Author's response to reviews

Title: General practitioners and carers: a questionnaire survey of attitudes, awareness of issues, barriers and enablers to provision of services.

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Author's response to reviews:

Re: MS: 9175805544559208

Title: General practitioners and carers: a questionnaire survey of attitudes, awareness of issues, services provided and barriers.

Nan Greenwood, Ann Mackenzie, Ruth Habibi, Christine Atkins and Ray Jones

22nd November 2010

Dear Professor Wilson

Thank you very much for sending us the very helpful and constructive reviewers’ comments. They have highlighted some important points and we feel that the paper has been much improved by incorporating and responding to their observations.

Our responses to the individual comments can be found below underneath the original reviewers’ comments. We have highlighted changes in yellow in response to Dr Bulsara’s comments and in blue for Dr Moore’s comments. To make the changes clear in this letter, our responses to the reviewers is in italics.

We hope that you will find our responses satisfactory.

Yours sincerely,

Nan Greenwood

Senior Research Fellow MSc, PhD

Editorial comments
1) Please state your research aim in the background section of the Abstract.

We have now added the following to the Abstract (red).

‘This study therefore aimed to identify GPs’ attitudes, awareness of issues, and perceptions of the barriers and enablers to provision of services.’

2) We recommend that you copyedit the paper.

This has been done. The majority of these changes were suggested by the reviewers (see below).

Reviewer: Caroline Bulsara

Reviewer’s report:

COMMENTS FOR AUTHORS

Discretionary Revisions

TITLE:

I would suggest that the authors reconsider to a more concise title: eg –“General practitioners and carers: Attitudes, awareness of issues and the barriers and enablers to provision of services.’

This has been done.

ABSTRACT

• Suggest that authors change ‘important point of contact’ to ‘first point of contact’.

This has been done.

• Results – suggest inserting the word ‘total’ before 95 GPs.

We have added ‘out of a total of...’

BACKGROUND

• 4th paragraph – ‘providing care’ needs qualification. E.g ‘providing informal /unpaid’ care.

We have inserted this qualification.

Also, would deterioration in health also include ‘psychological health’?

To make this clear, we have gone back to the references and now provided a reference that covers both physical and psychological health.

METHODS
• Would suggest that authors also emphasise in SETTING AND METHOD, that only GP responses were included given that the main focus was the GP perception of providing support.

We have made this clearer by saying: ‘Although representatives from a range of professions attended the workshops, only responses from the GPs are included here because of the small numbers representing other professional groups.’

• Questionnaire – line 4 – suggest adding ‘carer specific’ before ‘services’. Also, could authors expand on why using closed and open ended questions would capture a more complete picture. I understand why but this needs to be stated. For example, ‘given that GPs could articulate personal perspectives and issues in providing support and care through open ended responses...’ or similar.

We have inserted ‘carer specific and also added an explanation for why this approach might capture a more complete picture. It now reads:

‘This method was expected to capture a more complete picture of GP perspectives than using only one approach. The quantitative element provides numerical results whilst the open-ended question gave the GPs the opportunity to articulate personal perspectives and describe experiences and issues not covered by the Likert scales.’

RESULTS

• Page 9 – did the respondents specify in what ways they took an ‘active role’ in supporting carers?

Unfortunately this cannot be specified as the participants were responding to a Likert-style question which did not give participants the opportunity to expand on this.

• The second paragraph on page 9 is highly relevant and the crux of the matter in my opinion as to future education and training programs. I would suggest the authors perhaps put this paragraph first here.

We have swapped the paragraphs and changed the wording slightly to make it flow better.

• Page 13 – 1st paragraph – final sentence I would suggest adding ‘practical in their approach’ to complete the sentence.

We have done this.

• 2nd paragraph – it would be really useful if the authors could provide a brief recap of the other recommendations for which little progress had been made.

We have expanded this paragraph to include more detail to read:

‘Nearly a decade ago it was suggested that primary care teams could support
carers in a number of ways including acknowledging the problems they have and ensuring the general practice team are aware of them, flagging carers’ notes so that GPs were aware of their caring role, acknowledging the role they play, treating them as team members and provision of information for the carer relating for example to the condition of the person the carer is looking after and information about benefits and services [19]. The fact that the DH and the RCGPs organised these workshops suggests greater awareness of the importance of carers and the significant role they play but our findings suggest that many of these earlier recommendations still stand. Although most GPs here did agree that carers should be a partner in the care of the recipient of care, little progress seems to have been made with the other recommendations.’

