

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Do online communities change power processes in healthcare? Using case studies to examine the use of online health communities by Parkinson's patients
AUTHORS	Visser, Laura; Bleijenbergh, Inge; Benschop, Yvonne; van Riel, Allard; Bloem, Bastiaan

VERSION 1 - REVIEW

REVIEWER	Mark A. Hirsch Carolinas HealthCare System, U.S.A. M.A.H. has received research support from the Duke Endowment, the Carolinas HealthCare Foundation, the Park Foundation and the National Institutes of Health.
REVIEW RETURNED	10-May-2016

GENERAL COMMENTS	<p>I have a few comments which I hope will improve the quality of the paper.</p> <p>- First, I think it is important to define the term power and empowerment and how this relates to Parkinson's disease and social media. 'Empowering someone' is a paradoxical concept. If I have the power to give you power, then in fact, I am retaining that power in the giving of it to you. Thus, it is impossible to 'empower someone.' What is possible is to create empowering spaces, wherein "power does not reside within a position, but rather, within a relationship bounded by knowledge..." which, I think is the main point of your paper. So, please, first define empowerment.</p> <p>Powers P. Empowerment as treatment and the role of health professionals. <i>Advances in Nursing Science</i>. 2003;26(3):227-37; Polifroni EC. Power, right and truth: Foucault's triangle as a model for clinical power. <i>Nursing Science Quarterly</i>. 2010;23(1):8-12.</p> <p>- Authors should probably add a paragraph or two explaining that the use of social media is a surrogate for increasing social capital and health in Parkinson's disease and provide some foundational literature on social capital. Briefly introduce the concept of social capital, - it deals with power, issues of trust, and the value of networks. Gilbert KL, Quinn SC, Goodman RM, Butler J, Wallace J. A meta-analysis of social capital and health: A case for needed research. <i>J Health Psychol</i>. 2013;18(11):1385-99. Next, explain that patients with Parkinson's disease are rarely empowered in medicine - taking a pill is not empowering - , are rarely given "voice", -- paradoxically, PD is a condition in which voice may be literally dysfunctional - via pathology of the basal ganglia circuitry and - figuratively - less well understood - via self-stigmatization - as a problem of shame with public appearances (Nijhof, 1996). In</p>
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addition, (Parkinson) patient views and experiences (thoughts/feelings) have, until recently, been under valued in the medical literature. Next, explain what a focus on the patient view potentially adds to the value of care in PD and why it is important to empower patients up so that they are not treated as passive "objects" or "subjects" of care, but rather as "active participants", "colleagues" or "partners" and provide some literature to support your model. Authors hint to this in the last sentence of their paper. For example: Plouvier et al. Time intervals in diagnosing Parkinson's disease: The patients' views. Patient Education and Counseling, 2015, article in press; Soundy A, Stubbs B, Roskell C. The experience of Parkinson's disease: A systematic review and meta-ethnography. The Scientific World Journal. 2014, Article ID 61392; Moller UO, Hansson EE, Ekdahl C, Midlov P, Jakobsson U, Kristensson J. Fighting for control in an unpredictable life - a qualitative study of older persons' experiences of living with chronic dizziness. BMC Geriatrics. 2014,14:97; Findley LJ, Baker MG. Treating neurodegenerative diseases: What patients want is not what doctors focus on. BMJ. 2002;324:1466-7; Schipper et al. Living with Parkinson's disease: Priorities for research suggested by patients. PRD. 2014; Thorarinsdottir and Kristjansson. Patients' perspectives on person-centered participation in healthcare: A framework analysis. Nursing Ethics. 2014;21(2):129-47.

- Additionally, I think the paper by Wicks has data on ehealth in PD that adds to your discussion. Wicks P, Stamford J, Grootenhuis MA, Haverman L, Ahmed S. Innovations in e-health. Qual Life Res. 2014;23(1):195-203.

