

The Impact of Michael J Fox's Illness Narrative on the Experiences of Those Living with Young-Onset Parkinson's Disease

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Abstract

Michael J Fox is arguably the most well-known individual living with young-onset Parkinson's disease (YOPD) in the world. Since coming out with his diagnosis, he has published autobiographies detailing his experience with the disease, and has also made numerous television appearances, making his illness narrative available in the public domain. Previous work in the academic literature has analyzed the rhetoric of Fox's narrative, and the clinical anecdotal value of his autobiographies. Absent from the literature, however, is a greater appreciation for how Fox has impacted those living with YOPD in the words of those living with the disease. Methods: Through a secondary analysis of data collected from a grounded theory study, investigating the information behavior of 39 individuals living with YOPD, the role of Fox in the experience of participants is explored. Framed according to three categories of the impact of celebrity illness narratives, the role that Fox has played in public education about YOPD, and in providing inspiration and promoting advocacy in the lives of those living with YOPD are described. Fox's authentic illness narrative can be seen as a useful device in helping others living with YOPD in their adjustment to living with the disease.

Key Words: Education; Inspiration; Advocacy; Adjustment; Control

Introduction

Parkinson's disease, typically considered a disease of old-age, can also occur in young- and middle-aged adults where it is referred to as young-onset Parkinson's disease (YOPD)(Quinn, Critchley, & Marsden, 1987; Rana, Siddiqui, & Yousuf, 2012). Perhaps the most identifiable person in the world living with YOPD is Michael J Fox, who has published autobiographies detailing his experience with the disease and starting the Michael J Fox Foundation for Parkinson's Research. These autobiographies include *Lucky Man*(2002) and *Always Looking Up*(2009). Fox has also been very active in the public light since disclosing his diagnosis, appearing on various sitcoms and television interviews.

A medical focused analysis of *Lucky Man* completed by Kempster(2004) details the anecdotal value of the autobiography in terms of demonstrating preclinical characteristics of YOPD, fluctuations in motor function and medication strategies used over time. Work by Mazanderani, Locok and Powell (2013) has illustrated that knowledge from others living with a specific medical condition, informed by their 'authentic' experience, is highly valued by patients especially in comparison to technical medical literature. Specifically Mazanderani et al. described how celebrity association with a disease can raise public awareness, in addition

to helping fund research. As their work was done in the United Kingdom, participants used the example of Michael J Fox in the United States (US) and thought it would be valuable to have a celebrity with YOPD to do the same in their country.

Case studies of Michael J Fox have also been conducted in the disability studies literature, especially in relation to the rhetoric of concealing and revealing his disability (Moe, 2012) and of passing and masquerading (Quackenbush, 2011). More specifically, these cases focus on how Fox has used his body in public settings, where disability has typically been concealed, to act as an advocate for Parkinson's using his words and his body to reveal disability. Two instances in particular, analyzed in these case studies, are Fox's address to a US Senate Subcommittee to increase research funding for Parkinson's and in his support for stem cell research. In these settings he uses military metaphors, more typical of able-bodied rhetoric, and challenges ableist ideology of stigma. Indeed, Fox has been able to leverage his celebrity status to establish a new public role as advocate.

Absent from the academic literature, however, is a greater appreciation for how Fox has impacted those living with YOPD in the words of those living with the disease. In coming to learn about the information behavior of those living with YOPD, the impact of information accumulated related to Michael J Fox was

subject to secondary analysis and will be presented in this paper.

Background on Initial Study

The original study employed grounded theory methodology (Charmaz, 2006, 2014), to try and better understand how those living with YOPD used health information in managing with the disease over time (Ravenek, Laliberte Rudman, Jenkins & Spaulding, 2017). Thirty-nine individuals living with YOPD in Ontario, Canada consented to take part in interviews, focus groups and/or an online discussion board. Ethics approval to conduct the study was received from the University of Western Ontario – Health Sciences Research Ethics Board, prior to the start of data collection. As part of this methodology, data were coded at multiple levels starting with line-by-line coding, then focused coding, and finally theoretical coding. In each of these steps, new data collected were compared with previous codes that were generated in an effort to fill out the developing theory. Through this process, codes related to Michael J Fox were created but not elaborated in the overall theory related to information behaviour of those living with YOPD. In other words, codes were generated in identifying Fox's narrative as a source of information, but given the scope of the initial study these codes were not further explored with participants. Instead, Fox's narrative was combined with the narratives of others living with YOPD as a specific type of information source used in the management of YOPD.