• Page 14 – it would be useful if the authors could provide a brief explanation of what a ‘carer champion’ is?

We have inserted the following: ‘Such carers champions are a member of the general practice staff who can recognising the needs and difficulties of carers and be able to offer them information and respond to their enquiries.’

Minor Essential Revisions

ABSTRACT

• Abstract background – 2nd sentence requires rewrite specifically around the phrase, ‘...and to require support’.

We have made this clearer: ‘This role is known to sometimes have a negative impact on carers and to require support both informally and from statutory services.’

• Avoid using terminology such as ‘close to’ when reporting survey data. It is preferable to use ‘approximately’ and similar more precise terminology.

We have changed this both here and throughout the article.

• Abstract results – ‘...lack confidence in meeting carers’ needs’. Could the ‘needs be briefly noted in a word or two. .g Psychological needs, support needs, educational needs?

Unfortunately we are unable to specify this as the participants were showing the extent of their agreement or disagreement with the following statement: ‘In general I feel confident that I meet the needs of carers’

BACKGROUND

• Page 4 – what sorts of demographic changes are expected? Could the authors clarify? Eg An ageing population.

To clarify this we have inserted ‘with the ageing population and greater numbers of severely disabled people living longer’.
• 3rd paragraph – missing an ‘of’ in sentence, ‘Over half these carers are women...’.

We have inserted ‘of’.

• Page 5 – 2nd paragraph – suggest change term ‘evidence is mixed’ to ‘evidence is inconclusive’.

We have done this as suggested.

• Page 5- 5th paragraph – Insert ‘In the UK’, at the commencement of paragraph.

We have done this as suggested.

RESULTS

• Page 8 - 2nd paragraph – again replace ‘close to’ with approximately’.

We have done this as suggested.

Also, sentence is a little clumsy and I would suggest rewording (i.e. ‘previous training in carers’).

We have done this as suggested and inserted ‘previous training in issues in supporting carers.’

• Reasons for attending the workshop – what type of ‘knowledge’ is being sought? Could the authors be more specific? Also advise adding ‘improve provision of services’ rather than just ‘improve services’.

We have added some examples here.

• ‘Two thirds of practices were identified as (replace ‘described’) urban’.

We have done this as suggested.

• Page 9 – 3rd paragraph – replace ‘knew this’ with ‘noted that they were aware of this’ and the word ‘about’ with ‘approximately’.

We have done this as suggested.

• Page 9 – would it be appropriate to say that ‘all-cause mortality rate is increased’ due to their caregiving role?

This was a response to the Likert scales so we are unable to specify this.

• Page 10 – it is customary when reporting survey data to use the term ‘multiple response’ rather than explaining why percentages did not ‘add up to 100%’. Also wording needs revising from ‘participants could give as many answers as they wished’ to ‘Respondents could provide more than one response to open ended questions’.

We have done this as suggested.
We have removed this from the text and the tables and done as suggested later so that [multiple response] appears in the titles of tables 3-6.

• I don’t think there is any need for the inclusion of terms such as ‘one in five’ as it doesn’t really lend anything to the findings. I would suggest omitting this from the results.

This has been done.

• Avoid slang terminology such as ‘topped’ the results. Replace with ‘were most often noted..’ or similar phrase with the percentage recorded in brackets afterwards.

This has been done.

• What sorts of problems amongst young carers were reported with education (47%)?

We have added some examples (e.g. missed schooling and poor academic performance).

• Again, there is no real need to mention who did not respond. This is relevant for a report but no need for mention in a paper.

This has been done.

• Page 11 – 1st paragraph – were the flu vaccinations offered to carers specifically?

Unfortunately we do not know the answer to this as the participants did not specify whether the service was specifically for carers or not.

• 2nd paragraph – first sentence not needed as it is not really clear to researchers why the GPs did not respond.

This has been removed.

DISCUSSION

• Again, please try to briefly mention why there is likely to be a future increase in numbers of carers.

This has been done.

• There needs to be some form of introduction to the paragraph beginning, ‘The identification of carers remains...’ such as, ‘Key issues to include would be the identification of carers...’ or similar wording. The paragraph doesn’t flow at present and detracts from the important issues being raised by the authors.