Specific comments:

page 5 of 18 - L5-12. Add sentences that in order for lasting changes in the way people are treated to occur requires changes at the social and policy level, and these do occur when populations as a whole come together and stand up for their rights. For example, in the U.S., the march on Washington D.C., and the civil rights era. Perhaps, social media is way of uniting the Parkinson community.

page 6 of 18, Line 23-27. Power dynamics due to position, title, etc., being what they are, the research team presence and their leadership of the interviews is nevertheless a source of bias in the interviewees' responses. In future studies, the interviews could be conducted by peer interviewers to minimize the bias introduced by having the interviews conducted by the research team.

page 8 of 18, Line 2-4. Please provide explanation how the validity of the data was determined, for example, by data triangulation, via the documentation of similar accounts by multiple people, "critical incident" questions about the participants' experience with the social media, and a member check (participant feedback on the results and interpretation). For example, add participants' responses to questions such as "What was it like for you when 'x' happened when you asked the doctor a question?"; and "Were there any challenges to your participation with asking questions or making comments about your Parkinson's disease using the social media." In addition, to further increase validity, please report whether you reported any preliminary findings of the research to the participants and, if they were given an opportunity to agree or disagree with your report, whether their comments and opinions were added point-by-point to the results and final analysis.

	page 9 of 18 - please state whether the patient quotes were translated from Dutch into English.
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REVIEWER	Peter Schmidt National Parkinson Foundation United States Funds from a discretionary grant from my organization supported this research.
REVIEW RETURNED	12-May-2016

GENERAL COMMENTS	This is an excellent and thorough report of a well-designed prospective study of a topic where most of the literature reports retrospectively on associations observed. The intervention, using an on-line community, was well described and, as described, seems appropriate to the aims. The qualitative evaluation, employing the well-chosen Foucault's framework, is well designed for an initial evaluation of key concepts in this relatively novel subject area. This report nicely sets up future work through establishing a framework based on patients who have engaged in online communities. The choice of a qualitative allowed the authors to consider the merits of measures that might have prospectively been selected as outcomes, such as numbers of posts, and see how actual usage varied from expectations. This will be a welcome addition to the literature.
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REVIEWER	Anne Rogers University of Southampton WEngland
REVIEW RETURNED	14-Jun-2016

GENERAL COMMENTS	This is a clearly written paper and discussed a contemporary issue of high contemporary salience. However I feel that there has been very little attention paid to the recent literature in this area and for this reason the paper does not add sufficient novelty. This is indicated by the dated references and failure to include up to date literature of participation in in online communities and the use of online communication and support between professionals and patients. There is no reference to the use of online communities for people with Parkinson's disease for example (e.g. A thematic analysis of patient communication in Parkinson's disease online support group discussion forums Article in Computers in Human Behavior 28(2):500-506 · March 2012). I thought that the data was rather thin in terms of developing a convincing bases for the claims made about power.
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VERSION 1 – AUTHOR RESPONSE

REVIEWER 1

(1) First, I think it is important to define the term power and empowerment and how this relates to Parkinson's disease and social media. 'Empowering someone' is a paradoxical concept. If I have the power to give you power, then in fact, I am retaining that power in the giving of it to you. Thus, it is impossible to 'empower someone.' What is possible is to create empowering spaces, wherein "power does not reside within a position, but rather, within a relationship bounded by knowledge..." which, I think is the main point of your paper. So, please, first define empowerment. (Powers P. Empowerment

as treatment and the role of health professionals. *Advances in Nursing Science*. 2003;26(3):227-37; Polifroni EC. Power, right and truth: Foucault's triangle as a model for clinical power. *Nursing Science Quarterly*. 2010;23(1):8-12.)

Authors' response: Thank you for this suggestion. Indeed, the term 'empowering someone' is paradoxical and with this article we have wanted to complicate the notion of implementing technology to empower patients. Thank you for pointing our attention to this relevant literature. We have drawn on the articles you suggest to make more explicit what we mean with the term patient empowerment, as you can see in the last section of our introduction and in our methods section, where we refer to the term 'empowering spaces' to contrast it to a definition of empowerment as changing positions.

(2) Authors should probably add a paragraph or two explaining that the use of social media is a surrogate for increasing social capital and health in Parkinson's disease and provide some foundational literature on social capital. Briefly introduce the concept of social capital, - it deals with power, issues of trust, and the value of networks. Gilbert KL, Quinn SC, Goodman RM, Butler J, Wallace J. A meta-analysis of social capital and health: A case for needed research. *J Health Psychol*. 2013;18(11):1385-99.

