. Please circle.

0 | 1 | 2 | 3
Not at all | Hardly | A bit | A lot

Can you describe how?
HUNCHING WHEN SITTING
TOUCHING FOREHEAD WITH LEFT ARM

9 Has their behaviour changed recently?
For example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing, wanting to be left alone? Please circle.

0 | 1 | 2 | 3
Not at all | Hardly | A bit | A lot

Can you describe how?
VERY SLEEPY, NOT EATING
WELL, MORE CONFUSED

Page 6

10 Are there specific activities that they find painful and resist doing?
For example washing, getting out of bed, climbing stairs.

GETTING OUT OF BED

11 Have you noticed any possible causes of pain?
For example cuts, bruises, arthritis or recent falls.

FELL 17/12 - FRACTURED
RIGHT HI?

12 Have they been on painkillers in the past? YES NO

If yes, do you know what kind and why? Were there any side effects as a result of the painkillers?

CAN'T REMEMBER NAME - BUT
THIS WILL BE 10 PAGES FROM
ONCE MORE

Page 7

B

13 Are there things that seem to help to soothe their pain?
For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.

BLANKET

14 Is there anything else you think is relevant or could help us to help them?

JUST CHEERFUL REASSURANCE
SHE CAN BE FEARFUL AND
CAN BE "NEEDY"
SHE LOVES ICE CREAM (VANILLA)

This is a trial leaflet. Your comments on filling it out would be helpful.

HOPE THIS HELPS HER DEMENTIA
DOES MAKE CARE MORE DIFFICULT
I THINK THIS FORM IS A GREAT
Thank you very much for your time.

GOOD IDEA. IS FROM
MISS SCOTLANDS.

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FIGURE 7

Examples of returns of questionnaires completed by carers in the trial, showing variation in response length. 7A and B are from the completed questionnaire of one participant, 7C and D from a second participant. The diversity of responses demonstrated that the questions (particularly those with example responses) had not constrained the information given by respondents.

C

8 Has their body language changed recently?
for example fidgeting, rocking, guarding part of the body, or hunching. Please circle.

0 1 2 3
Not at all Hardy A bit A lot

Can you describe how?
He clenches his jaw and his fists
while experiencing those spasms of
pain

9 Has their behaviour changed recently?
For example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing, wanting to be left alone? Please circle.

0 1 2 3
Not at all Hardy A bit A lot

Can you describe how?
Refusing to eat and increased confusion

10 Are there specific activities that they find painful and resist doing?
For example washing, getting out of bed, climbing stairs.

Swallowing

11 Have you noticed any possible causes of pain?
For example cuts, bruises, arthritis or recent falls.

He is in a cast shown by x-ray

12 Have they been on painkillers in the past? YES / NO
If yes, do you know what kind and why? Were there any side effects as a result of the painkillers?

Don't know which specifically.
Aspirin

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D

13 Are there things that seem to help to soothe their pain?
For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.

14 Is there anything else you think is relevant or could help us to help them?
Because he has been non-communicative
for much of the time while in hospital,
it's difficult to be specific. He also has
Ativan's and therefore has trouble with
his short-term memory.
This is a trial leaflet. Your comments on filling it out
would be helpful.

Thank you very much for your time.

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In two cases the body map, which we had seen as a parallel means to gather information to verbal questions, elicited responses that were not given elsewhere in the questionnaire. Particularly striking was an instance where a carer noted a second site of pain, which had not been the cause of admission. The pain was investigated and found to be the result of a pre-presentation, untreated fracture, which was then treated. In the second case the husband of a patient used the body map to illustrate pain in his wife's pubic area, which he had not discussed with a clinician or described verbally on the questionnaire.

Those who responded to the trial feedback question at the end of the questionnaire made positive comments on the questionnaire's potential usefulness, similar to the responses of staff when the questionnaire was introduced to them.

DISCUSSION

Our trial demonstrated that we had produced an intervention that was intrinsically effective, and was liked by its potential users. However the low level of uptake across the trial suggested limited potential for impact on clinical practice. It may have been that the relatively informal trial methods did not embed the questionnaire well enough in everyday ward process. However, as discussed in section 2.2, effort had been made during the trial to promote the questionnaire's use.

Subsequent discussion with dementia care support staff, the key link in this trial between hospital systems and patients, revealed that, while staff appreciated the potential benefit of the questionnaire, they felt they did not have time to introduce it into their routine. Other reasons given for lack of implementation included disruption of typical ward arrangement, following ward closures for cleaning. However, such disruptions are not unusual in busy hospitals and any design proposal should be robust enough to persist given such eventualities. There was no indication from staff reports that any relatives who had been asked to complete the questionnaire had declined.³

It appeared that, despite involvement of potential users in questionnaire development, we had stumbled over the problem, highlighted by Wright (1998, p 61), of producing an effective design, but not an appropriate design solution for the context in which it was to be used.

