Author's response to reviews

Title: Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study

Authors:

Fiona J Jurgens (fiona.jurgens@nottingham.ac.uk)
Philip Clissett (philip.clissett@nottingham.ac.uk)
Davina Porock (dporock@buffalo.edu)
John R Gladman (john.gladman@nottingham.ac.uk)
Rowan H Harwood (rowan.harwood@nuh.nhs.uk)

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Author's response to reviews: see over
Thank you for helpful and constructive comments which we have accommodated.

Responses to reviewers’ specific points:

Reviewer 1: Jackie Bridges

1. The authors mention an ethnographic study (p.4) and I assume that the interview data presented in this manuscript are a sub-set of that ethnographic study, but it would be helpful to know a little more about the ethnographic study.

Response: Correct. This paper is based on interview data alone, but we have added some explanation of ethnography and details of the observational study as well. Page 5

This leads to my next point about sampling. I am interested to understand more about how the final sample of 96 family carers approached for interview was arrived at. The authors report that 250 patients thought likely to have a mental health problem on the basis of screening were recruited to a follow-up study. I assume the interview population was drawn from family carers linked to this original sample of 250 but the manuscript does not make this clear, or does not report how decisions were made about who to approach for interview. In addition, the results clearly report the perspectives of family carers of people with dementia, not people “thought likely to have a mental health problem on the basis of screening”. The authors do not make it clear that focusing on people with dementia was the purpose of sampling.

Response: This has been made clearer. The original intention had been to interview carers of people whose care had been observed during non-participant observation, and to interview involved staff as well, but this proved difficult in practice. We also originally intended to study a range of mental health problems, but cognitive problems predominated, especially in the group that agreed to take part in the interview study. Cognitive problems included delirium and dementia, ‘confusion’ for shorthand (reflecting common usage in the hospital). For simplicity we originally omitted mention of the non-delirium/dementia patients, but I have now added them back in. Page 5-6.

3. In relation to the interview method reported, it would be helpful to have a copy of the original topic guide or a description of the questioning focus. The authors state that family carers’ experiences were variable but then only the negative experiences are reported and used to inform the development of the framework presented. Are there any examples of positive experiences and helpful practices in the data, and if so, what can be learned about how the cycle of discontent could be prevented or halted? If the authors
continue to focus solely on the negative experiences, I think they need to give rationale for this, given that they report that experiences were variable.

Response: We did not want to imply that all experiences were negative, but to explain why discontent or anger could arise in some carers. This is more explicitly stated, with a rationale (methods, page 6 last paragraph). A broader view of carer experiences has been written up separately and has been referenced (happy to supply a copy if wanted).

Reviewer 2: Anna Azulai

1. The location of the study is revealed for the first time in the end of the discussion section. It would be helpful to mention the location early in the study, for example in the method section, as well as in the abstract.

Response: Done, abstract and methods page 4

2. COREQ Qualitative study checklist. It is unclear whether this supplement document is an Appendix to the main text or a table related to the method (or other) section. In any case, I would suggest that this document is titled and located as either appendix or a table; or, alternatively, excluded from the submission. If the document is used for submission, it should be cited somewhere in the main text, referring the reader to the document when appropriate (for example, in the methods section). In addition, the Location/comment column in the table could be more effective if it contains concise answers to the corresponding 32 questions posted in the preceding column. Simply referring the reader to the page number in the main text and leaving the reader to figure it out by him/herself raises a question of the document’s usability.

Response: Exclude from submission. Many journals now request a systematic quality checklist with submissions (such as CONSORT for trials). This is intended as an aid to reviewers, but is not for publication. This practice is not so common for qualitative papers, and there is no universal agreement on the contents of the checklist for qualitative papers. COREQ is recommended by the EQUATOR network.

3. Participants: There is some inconsistency and confusion throughout the paper in terms of reporting who are the participants of the study. Are these older patients? Or their family carers? Or both? In the abstract, the authors stated that the interviews were conducted with carers. In the sample description and the method section, however, the authors mentioned that some interviews were conducted with both older patients and their cares present. In the results section, the authors provided some descriptive statistics of the older patients, calling them ‘participants’. When discussing limitations of the study, however, family carers are called participants, while older patients are not mentioned at all.

Response: Predominantly this is a report of family carers’ views. Our study defined patient-participants and carer-participants. The majority of patients had dementia, and some had died by the time of interview. Interviews were ‘naturalistic’, and patients were not excluded from them, although limited information was gained from them in many cases. The main focus was carers. This is stated on Page 5-6.

