ORIGINAL RESEARCH & CONTRIBUTIONS

Use of a Graphic Memoir to Enhance Clinicians' Understanding of and Empathy for Patients with Parkinson Disease

Kimberly R Myers, PhD, MA^{1,2}; Daniel R George, PhD, MSc¹; Xeumei Huang, MD, PhD³; Michael D F Goldenberg, MA¹; LJ Van Scoy, MD^{1,2,4}; Erik Lehman, MS⁴; Michael J Green, MD, MS^{1,2}

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ABSTRACT

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Context: Parkinson disease (PD) can be physically, emotionally, and financially burdensome. Understanding its impact from the patient's perspective is an important way to sensitize clinicians to the challenges of living with PD.

Objective: To evaluate whether a book-length graphic memoir (an illness story in comic form) can help clinicians appreciate PD from the patient's perspective.

Design: A convergent mixed-methods study of clinicians working in a multidisciplinary movement disorders clinic. Participants read *My Degeneration* and completed preintervention and post-intervention questionnaires. They also attended a book group discussion. Quantitative findings were compared before and after the intervention, and qualitative data were analyzed for themes.

Main Outcome Measures: Clinicians': 1) confidence in understanding patients' experiences with PD, 2) knowledge about PD, and 3) empathy toward patients and families.

Results: After reading the book, participants' confidence in understanding patients' experiences with PD increased significantly in the areas of stigma and disease impact on patients and families. Clinical knowledge was unchanged. Qualitative analysis revealed 3 main themes: 1) the book provides a meaningful way for clinicians to learn about the experience of living with PD; 2) the medium of comics engages clinicians in ways different from other mediums; and 3) benefits of the book may extend beyond the clinical team.

Conclusion: Clinicians who read *My Degeneration* gained insight into the psychosocial effects of PD on patients and their loved ones. The book helped facilitate deeper understanding of patients' experiences living with PD and fostered greater empathy and self-reflection.

INTRODUCTION

Parkinson disease (PD) is the second-most common neurodegenerative disorder, affecting more than 10 million people world-wide. In the US, approximately 60,000 individuals are diagnosed with PD each year, resulting in annual direct and indirect costs of approximately \$25 billion. Although understanding treatment options for physical manifestations of PD is important, understanding the subjective experience of the disease is also crucial if we are to improve patients' well-being.

Comics, a medium that combines text with images to tell a story, have increasingly been used as an innovative tool in medicine, and in recent years, have been integrated into curricula for teaching health professionals. Studies have shown that reading and/or creating health-related comics can help medical students better understand the particulars of patients living with illness and can even improve a variety of doctoring skills, such as communication, attention to nonverbal cues, and awareness of physician

bias. Despite a growing literature on the benefits of using comics in medicine, ^{7,8} little research exists on the application of comics with clinicians. We hypothesized that the dynamic, visual form of a comic can enhance clinicians' understanding of illness from patients' perspectives and can stimulate empathy.9 To test the hypothesis, we evaluated the response of a group of clinicians to reading and discussing a book-length graphic memoir (an illness story in comic form) about PD, Peter Dunlap-Shohl's10 My Degeneration: A Journey through Parkinson's. Specifically, we examined whether reading this comic would positively affect clinicians': 1) confidence in understanding patients' experiences, 2) knowledge of PD and perceptions of understanding patients' attitudes toward potential consequences of PD, and 3) empathy toward patients and their families. We also explored the readers' attitudes about the potential use of this comic as an educational tool for their patient population.

METHODS

Overall Study Design

We used a convergent mixed-methods approach to ascertain the effect of the comic on clinicians.¹¹ We collected qualitative and quantitative data concurrently, analyzed them separately, and then integrated the data sets to determine whether the qualitative and quantitative results converged or diverged. The institutional review board at Penn State College of Medicine in Hershey, PA, deemed this research exempt from formal review (protocol no. 00007131).