We have changed this: ‘Key issues highlighted include the identification of carers - some GPs are aware that they are not identifying all carers in their practices
and would like to be guided on how best to do this.

- Page 12 – could the authors specify who reported the carer registers – GPs? Respondents?
  
  This is now specified.

- All mention of ‘the cared for’ needs replacing with correct terminology – ‘care recipients’ or ‘person being cared for’ as appropriate.
  
  This has been done in the text but on advice this was the phrase used in the questionnaire and therefore cannot be changed here.

- Page 13 – 1st paragraph – second sentence – what does ‘this’ refer to in ‘expected to offer this’? Suggest replacing with ‘support services’ or similar for clarity.
  
  We have put in ‘such support’.

- 2nd paragraph – when the authors mention ‘flagging notes’ could they specify in regard to what? For example, illness or stress of a carer?
  
  To clarify this we have inserted ‘so that GPs were aware of their caring role’.

  Also, to what does ‘information provision’ pertain? Is this regarding the carer as a source of information in regard to the care recipient health?

  We have added ‘provision of information for the carer relating for example to the condition of the person the carer is looking after and information about benefits and services’

Major Compulsory Revisions

ABSTRACT

- Authors need to state at the outset that the survey was distributed at the workshops as this does affect the response rate. At the moment it is only mentioned later in the manuscript.

  This has been done. It now reads ‘Using a self-completion questionnaire distributed at a series of workshops’.

- Any tables with multiple responses need to be identified as such in brackets after the title of the table without any need for the explanation of percentages not adding up to 100%. This is already usually understood by persons who are familiar with survey data. For example, ‘Table 2: Summary of responses to Likert Scales [multiple response]’. This is all that is required.

  This has now been done (see earlier).

Reviewer: Tim Moore
Reviewer’s report:

This is an interesting and timely study which provides us with some preliminary ideas about GPs knowledge of and response to carers. Although I believe that some of the questions may have been further clarified to ensure that participants were better able to assess their views, the outcomes can be used to support the call by carer organisations and peaks to better educate and support GPs in their work with and for carers. If the paper is to be published in an international journal, I would strongly recommend that references to local initiatives and policies be further explained so that the reader can understand the local context. I have also included some clarifications that may further justify your conclusions.

Corrections and clarifications (Minor Essential Revisions)

Page 1 - Few services were described “that” targeted at carers.
This has been corrected.

Page 5 – please lengthen “NHS”
This has been done.

On page 5 you state:
Research in Australia [16] focussing on GPs’ perceptions of carer emotional needs highlighted that although GPs were aware of carers’ increased emotional needs, the services they offered were almost exclusively practical. GPs preferred to refer carers to community services although some did offer counselling described as ‘informal sharing or ‘coffee cup counselling” (p4).
Please explain what non-practical support might also be offered.
We have provided examples to read: ‘(including referring and directing carers to services to ensure the carer had practical assistance).

On page 5 you write:
“GP contracts currently give three points in the Quality and Outcomes Framework (QOF) for the establishment of a system to identify and refer carers to local authorities for assessment of their needs.”
Please clarify what this framework hopes to achieve and what these 3 points are (are they strategies / obligations / responsibilities?)
We hope we have now described this more fully. This section now reads:
‘GP contracts in the UK currently give three points in the Quality and Outcomes Framework (QOF) for the establishment of a system to identify and refer carers to local authorities for assessment of their needs. The Quality and Outcomes
Framework (QOF) rewards GP practices for how well they care for their patients and helps fund improvements in the care they deliver. It is based on performance against specified indicators or measures of achievement. Each indicator is worth a maximum number of points and GP practices are rewarded financially according to how many points they achieve.

On page 6 you write:

“The Department of Health (DH) in partnership with the RCGP commissioned a pilot workshop training programme for GPs and other members of primary care teams to learn about carers.” Please clarify: is this a national or local department?

This now reads:

‘The Department of Health (DH) in partnership with the Royal College of General Practitioners (RCGP) commissioned a pilot workshop training programme for GPs and other members of primary care teams across England to learn about carers. The findings reported here were gathered from questionnaires completed by GP participants prior to the workshops and was part of the programme’s evaluation.’

On page 6 you refer to the RCGP, what is this?