Next, explain that patients with Parkinson's disease are rarely empowered in medicine - taking a pill is not empowering - , are rarely given "voice", -- paradoxically, PD is a condition in which voice may be literally dysfunctional - via pathology of the basal ganglia circuitry and - figuratively - less well understood - via self-stigmatization - as a problem of shame with public appearances (Nijhof, 1996). In addition, (Parkinson) patient views and experiences (thoughts/feelings) have, until recently, been under valued in the medical literature. Next, explain what a focus on the patient view potentially adds to the value of care in PD and why it is important to empower patients up so that they are not treated as passive "objects" or "subjects" of care, but rather as "active participants", "colleagues" or "partners" and provide some literature to support your model. Authors hint to this in the last sentence of their paper. For example: Plouvier et al. Time intervals in diagnosing Parkinson's disease: The patients' views. *Patient Education and Counseling*, 2015, article in press; Soundy A, Stubbs B, Roskell C. The experience of Parkinson's disease: A systematic review and meta-ethnography. *The Scientific World Journal*. 2014, Article ID 61392; Moller UO, Hansson EE, Ekdahl C, Midlov P, Jakobsson U, Kristensson J. Fighting for control in an unpredictable life - a qualitative study of older persons' experiences of living with chronic dizziness. *BMC Geriatrics*. 2014,14:97; Findley LJ, Baker MG. Treating neurodegenerative diseases: What patients want is not what doctors focus on. *BMJ*. 2002;324:1466-7; Schipper et al. Living with Parkinson's disease: Priorities for research suggested by patients. *PRD*. 2014; Thorarinsdottir and Kristjansson. Patients' perspectives on person-centered participation in healthcare: A framework analysis. *Nursing Ethics*. 2014;21(2):129-47. Additionally, I think the paper by Wicks has data on ehealth in PD that adds to your discussion. Wicks P, Stamford J, Grootenhuis MA, Haverman L, Ahmed S. Innovations in e-health. *Qual Life Res*. 2014;23(1):195-203.

Authors' response: Thank you for these wonderful and thorough suggestions, as well as the literature suggestions. We ended up integrating both your suggestions and most of the recommended literature in our introductory section, where we now spend more text explaining the need for empowerment, why it hasn't been achieved and how technology could aid (or not) in this process. Your suggestions for citations were very helpful in further developing this section.

(3) page 5 of 18 - L5-12. Add sentences that in order for lasting changes in the way people are treated to occur requires changes at the social and policy level, and these do occur when populations as a whole come together and stand up for their rights. For example, in the U.S., the march on Washington D.C., and the civil rights era. Perhaps, social media is way of uniting the Parkinson

community.

Authors' response: This is also a helpful suggestion and we actually felt that it would benefit most from being mentioned in the discussion section of our article. In the last sections of the article, we have now added a couple of sentences describing the top-down and bottom-up processes that are simultaneously needed in order to make those lasting changes.

(4) page 6 of 18, Line 23-27. Power dynamics due to position, title, etc., being what they are, the research team presence and their leadership of the interviews is nevertheless a source of bias in the interviewees' responses. In future studies, the interviews could be conducted by peer interviewers to minimize the bias introduced by having the interviews conducted by the research team.

Authors' response: Thank you for pointing this out. We have been very aware of these power dynamics throughout the entire process of data collection, analysis and writing of the article, although we did not explicitly reflect on this in the manuscript. In the methods section, we have now included additional more discussion on the role the position of the interviewee played in the interviewee process, and we hope this clarifies how it may have played a role.

(5) page 8 of 18, Line 2-4. Please provide explanation how the validity of the data was determined, for example, by data triangulation, via the documentation of similar accounts by multiple people, "critical incident" questions about the participants' experience with the social media, and a member check (participant feedback on the results and interpretation). For example, add participants' responses to questions such as "What was it like for you when 'x' happened when you asked the doctor a question?"; and "Were there any challenges to your participation with asking questions or making comments about your Parkinson's disease using the social media." In addition, to further increase validity, please report whether you reported any preliminary findings of the research to the participants and, if they were given an opportunity to agree or disagree with your report, whether their comments and opinions were added point-by-point to the results and final analysis.

Authors' response: Thanks to your comments, we now added to our methods section a separate paragraph detailing two different ways in which we ensured the validity of our results through triangulation, drawing on the foundational work of Yin (1993). We explain how we used methodological triangulation and researchers triangulation. Moreover, we explain why we did not ask the interviewees for comments on the analysis and how report back to them after the research project is finished.