Participants and Recruitment

All individuals who worked in a multidisciplinary, tertiary referral center for movement disorders patients at a Mid-Atlantic academic medical center were eligible to participate. The care team included 18 clinicians: 4 movement disorders neurologists, 1 neurosurgeon, 2 neuropsychologists, 3 nurses/physician extenders, 3 physical/occupational therapists, 1 speech therapist, and 4 movement disorders clinical researchers/educators/other clinicians. The research team recruited potential participants during a monthly

Author Affiliations

¹ Department of Humanities, Penn State College of Medicine, Hershey, PA

² Department of Medicine, Penn State Milton S Hershey Medical Center, Hershey, PA

³ Departments of Neurology, Neurosurgery, Radiology, Pharmacology, and Kinesiology, Penn State Milton S Hershey Medical Center, PA

⁴ Department of Public Health Sciences, Penn State College of Medicine, Hershey, PA

Corresponding Author

Michael J Green, MD, MS (mjg15@psu.edu)

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team meeting of the multidisciplinary movement disorders clinic. As incentive to participate, the care team members were offered a copy of *My Degeneration*¹⁰ and the opportunity to discuss the book as part of a focus group with their colleagues over a homecooked meal by the leader of the clinic (XH).

Description of the Intervention

The intervention was the aforementioned book, *My Degeneration: A Journey through Parkinson's*, by Peter Dunlap-Shohl. Written in a comic format, this memoir tells the author's story of living with PD, describing the impact of his diagnosis, the effects of his illness on his personal life, and the challenges of managing his symptoms (Figure 1). The memoir has been favorably reviewed both inside¹² and outside¹³ the PD community and offers a perspective, mode of delivery, and aesthetic experience for the reader that differs from that found in conventional neurology textbooks and medical journal articles.

Study Protocol

During a monthly comprehensive care conference for all members of the movement disorders care team, study participants were





Figure 1. Piano Crash (upper) and Silly Walks (lower): Sample images from My Degeneration. 10

Reprinted from: Dunlap-Shohl P. My degeneration: A journey through Parkinson's. University Park, PA: The Pennsylvania State University Press; 2015.

provided a set of self-administered preintervention survey questions. On completion of the questionnaires, participants received a copy of *My Degeneration* to read at home. Approximately 4 weeks later, participants attended 1 of 2 semistructured book group-style discussions. Immediately before the discussion, postintervention measures were repeated (these were identical to preintervention measures, excluding demographics). The discussion sessions lasted between 1 and 1.5 hours. Audio files were transcribed verbatim by an experienced transcriptionist who noted all pauses and stops.

Measures

Self-efficacy was measured using a 7-item instrument that was created for this study. Using a 0 to 100 scale (where 0 = "cannot do it at all" and 100 = "highly certain I can do it"), the self-administered tool assesses clinicians' confidence that they are able to understand what it is like for patients to live with PD (eg, the stigma experienced by patients and the impact of PD on family members). It also measures their confidence in providing compassionate care.

Knowledge was measured using a 13-item true/false test that was modified from that of Moore and Knowles.¹⁴ The tool addresses common facts and myths about the disease and has been used in prior research.

Clinicians' perceptions of patients' attitudes toward potential consequences of PD were measured using a 15-item instrument that was also modified from that of Moore and Knowles. ¹⁴The tool asks participants to express how much they think patients worry about a variety of consequences of PD, such as disability, dependency, social support, and stigmatization, using a 4-point scale: "not at all," "very little," "somewhat," and "a great deal."

Attitudes toward comics were measured using 2 instruments: A 9-point Comic Attitude Scale modified from Hosler and Boomer, ¹⁵ and a semantic differential scale created for this study. ¹⁶ Semantic differential scales have been used in a wide variety of contexts to measure people's reactions to contrasting words (eg, good vs bad) to derive attitudes toward the concept or subject (in this case, comics).