Secondary Analysis

In reviewing literature related to the influence of celebrity health narratives, the initial codes generated, and data collected, related to Michael J Fox were further explored. More specifically, in a detailed analysis of 157 celebrity narratives, Beck, Aubuchon, McKenna, Ruhl, and Simmons (2013) describe how celebrity health narratives can provide public education about a condition, provide inspiration, and promote activism. These categories provided the framework upon which the codes and data related to Michael J Fox were compared and analyzed. Indeed, examples of all three of these areas, education, inspiration and activism, were identified through analysis of participants' experiences living with YOPD who participated in the original study. This paper is organized according to these three foci. In the participant passages below, pseudonyms have been provided to protect the identities of individuals who took part in the study.

Providing Education

With respect to education, Beck et al. (2013) describe how this could involve clarifying misconceptions about the disease, as was the case for Fox who illustrated that Parkinson's can affect those younger in life. In contrast to some of the other information sources drawn on by participants, which did not seem to emphasize the possibility of YOPD, several individuals spoke of knowing about YOPD prior to their diagnoses only because of seeing and hearing about Fox in the media. Although this knowledge lacked the depth of other sources, as it only provided individuals with a brief description of the disease, it was impactful in the sense that it gave an exemplar face of someone living with YOPD.

Shanna: The only thing that I could relate to was just knowing the little bit about Parkinson's, but I'd never done research and I think it was probably just from Michael J. Fox coming out with his diagnosis.

Patti: I thought, "How can I have Parkinson's? I'm not 80." You know, like that typical onset and then found out, oh gee, you know, Michael J. Fox isn't 80. And, at that time, it was sort of you know, the only other person you knew about.

The result of this knowledge was that the autobiographies written by Fox in the years after he publicly disclosed his diagnosis became initial books that participants would often turn to, or would receive from others, after their own diagnoses.

Lilia: I've read all of Michael J. Fox's books... I needed to learn. I needed to know what's going on and, and what these people experience and like Michael J. Fox has been a real role model for me. He's been so positive. You know I just admire him so much.

Kalvin: The Michael J. Fox books have been very informative as to how his life has been, how long he's had it, how he's dealt with it, how his family and kids and parents deal with it. He talks about what he's still accomplished, even with having this. He still lives a pretty, well what I would call, up 'til now, he lives a pretty normal life.

Information that Fox details in his books about how he managed with his diagnosis and acceptance of the disease was not only a source of education for participants but, as alluded to in the passages above, were also a source of inspiration.

Providing Inspiration

Beck et al.'s (2013) analysis also describes how Fox has become a public face of Parkinson's, representing not only his experience with YOPD but the experience of many others who do not have the same public reach for raising awareness. This work and the way in which he managed, and continues to manage, with his disease was described as a source of inspiration by those who took part in this study. In the passages below, Calvin and Alecia describe why they were drawn to Fox's narrative.

Calvin: I think it's because you know him. You know because you've seen him so much. But I think overall, I think it's because it's somebody with young Parkinson's. And I think it's somebody that's not just sitting on their behind and letting it fester. He's out there doing his thing ... [It] gives you an insight as to what's to come, how he deals with it and all that kind of stuff. It gives it to you in a way that you can hear it better, a little softer than some of the other ways you can hear it. His books are good so far as they give you, well, I wouldn't say hope, but they certainly give you a comforting feeling that there's things to do out there to make things better.

Alecia: Well, because he's been such an advocate for the disease, and I like to read, so I enjoyed his first book a lot. In his second book, he gets more into the research ... It just made you feel like he was part of the family of Parkinson's you know, like these people that have it and you just felt, you know, there's a lot of support out there for him, which was great. And it just gave you a positive feeling about being part of this disease, you know, that you weren't alone.

Through the ability to relate to others living with the disease, including Fox, participants were able to reduce perceptions of isolation, and were also given the impression that there were things they could personally do to make the best of a difficult situation. In other words, the knowledge they gained from Fox's narrative helped to increase their resilience to Parkinson's. As Trevor describes in the passage below, knowledge related to Parkinson's through Fox's narrative played an important role in fostering control beliefs.

Trevor: I think what his books have done for me have shown me that I have some level of control, coming back to one of the original issues, that I can influence the outcome.

In helping to re-establish a sense of control lost to the disease, participants described a desire to be more active in the Parkinson's community, raising awareness and funding for Parkinson's research following the example set by Fox.

Promoting Advocacy

With respect to promoting advocacy, Fox has been instrumental in advancing Parkinson's research, using his celebrity status to fund research focused on finding a cure, especially through his Foundation. However, in doing so, he has also been a model for others living with YOPD to get involved in advocacy and fundraising work and to participate in research.

Interviewer: What was your motivation behind doing the fundraiser? Shanna: Find a cure for sure. And I think the big thing was that in this area and surrounding areas I'd never seen a fundraiser for it. So just for awareness, and the lack of awareness out there. Because there's certain things that are so focused on when there's all these other things that aren't in the forefront.

Interviewer: What has motivated you to want to participate in research? Kenneth: If I can help out in any way I want to help. I was inspired by Michael J. Fox. It's my way of giving back I guess in some respect. Because I want to help find a cure ... And actually I was thinking about doing some fundraising coming up here shortly.

