Author’s response to reviews

Title: #Deathbedlive: the end-of-life trajectory, reflected in a cancer patient's tweets

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Author’s response to reviews:

Message to the editor and reviewers

Dear Drs Booth, Arber and Taubert,

Many thanks for taking the time to review our article and for providing these thoughtful and constructive comments. We are pleased that there is consensus around the value and publishability of the research (subject to minor revisions) despite the methodology being unusual for this area. It is particularly encouraging to learn that Dr Taubert knew Kate Granger personally and feels that she would have approved of our analysis.

We have integrated your suggestions into the current version and feel this has strengthened the paper. We also noticed some minor typographical inconsistencies, which we have taken the opportunity to correct, and have slightly updated the abstract to improve the structure. Answers to your specific points are given below.

With best wishes,

Claudia Pagliari and Joanna Taylor

Editor and Peer Reviewers’ Comments and Authors’ Responses

Editor

Comments to the Author

Technical Comments: I would like to be certain that Chris Pointon (the husband) is happy for this to be published as the reviewers asked - I see permission has been given but would be good to reiterate this.
Response: Chris Pointon is indeed happy for this paper to be published, and we are sending you a copy of our correspondence with him, which took place via Twitter and email. In addition to informing him of our intentions and seeking his consent, we also shared a copy of our draft manuscript with him prior to submission, to ensure that he was comfortable with our use of Kate’s tweets and our interpretation of the results. We have made some amendments to the ‘Ethical approval and consent to participate’ and ‘Consent to publish’ sections of the Declarations, in order to clarify this [Page 13, lines 399-403]. It has also been mentioned in the updated abstract (Page 1, line 24).

This is a very interesting paper and an important one.

Response: Thank you for your positive comments. We are pleased that you find our paper interesting and important and hope that it encourages members of the palliative care community to consider the potential value of social media for supporting innovative research and practice.

Anne Arber (Reviewer 1):

Comments to Author

This is a carefully crafted article on an important aspect of research using digital media. The article is well structured and was clearly focused on the last 6 months of life using Twitter posts. Data analysis was detailed and the tables are very helpful in identifying the process of content analysis.

Response: Thank you. We are pleased that you found our article to be well structured and the data analysis helpful in illustrating the research process. We are conscious that this approach has not yet been widely used in the context of palliative care research and will be unfamiliar to many readers of the journal, and therefore tried to make it as accessible as possible.

Comments to Author

One of the surprising aspects was that Kate describes struggling with 'horrible achy pain' despite being under palliative care.

Response: We take your point. Clearly there are individual differences between patients in terms of what they are prepared to tolerate to minimise the side effects of pain medication. Kate’s determination to maintain her campaigning and personal life suggests that remaining mentally alert was a priority for her and this may have affected her choices. Since we are reluctant to over-speculate we have not added any further text in relation to this but we will share your comments with Kate’s widower, who has taken an interest in our paper and may wish to be involved in follow up commentary after the paper is published.
Regarding the use of Emmanuel and Emanuel's framework for a good death when classifying the data it would be useful to identify the limitations of this framework for this research.

Response: Thank you for this recommendation. We are conscious that the definition of a ‘good death’ can be somewhat ambiguous and the framework that we selected, although well established, does indeed have limitations. We have added some extra text to the limitations section, to emphasise this. (Page 12, lines 363-367)

Comments to Author

A very good analysis of the last 6 months of Kate Grainger's life on Twitter.

Response: Many thanks. We are glad you think so

Mark Taubert (Reviewer 2):

Comments to Author

Dear authors.

I read this article with interest. I knew Kate and we worked on a few projects together, and I have since met her husband Chris and was privileged to do a talk in the same symposium as him. I think this is quite a bold paper. I have submitted this kind of thing in the past and received puzzled rejections. Of course, you already note in your Limitations section that in traditional research terms with high n= numbers, this stands out and is unusual in its approach and methodology. But then again, there is a some very rich dialogue held within Kate’s Tweets, that will help us understand and learn new angles. I think it is time that we incorporate this into our mixed methodology approaches.