(6) page 9 of 18 - please state whether the patient quotes were translated from Dutch into English.

Authors' response: We have elaborated our analysis paragraph (in the methods section) that explains the process of translation in relation to the analysis. Thank you for pointing to this omission.

REVIEWER 2:

This is an excellent and thorough report of a well-designed prospective study of a topic where most of the literature reports retrospectively on associations observed. The intervention, using an on-line community, was well described and, as described, seems appropriate to the aims. The qualitative evaluation, employing the well-chosen Foucault's framework, is well designed for an initial evaluation of key concepts in this relatively novel subject area. This report nicely sets up future work through establishing a framework based on patients who have engaged in online communities. The choice of a qualitative allowed the authors to consider the merits of measures that might have prospectively

been selected as outcomes, such as numbers of posts, and see how actual usage varied from expectations. This will be a welcome addition to the literature.

Authors' response: Thank you very much for this positive feedback and the compliments!

REVIEWER 3:

(1) I feel that there has been very little attention paid to the recent literature in this area and for this reason the paper does not add sufficient novelty. This is indicated by the dated references and failure to include up to date literature of participation in in online communities and the use of online communication and support between professionals and patients. There is no reference to the use of online communities for people with Parkinson's disease for example (e.g. A thematic analysis of patient communication in Parkinson's disease online support group discussion forums Article in Computers in Human Behavior 28(2):500-506 · March 2012).

Authors' response: Thank you for this feedback and especially for pointing towards relevant articles we missed in our discussion of the literature. We believe this omission was due to the fact that we had limited our literature search to personal online health communities in relation to power processes. We have gone back to the literature to update our introductory section, and we have incorporated your suggested readings as well as those of the other reviewers. Additionally, we have now rewritten our introductory section to do better justice to the wider literature, while at the same making it much clearer what our specific focus is. Your comment was important to better structure this introduction.

(2) I thought that the data was rather thin in terms of developing a convincing bases for the claims made about power.

Authors' response: We appreciate this comment. We think it is important to emphasize that, although we only show a small number of quotes in the manuscript, we have a much larger database of examples of quotes that express similar sentiments. Due to space restrictions we could not display all those examples, although we agree with this reviewer that more examples would have added an interesting 'thickness' to our analysis. We have added a sentence to the beginning of our results section that describes the fact that these quotes are illustrative rather than exhaustive, thus aiming to show the reader that there is a larger analysis behind the displayed quotes. Regarding the overall sample size (n=18), we agree that this is not exhaustive. The small sample size allowed us to analyse in-depth but not across a wide range of different patients, and this balance is an aspect of qualitative research more generally. These patients were representative of those active in online communities, but may not have reflected the full spectrum of disease severity and disease duration that characterizes Parkinson's disease. We now mention this drawback in more detail in the revised discussion, and also point to the importance of further work to establish a more comprehensive overview of the online activities of other patients with Parkinson's disease.

VERSION 2 – REVIEW

REVIEWER	Mark A. Hirsch, PhD Senior Scientist, Carolinas Rehabilitation Director, Carolinas Department of Physical Medicine and Rehabilitation Core Laboratory Director, Resident Research Education (PM&R) Dept of Physical Medicine and Rehabilitation, Carolinas Medical Center Adjunct Associate Professor & Associate Graduate Faculty, University of North Carolina, Charlotte campus
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	<p>Carolinas HealthCare System</p> <p>Mailing: Carolinas Rehabilitation Dept of PM&R 1100 Blythe Blvd. Charlotte, NC 28203, USA</p>
REVIEW RETURNED	10-Aug-2016

GENERAL COMMENTS	Thank you for addressing my concerns
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REVIEWER	<p>Peter Schmidt, PhD National Parkinson Foundation USA</p> <p>I have collaborated on a research project and written a paper with Bastiaan Bloem in the past.</p>
REVIEW RETURNED	30-Aug-2016

GENERAL COMMENTS	<p>This is a valuable contribution of a study that represents the systematic evaluation of real-world efficacy for elite responders to an online community intervention. This analysis is valuable as it offers insight into the characteristics of individuals who respond to an on-line community and the nature of their response and is a critical first step in understanding and designing future research on this topic. The edits to the paper have improved its clarity.</p>
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