4. ‘Confused older people’: How do the authors define confusion? What does this mean ‘confused older people’ in the context of the study? Whose judgment of being ‘confused’ is it and based on what? Were the patients observed as disoriented? Were they diagnosed
with delirium or any other psychiatric or neurological condition directly associated with disorientation? Was their cognitive state evaluated by the Mini Mental State Examination or other standardized test? Being diagnosed with dementia and/or mental health condition does not automatically mean that the person is confused. The degree of confusion may vary at different stages of the disease. For instance, the authors indeed reported that some older patients in the study were found competent and capable to sign an informed consent, while others were not able to do so. Were the capable patients also ‘confused’?

Response: The inclusion criteria were patients screening positive on tests for cognitive impairment and depression, or showing evidence of other mental health problems. We used ‘confusion’ as convenient shorthand, as it is what clinicians of many disciplines say, and summarises the rather messy mix of dementia and/or delirium and/or other problems that characterises older hospital patients in acute hospital environments. It described a problem not a diagnosis, and we concede it is vague. Precise diagnosis is often not done. Various other mental health problems (including mania, and schizophrenia) have been described as ‘confusion’ by non-specialist clinicians in acute medical admissions areas. This may reflect vernacular British medical usage so this has been made explicit (our study psychiatrist strongly dislikes the term). In this usage, almost all patients with delirium or dementia are ‘confused’, although the converse does not hold (ie not all ‘confused’ patients have delirium or dementia). In English law a cognitively impaired patient can have capacity, depending on level of understanding for the decision to be made.

5. Limitations of the study: Given that some interviews were conducted with both older patients and their family carers present, it remains unclear how did family relationships between the patients and their carers impacted the interview data?

Response: Paragraph added at start of results.

6. Ethnography: On page 4, the authors stated “We report on an ethnographic study of older people with mental health problems admitted to medical or trauma orthopedic wards as an emergency, and their family carers”. What properties of this study situate it as ethnography? There is no further information related to this methodology in the study report.

Response: See reviewer 1 point 1

7. Grounded theory: The authors stated that they used grounded theory approach in the study. What type of grounded theory (GT) was used remains unclear. Was it a classic Glazerian approach, the Straussian approach, or the constructivist grounded theory by Charmaz? These types of the GT differ in their goals, principles and types of coding, approach to the literature, data reporting strategies and presentations of the results. Clearly defining which GT approach was used in the study would help the reader to better understand the process of data analysis and how did the researchers arrive to the results.

Response: Charmaz. Reference added.

8. Results: The authors clearly stated main themes that had emerged from the data analysis. The less common or marginal themes, however, are not clearly outlined. Differentiation between the common major themes and divergent data could be helpful to better understand the results of the study.
Response: We have focussed on why some family carers become dissatisfied or angry, rather than attempting a more comprehensive explanation of satisfaction or dissatisfaction. See reviewer1 point 4.

9. Discussion: I would suggest locating the study and its original contribution within the knowledge base that already exists. For example, what added value does the ‘cycle of discontent’ offer that is different or new in comparison to already existing models and theories in the area of expectations and satisfaction with care (e.g. consumer satisfaction models such as SERVQUAL, Expectation Confirmation Theory (ECT)/Expectation Disconfirmation Theory (EDT), Expectancy-value theory of Linder-Pelz, etc.). Also, what new insights and usability does the model offer when compared to other grounded theory studies of older patients’ satisfaction with healthcare in hospital settings? The following citation is only one example of a grounded theory study that could be helpful to the authors. Raftopoulus, V. (2005). A grounded theory for patients’ satisfaction with quality of hospital care. ICUs and Nursing Web Journal, 22, 1-15. Retrieved from: http://ktisis.cut.ac.cy/bitstream/10488/269/1/RAFTOPOULOS%20GROUND%20THEORY%20FREE.

Response: This is a good point that we do not feel we can fully address. We have added material on satisfaction, although there is little specific to dementia and acute hospitals, and expanded the section of carers’ experiences and concerns to reflect broader patients groups. Page 16-17.

There is a clear correspondence with the suggested ECT/EDT, for which thanks, and which we have added in the text, although the cycle of discontent goes further. Page 17-18. Servqual and expectancy value theory seem less pertinent, and we have not included these. The study of Raftopoulus is about the experiences of older patients, not about their family carers, so we have not included it.

10. Conclusion: On page 16, in the final sentence of the conclusion section, the authors wrote “we propose that recognizing stages of the cycle of discontent by staff can pre-empt problems, and better address family carer needs through inclusion and proactive communication”. This is an important implication. However, if older patients are considered as participants for this study, then I would suggest to also include implications for the care and needs of the older patients. Further, what research and policy implications can the study have?

Response: is primarily about why family carers get angry. There are clear implications for practice which are set out. Page 18. We have added some material on research, and about policy. Page 18-19.