We have used the full title to read: Royal College of General Practitioners (RCGP).

On page 6 you state that the questionnaires were administered at a training workshop. Can you please briefly explain the nature and purpose of these workshops and what kinds of GPs might therefore have participated. (I note that you do this later in the paper but a clearer explanation up front would be helpful, including recruitment strategy).

We have added ‘The aim of the workshops was to give participants a better understanding of the problems facing carers and the role that primary care might take in supporting them.’ We have not commented on the impact of this at this stage but have already mentioned this as a limitation.

On page 7: what do you mean by ‘yeah saying’?

We have clarified this to now read:

Questions were phrased both positively and negatively to reduce the chances of response bias where participants may tend to agree rather than disagree with statements, a behaviour sometimes referred to as ‘yeah saying’.

On page 7 you write: “When contacted the National Research Ethics Committee said this study did not require ethical review by a NHS Research Ethics Committee.” Can you please explain why they did not believe that ethics approval was required.
We have added some detail here to read:

When contacted the National Research Ethics Committee said this study did not require ethical review by a NHS Research Ethics Committee because the study did not fit the criteria for research and was deemed to be an educational evaluation. However the study was conducted with ethical principles such as informed consent and respect for confidentiality.'

On page 7 you state: “This method captures a more complete picture of GP perspectives than using only one approach.” Have you got evidence that this is the case? If not, it might be useful to put in a disclaimer ie “We believed that this method would capture a more complete…”

Both the reviewers commented on this so we have now changed this to read: ‘This method was expected to capture a more complete picture of GP perspectives than using only one approach. The quantitative element provides numerical results whilst the open-ended questions gives the GPs the opportunity to articulate personal perspectives and describe experiences and issues not covered by the Likert scales.’

On page 8 you write: “GPs were asked an open-ended question about why they attended the workshop and the main reasons they gave were to increase their own (38%) or their practices’ (10%) knowledge and to improve services (24%).” Was this knowledge related to carers, how to work with them, how to provide services or something else? Please clarify.

We have clarified this to read: GPs were asked an open-ended question about why they attended the workshop and the main reasons they gave were to increase their own (38%) or their practices’ (10%) knowledge. For example, they hoped to improve their own knowledge in issues facing carers and how best to identify them. Some explicitly mentioned they were attending with the intention of sharing the information gained with others in their practice. A quarter said they hoped to be able to improve the provision of services for carers (24%).

On page 9 you write: “maintaining confidentiality was recognised as difficult by the majority of these GPs (92%)” please clarify: who’s information? The clients or the carers or both?

This referred to the recipient of care and has been clarified.

On page 9, you write: In terms of knowledge, awareness that carers are more likely to suffer from emotional problems was high. Three-quarters (75%) knew this but about a quarter did not. Two-thirds of GPs (64%) agreed that carers’ all-cause mortality rate is increased whilst a fifth (21%) said they did not know.

Would it be useful for the reader to be pointed to the evidence related to these claims that were being tested?

We have not added anything here as it is the Results section but it is referred to in the background section.
On page 10 you state: “When asked about social issues amongst carers that they would look out for, approximately a quarter of GPs (27%) provided no answer.” Do you have any idea why they might not respond?

We have not added anything here as it is the Results section but have picked it up in the Discussion where we now say they: ‘lacked some knowledge and awareness of likely problems amongst carers (as suggested by the questions where they failed to answer or were unaware of some facts about carers)...’

Table 3 includes mental health, fatigue, health and stress under “social issues” – why are they not health issues?

We apologise - this was unclear and we have now changed the table headings to show the question participants were asked – the table now shows that the issues they came up with were their responses to the questions asked, rather than how we categorised their responses.

On page 11 you write: “Against the backdrop of the likely future increase in numbers of carers” can you please point to some evidence for this.

We have added reasons for this projected increase which according to Carers UK is: ‘because of an ageing population and more people living with improved healthcare so that more people live with disability for longer’

On page 13 you write: “A possible approach here is increasing the numbers of carers’ leads or champions in primary care teams [20].” Can you briefly explain what a carer lead and champion is.

This was also a query from the first reviewer and to try and respond to both reviewers we have now said: ‘Such carers champions are a member of the general practice staff who can recognising the needs and difficulties of carers and be able to offer them information and respond to their enquiries’