Response: Dear Dr. Taubert, thank you very much for your comments. We are encouraged to learn that you knew Kate and are therefore able take a personal interest in our study. It is disappointing to hear of your past experiences with journal reviewers and we hope this article helps to raise awareness of the value of these methods for the study of death, dying and palliative care. It has been fascinating for us to become so deeply involved in Kate’s story, albeit at a vicarious level. We have found the experience to be quite different from our previous research using larger but shallower social media datasets to study health conditions such as diabetes or infectious diseases. The project has provided a welcome opportunity to learn more about the potential of digital ethnographies to shine a light on peoples lived experiences, and we were surprised at the richness of the longitudinal narrative demonstrated in Kate’s postings, despite Twitter’s 140 character limit (until recently). The results have given us further impetus to undertake a larger study looking at more patients with different types of cancer and using a range of social media platforms, which is currently underway. We look forward to learning more from
other members of the research community, including yourself, as they embark on future studies in this space.

Comments to Author

I have very little to add to your paper. Perhaps, given that I suspect you will have a very high readership for this, there is scope for novices to the approach you used to learn more about which social media analytics tools are out there (this could be a very short segment, but could be of value).

Response: Thank you for this suggestion. We have added a short segment highlighting some of the automated social media mining tools available on the market (Page 10, lines 297-300) and their limitations in terms of undertaking depth studies such as the one reported in our manuscript (Page 12, line 356-360).

Comments to Author

Also, do chat to the Editor-On-Chief about making this article open-access, because nothing gets Twitter more annoyed than prohibitive paywalls.

Response: We absolutely agree with your comment about Open Access and this was one of the reasons we decided to submit our paper to BMC Palliative Care. We look forward to sharing the paper widely in this way.

Comments to Author

Kate was also one for honest language. She did not like the violence and battle metaphors in cancer, and did not want to be remembered as a 'loser' in her 'fight' against cancer, which I felt was one of the big key messages.

Response: Thank you for sharing your personal knowledge of Kate’s attitude to violence and battle metaphors. This not something we had explicitly considered in our analysis, however after reading your comment we took the opportunity to examine the raw data again and found no such references, which is consistent with your observation. We have included a new subsection about this in our updated manuscript, whilst focusing on the data and what has been written about the pros- and cons- of these metaphors in the literature (Page 9-10, lines 277-282) We hope that you will be able to contribute this and other anecdotes to the online commentary post-publication.

Comments to Author

I am also very glad that you sought permission from Chris Pointon for this to go ahead, because I would have asked you to seek it out had you not done so.
Response: As we have noted in our manuscript, and in an article published last month, the ethical guidelines for research based on social media mining remain unclear, but we felt that it would be very important to contact Chris at the beginning of our study, to seek his consent, and then to share our draft manuscript with him for comment. We are very pleased that he has taken an interest in the study and hope to remain in touch with him after the article has been published. A copy of our correspondent, highlighting key consent questions and responses, is being included along with our revised manuscript.

Comments to Author

Kate was a real pioneer, and she would have liked this approach and this foray into research with social media and Twitter. It will have its critics, and I would not be surprise if Reviewer No 2 says 'Reject', but I strongly support this getting published. Hope to connect sometime in the future.

Best Wishes, Mark @DrMarkTaubert

Response: Many thanks indeed. We are delighted that you feel Kate would have liked our approach. Alas neither of us had the opportunity to meet her when she was alive, but it has been a privilege to get to know her through reading and analysing her tweets. She was a truly remarkable and inspiring individual and we hope that our modest study is in keeping with her legacy. Thankfully, Reviewer 2 did not ‘Reject’ our paper and we are happy to learn of its potential publication. Given our mutual interest in this area, we would be pleased to connect with you in the future and to discuss potential collaborations. @JoTaylor6 and @EeHRN