As Wright continues, in these circumstances testing indicates the need for a change of approach, rather than refining the existing solution. This trial suggested the potential effectiveness of the questionnaire as a means of gathering information about patients, but not as a tool that could be implemented in routine patient care. Hence, rather than abandon a project that was agreed by all parties to be well founded, we then sought a new approach to questionnaire design that would increase the likelihood of implementation and eventual impact on pain relief and prescription practices.

SECOND DESIGN ITERATION

BUILDING ON FIRST ITERATION FEEDBACK

In order to ensure uptake of the questionnaire, without adding significantly to the burden of care staffs' daily routine, we needed to integrate it directly into existing practice. We were aware that the professional version of the Abbey Pain Scale was administered routinely on patient admission to a ward and, subsequently, at regular time intervals. Therefore we decided to link the carer pain questionnaire to the first use of the Abbey Pain Scale, by combining the two

in the same document. We also sought to minimize any further barriers to uptake by reducing the questionnaire to a single sheet that could be printed on demand (as discussed in Section 2.1), rather than an eight-page, pre-formatted booklet. These two, new requirements created a 'squeeze' on the spatial layout of the questionnaire which we had sought to avoid initially. Hence there were compromises in subsequent design, which we felt would be offset by increasing the likelihood of carer input to pain assessment.

CONTENT AND LANGUAGE

We tightened the focus of questionnaire content, removing two questions that did not target pain relief directly: a general question, 'Is there anything else you think is relevant or could help us to help them?' and the trial feedback question about the usefulness of the questionnaire. The general question received some extensive answers in the trial but these tended to diverge from pain relief. Since there was no clear nursing route for response to information carers gave here, it may have set up an expectation of response that might not have been met.

The remaining questions were the same as those in the first iteration design but, following input from a carer while this revision was in preparation, we added an instruction to guide the user to continue filling out the form, even if their response, to the first question 'Does the patient ever complain of pain?' was negative. We partly reordered the question sequence to ensure best fit of content into the available space.

Debate about whether to exclude the body map, which took up considerable space in the first iteration design, concluded that it should be retained, since it had revealed information that had not been given elsewhere in trial questionnaires. It was also seen as a direct means of communication with staff, which did not rely on their reading detailed information (Nygren, Wyatt and Wright 1998).

GIVING FORM

The most significant changes in the re-design resulted from the move from A5 booklet to a single A4 sheet, and the inclusion of the professional Abbey Pain Scale. In consequence, the new form featured reduced type size, reduced space for responses and smaller body map images, all set within a two column layout (see *Figure 8*).

Royal Berkshire NHS Foundation Trust

Is your friend or relative in pain?

Help us to look after the people you care about

People who have difficulty understanding and communicating may feel pain but may not be able to tell us about it. In many cases, simple pain medication can make them more comfortable and prevent distress and suffering. This leaflet is to help plan care for your friend or relative. We recognise that you know this person well, and would like your help completing their pain assessment.

1 Does the patient ever complain of pain?
 Yes No, please continue with any questions that seem relevant to you.

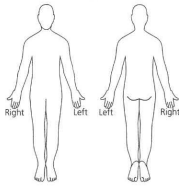
2 What words do they use to describe their pain?
 For example, burning, shooting, stabbing, pinching, stinging, aching.

 Are there other things they say when in pain?

3 How often do they feel pain?
 For example, is it constant, does it come and go, is it very sudden and short, or is it only during specific activities?

4 Do they cry out with pain? Please circle.
 0 1 2 3 4
 Never Sometimes Frequently Constantly

5 Have they complained of pain in the past but stopped telling you about it recently?
 Yes No

6 Where does it hurt them?
 Please show us on this drawing.


7 Does their face ever show pain?
 For example by looking tense or frightened or by frowning?
 0 1 2 3 4
 Never Sometimes Frequently Constantly
 Can you describe how?

Please turn over →

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 Written by: Annette Gibbs, Matt Longwell & G. L. Last, published in collaboration with Department of Neurology & Geriatric Communications, University of Reading, February 2013. Review due March 2014.

FIGURE 8A

Second design iteration with questionnaire revised to fit a single A4 sheet and to include a professional pain assessment (using the Abbey Pain Scale) alongside the carer questionnaire (see 8B).