To date, the Michael J Fox Foundation for Parkinson's Research (2015) has awarded more than \$450 million to researchers working towards the goal of finding a cure for Parkinson's disease. As part of their own adjustment to living with YOPD, and feeling a part of the Parkinson's community, participants in this study became advocates for the disease in their own ways, emulating the example set by Fox in raising money, participating in research and, ultimately, working to find a cure.

Discussion and Conclusion

A secondary analysis of data collected in a grounded theory study on the information behavior of individuals living with YOPD has illustrated the impact of Michael J Fox's illness narrative on their experiences living with the disease. Using Beck et al.'s (2013) categories describing the impact of celebrity illness narratives, this paper illustrates how Fox's narrative has provided education and inspiration, and promoted advocacy work in those living with the disease. Beck et al. acknowledge that there is overlap in their

categories, and this overlap was also evidenced in the passages from participants included. Overall, this paper illustrates how Fox's authentic illness narrative was a useful device used by individuals living with YOPD in managing with the disease, similar to the usefulness of such narratives described by Mazanderani et al. (2013).

The important role that financial wealth can play in the experience of illness, including for Fox, has also been described in research on decision making in PD (Abendroth, Lutz, & Young, 2012) and was also acknowledged by participants of this study who were of varying socioeconomic backgrounds. However, such a perception did not detract from seeing the value in what Fox has done for those living with YOPD. Future research should further examine the relationship between socioeconomic status and the value of celebrity illness narratives in managing with illness.

Given that this paper presents the results of a secondary analysis of data collected investigating the health information behaviour of those living with YOPD, it is likely that a primary investigation on the impact of Fox's narrative may yield additional insights. A main drawback of secondary analysis, of course, being that the data were not specifically sought or probed to address this topic. Instead, through the analysis of the data collected, it became apparent that Fox's narrative had impacted the experiences of participants. Also important to consider is that the data collected for this analysis finished prior to the start of *The Michael J Fox Show*, which aired between September 2013 and January 2014. In this show, Fox played the main character who has been diagnosed with Parkinson's disease. Had data been collected during or after the airing of this show, greater discussion would likely have occurred about the role of this show on the information behaviour of participants.

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References

- Abendroth, M., Lutz, B. J., & Young, M. E. (2012). Family caregivers' decision process to institutionalize persons with Parkinson's disease: A grounded theory study. *International Journal of Nursing Studies*, 49(4), 445-454. doi: 10.1016/j.ijnurstu.2011.10.003
- Beck, C. S., Aubuchon, S. M., McKenna, T. P., Ruhl, S., & Simmons, N. (2013). Blurring Personal Health and Public Priorities: An Analysis of Celebrity Health Narratives in the Public Sphere. *Health Communication*, 29(3), 244-256. doi: 10.1080/10410236.2012.741668
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis* (1st ed.). Thousand Oaks, California: SAGE Publications.
- Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). Thousand Oaks, California: SAGE Publications.
- Fox, M. J. (2002). *Lucky man: a memoir*. New York, New York: Hyperion.
- Fox, M. J. (2009). *Always looking up: The adventures of an incurable optimist*. New York, New York: Hyperion.
- Kempster, P. A. (2004). Michael J. Fox and his Parkinson's disease. *Movement Disorders*, 19(1), 105-106. doi: 10.1002/mds.10640
- Mazanderani, F., Locock, L., & Powell, J. (2013). Biographical value: towards a conceptualisation of the commodification of illness narratives in contemporary healthcare. *Sociology of Health & Illness*, 35(6), 891-905. doi: 10.1111/1467-9566.12001
- Michael J. Fox Foundation for Parkinson's Research. (2015). Our Impact. Retrieved June 27, 2015, from <https://www.michaeljfox.org/foundation/where-does-your-money-go.php>
- Moe, P. W. (2012). Revealing Rather Than Concealing Disability: The Rhetoric of Parkinson's Advocate Michael J. Fox. *Rhetoric Review*, 31(4), 443-460. doi: 10.1080/07350198.2012.711200
- Quackenbush, N. (2011). Speaking of—and as—Stigma: Performativity and Parkinson's in the Rhetoric of Michael J. Fox. *Disability Studies Quarterly*, 31(3).
- Quinn, N., Critchley, P., & Marsden, C. D. (1987). Young onset Parkinson's disease. *Movement Disorders*, 2(2), 73-91.
- Rana, A. Q., Siddiqui, I., & Yousuf, M. S. (2012). Challenges in diagnosis of young onset Parkinson's disease. *Journal of the Neurological Sciences*, 323(1-2), 113-116.
- Ravenek, M.J., Laliberte Rudman, D., Jenkins, M.E., & Spaulding, S. (2017). Understanding uncertainty in young-onset Parkinson's disease. *Chronic Illness*, Early Online.