Overall satisfaction with the book was measured with the Net Promoter Score (NPS). This is a single question asking, "How likely is it that you would recommend *My Degeneration* to a friend or colleague?" with responses ranging from 1 to 10. The NPS is calculated by first categorizing responses as detractors (0-6), passives (7-8), or promoters (9-10), and then subtracting the total percentage of detractors from the percentage of promoters. The NPS scores range from -100 to +100. The NPS is a reliable and valid measure that accurately assesses satisfaction and loyalty to a product or service and has been widely used. ^{17,18} This item was measured at baseline, before the book discussion, and immediately following the book discussion.

Data Analysis

Quantitative Data

All variables were summarized before analysis, and the distributions of continuous variables were assessed using histograms and normal probability plots. Because our outcome variables were

either ordinal Likert scale variables or were skewed, we used a Wilcoxon signed rank test to make comparisons between preintervention and postintervention and medians and interquartile range to quantify the magnitude and direction of significant differences. To compare the preintervention and postintervention proportion of correct answers to individual knowledge questions, a McNemar test was applied. Statistical significance was set at p < 0.05, and all analyses were performed using statistical analysis software (SAS version 9.4, SAS Institute, Cary, NC).

Qualitative Data

Qualitative data were analyzed using a content analysis approach to identify emergent themes. This method of coding is appropriate for studies whose intent is to provide knowledge and understanding about a concept or phenomenon. First, 4 members of the research team independently reviewed the transcript for one focus group (50% of the data) to create broad categories that emerged from the data. This process continued until data saturation was achieved and select passages from the data were randomized by a noncoding member of the research team. The team then organized categories into a preliminary codebook through an iterative process that included broad categories as well as subcategories (codes). Exemplars were selected to represent each of the categories to further define the codes.

Next, this preliminary codebook was used by 4 members of the research team to code the second focus group transcript. These codes were reviewed, and differences in coding were reconciled via group discussion. The codebook was refined accordingly. Once consensus was achieved, the final codebook was used to code the entire dataset (2 coders per transcript). After coding had been completed, the coders met to discuss codes and reconcile differences via group discussion. Finally, codes were reviewed by the entire research team and were collapsed into themes using the constant comparison method. ^{20,21}

Data Integration Strategy

Data integration was achieved using a joint display, which is a table that aligns quantitative and qualitative findings so that conclusions from each dataset can be drawn separately and then compared. This approach yields a more robust understanding of study findings than either dataset alone. Divergent responses were managed through group discussion.

RESULTS

Demographics

Twelve clinicians participated in all phases of the study: 3 neurologists, 2 nurses, and 2 physical therapists or occupational therapists, and 5 "other" (physician assistants, nurse practitioners, or psychologists). Participants' ages ranged from 24 to 64 years, and they were predominantly women (83%). The average length of time working with patients with PD was 7.1 years (range = 0.3 to 20 years).

Ouantitative Results

Self-Efficacy

After reading *My Degeneration*, participants' confidence in understanding patients' experiences of PD increased significantly over baseline, with overall self-efficacy increasing from 73 to 85 (p = 0.001). The greatest changes in self-efficacy related to issues of stigma and the impact of the disease on patients and their families (Table 1).

PD Knowledge and Perception of Patients' Attitudes

Not surprisingly for this seasoned group of clinicians, clinical knowledge about PD did not increase after reading My Degeneration; the percentage of correct responses on a knowledge quiz remained steady (preintervention = 85%, postintervention = 85%, p = 0.563). Clinicians' perceptions of their patients' worries regarding the potential consequences of PD also did not change (preintervention score = 55, postintervention score = 56, p = 0.166, where 15 = 100 worry and 1000 = high worry).

Attitudes Toward Comics

Two scales were used to assess attitudes toward comics. On the Semantic Differential Scale, individuals expressed significantly more positive views about the value of comics after reading the book (Figure 2). On the Comics Attitude Scale, no change was seen. Spearman correlations between participants' attitude toward comics and their self-efficacy, knowledge, or attitudes toward potential consequences of PD showed no significant relationship.