Since some of the carers' responses in the first trial were brief we felt the compromise in response space was acceptable, even though less than ideal and potentially limiting to those who wished to respond expansively. Type size reduction (to 12pt Frutiger) maintained a relatively large appearing size, albeit at the lower end of the 12–14pt range that is usually specified in accessibility guidelines (RNIB 2011).

We reduced the size of the body map images as far as we felt acceptable to allow a respondent to mark a pain area accurately. The map was smaller than typically presented in medical settings. However relatively small body map images have been used successfully; for example, those used in Kwikpoint communication cards to support communication across language barriers in war zones (Eldredge 2013).

The compressed space allowance necessitated the use of horizontal rules to separate the questions. A tinted (grey) rule was used in order to reduce interruption as carers read down the questionnaire. The rules had the benefit of reinforcing the column structure of the document and, together with prominent question numbers, indicated direction of reading.

FOR HOSPITAL USE

The Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise

How to use scale: While observing the resident, score questions 1 to 6.

0 1 2 3
 Not at all Hardly A bit A lot

8 Has their body language changed recently?
 For example fidgeting, rocking, guarding part of the body, or hunching. Please circle.
 Can you describe how?

9 Has their behaviour changed recently?
 For example increased confusion, refusing to eat, problems sleeping, irritable or aggressive behaviour, increase in swearing, wanting to be left alone? Please circle.
 Can you describe how?

10 Are there specific activities that they find painful and resist doing?
 For example washing, getting out of bed, climbing stairs.

11 Have you noticed any possible causes of pain?
 For example cuts, bruises, arthritis, recent falls.

12 Have they been on painkillers in the past?
 Yes No
 If yes, do you know what kind and why?
 Were there any side effects?

13 Are there things that seem to help to soothe their pain?
 For example having a hot drink, blankets, hot water bottles, cold compress, smoking, having an alcoholic drink.

Thank you for filling in this questionnaire.

7 Patient Name: _____
 Name and designation of person completing the scale: _____
 Date: _____ Time: _____
 Pain relief given: _____ at: _____

Q1 Vocalisation eg. whimpering, groaning, crying
 Absent 0 Mild 1 Moderate 2 Severe 3

Q2 Facial expression eg. looking tense, frowning, grimacing, looking frightened
 Absent 0 Mild 1 Moderate 2 Severe 3

Q3 Change in body language eg. fidgeting, rocking, guarding part of body, withdrawn
 Absent 0 Mild 1 Moderate 2 Severe 3

Q4 Behavioural change eg. increased confusion, refusing to eat, alteration in usual patterns
 Absent 0 Mild 1 Moderate 2 Severe 3

Q5 Physiological change eg. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
 Absent 0 Mild 1 Moderate 2 Severe 3

Q6 Physical changes eg. skin tears, pressure areas, arthritis, contractures, previous injuries
 Absent 0 Mild 1 Moderate 2 Severe 3

Add scores for Q1 to Q6 and record here
 Total pain score

Now tick the box that matches the total pain score

0-2	3-7	8-13	14+
No pain	Mild	Moderate	Severe

Finally, tick the box which matches the type of pain
 Acute Chronic Acute on chronic

Abbey J, De Bellis A, Piller A, Espartero A, Giles L, Parker D, Lomasco B
 The Abbey Pain Scale. Funded by the Jt & St. Doris Medical Research
 Foundation (1988-2002). This document may be reproduced with the
 acknowledgement (see above).

The professional Abbey Pain Scale was included on the sheet in a tinted column, to distinguish it from the carer-facing questionnaire. While acknowledging that all users need to see text at a legible type size we felt it appropriate to reduce the type size here to a (still legible) 10pt Frutiger, increasing the distinction between professional and public-facing tools.

END USER INPUT

During this iteration we gathered informal input from potential users (as with the first iteration four current family carers and, additionally, members of dementia care support staff), paying particular attention to navigation through the new, two-column structure and the potential impact of reduced space available for responses. As mentioned in discussion of Content and Language, above, this consultation led to the inclusion of additional instructions to continue completing the form, even if the answer to the first question was negative.

The re-designed questionnaire is now due for further trial which will provide the opportunity to reassess its extrinsic effectiveness (i.e. its fit with hospital routine and potential for impact on pain relief practices). Longer term, once the questionnaire has become an established part of clinical practice, it will be possible to assess its impact on prescription of analgesic and anti-psychotic medication.

DISCUSSION AND CONCLUSION

The contribution of family carers (typically adult children or spouses) to the health outcomes of people with dementia is well understood (Brodaty, Green and Koschera 2003). Published strategies for dementia care in many countries recommend involving carers as partners in care-giving, e.g. in the US (Alzheimer's Association et al, 2004), UK (Banerjee and Owen 2009) and Australia (Dow et al. 2004). Our study draws attention to the requirement for design to respond to the communication needs of both sides of such a carer-professional partnership.

In many reported cases of forms or questionnaire design initial, systems-focused design solutions require adaption to satisfy the needs of end users (Barnett 1988, 12–19). Unusually, perhaps, in our case the situation was reversed with an initial approach that favored the end user at the expense of the organizational user or system. Our initial approach was taken with the full endorsement of organizational users (professional dementia care staff) but it failed as a communication tool because they found it difficult to integrate it into their ward routines. It is possible that staff were already aware of the potential difficulties of the first design iteration but felt unable to express their concerns when the intervention was presented to them (Kramer and Schmalenberg 2003). Alternatively they may have overlooked practical difficulties

with the first iteration design because of its visual similarity to the popular *Information About Me* booklet (a similar effect has been reported in Keller-Cohen, Meader and Mann 1990) or because its visual simplicity gave an immediate impression of usability (Song and Schwartz 2010). However, sometimes contextual influences, such as the communication demands of a busy hospital (Coeira and Tombs 1998), can only be discovered through testing within the full context of use and constellation of potential users (Black 1998).

Design literature, in common with the literature of other disciplines (see, for example, Rosenthal 1979, Giner-Sorolla 2012), rarely reports failure of an intervention (although design failures are often highlighted in popular Internet design forums). Nor does design literature tend to report solutions where user feedback changes a design approach significantly, i.e. where the initial design solution appears to be substantively wrong. In our case, feedback resulted in a shift in approach from a discursive questionnaire to a far more constrained means of information exchange. As mentioned in Section 3.1, we are aware that the limited space for responses in the second iteration design solution may constrain family carers who wish to supply detailed information. However our priority is to ensure family carers' knowledge feeds into professionals' decision-making and have aimed to balance carers' and professionals' needs in developing this tool for information exchange. Further ahead we might envisage digital versions of such a tool which, provided they could be made available for carers to give input, might place less constraint on the amount of information a carer provided (although would also need to take into account the demand on professionals of absorbing the amount of information given). However, in the setting described, where electronic patient records and prescribing systems are not yet linked, paper forms provide an interim system.

Many academic design research reports do not extend to testing in context of use or after implementation (see, for a recent medical forms example, Frascara and Guillermina 2010). Testing interventions in a clinical setting is complex and the timescales needed for approval and permissions can be an impediment to it being carried out at all. The focus in health care research on clinical interventions, rather than on communication or other aspects of care, may also reduce the likelihood that such interventions will be tested. However concern that design interventions are not tested through to impact on patient outcomes has been expressed by Katz, Kripalani and Weiss (2006). With this concern in mind we await the outcomes of a trial of the revised questionnaire, aware that further refinement may be needed to ensure its effectiveness as a communication tool. Once its usability for both carers and professionals has been established we will then be able to progress to full trial in order to establish its impact on prescribing practice.

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ENDNOTES

- 1 We are grateful to the authors of the Abbey scale for their permission to draw directly on their work.
- 2 Designers may be surprised by the constraint of on-demand printing but this is common practice for many documents used in NHS settings and we aimed to work within existing constraints. Since the study reported here, two of the authors have attracted funding to develop professionally reproduced post-diagnosis documentation to support family carers of people with dementia, and this new project will allow some comparison of the impact of the new documentation with current, photocopied provision.
- 3 Another possible explanation for low uptake might have been lack of compensation to staff for taking part in a trial. Compensating staff would be unusual in an NHS trial such as this, where a new process is being piloted as part of everyday care practice.

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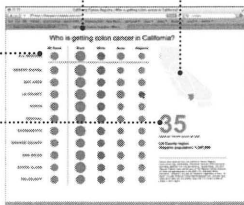
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rates plotted together,
organized by groups
& coded by color;
macro view of all data

rates show as
precise numbers



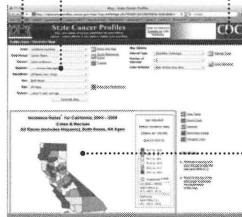
straightforward
titles

map identifies
location of
10 regions

recognizable
brand

drop-down menus require
pre-selection of data

recognizable
brand



rates plotted for
selected group by region;
data shown as color-
coded to ranges, not
by precise numbers;
map broken down
to many regions

A	78% CORRECT	62% CORRECT
B	91% CORRECT	61% CORRECT
C	75% CORRECT	16% CORRECT

A Who gets more colorectal cancer in California, people living in Orange Country or in La Country? 78/62

B Who gets more colorectal cancer in California, Blacks or Whites? 91/61

C Who gets colorectal cancer the least in California? 75/16