Net Promoter Score

Before reading *My Degeneration*, the likelihood that participants would recommend the book was low, with a NPS of -50 (scale of -100 to +100, where -100 = "would not recommend book to family or friends" and +100 = "would highly recommend

Table 1. Clinicans' self-efficacy (N = 12)							
How confident are you that you are able to (0-100 points) ^a	Preintervention median	Postintervention median	Difference	p value ^b			
Understand the stigma that patients with Parkinson disease (PD) experience	70	85	15	0.008			
Understand what it's like for a patient to live with PD	70	80	10	0.002			
Understand the impact of PD on family members	70	88	18	0.004			
Help patients cope with PD	70	80	10	0.023			
Explain treatment options for PD	70	80	10	0.039			
Provide compassionate care to patients with PD	90	90	0	0.281			
Explain to patients what they can expect about the course of their illness	75	80	5	0.344			
Overall	73	85	12	0.001			

^a 0 = "cannot do it at all" and 100 = "highly certain I can do it."

^b Wilcoxon signed-rank test.

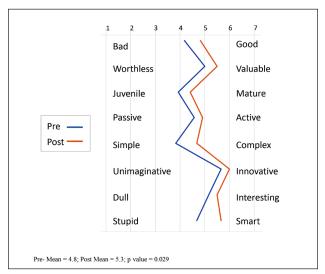


Figure 2. Semantic Differential Scale (n = 12): Shift in attitudes toward comics, before and after intervention.

book to family or friends"). After reading the book (but before the discussion), the score increased to +38; after discussion, it increased even more, to +77.

Qualitative Results

Content analysis of the transcripts from the group discussion revealed 3 major themes: 1) My Degeneration provides a meaningful way for clinicians to learn about the lived experience of patients with PD, 2) the comic form engages clinicians in ways that differ from other mediums, and 3) the benefits of the book may extend beyond the clinical team.

Theme 1: My Degeneration Provides a Meaningful Way for Clinicians to Learn about the Lived Experience of Patients with Parkinson Disease

The process of witnessing the private, psychological impact of PD as externalized through Dunlap-Shohl's drawings offered participants new inroads to understand how patients fare both inside and outside the clinic. Reflecting on the impact of receiving a diagnosis of PD, a neurologist commented: I have to put myself in their shoes—to go home and, gosh, I have to tell my wife I have Parkinson's I can do research, I can give a pep talk, and



Figure 3. Doctor Stereotypes: Ineffective ways to communicate with patients about Parkinson disease. 10

Reprinted from: Dunlap-Shohl P. My degeneration: A journey through Parkinson's. University Park, PA: The Pennsylvania State University Press; 2015.

everything. But in their minds, [they are thinking] I have to tell my husband or wife [J]ust that part, it never occurred to me.

The book also prompted clinicians to examine the impact of their communication with patients, specifically, the way the information they impart is received by patients. Recalling Dunlap-Shohl's stereotypes of various doctors (eg, "The cheery prophet," "The cockeyed optimist," and "Dr. Doom") (Figure 3), one participant said: You know, you think that you're doing something for your patients ... but ... seeing that page, in particular—I started to have myself go through the lines that I say in the clinic and say, "Wow, did I use that before? Have I done that? Was that the way that was interpreted?"

Relatedly, participants indicated that reading the book led to greater self-awareness, which was sometimes surprising to them: I thought it was really, really insightful about the thought process It just never occurred to me, like every day, they wake up thinking . . . "Okay, what am I going to lose today?"

Perhaps the most important finding was that participants felt that reading the book enhanced their empathy for patients with PD. One image was found to be particularly powerful (Figure 4). As one participant said: And humans are on this teeny tiny little boat, and they're trying to do something against this monster ... I thought, "Yeah! That must be how a newly diagnosed patient feels."... You just turn the page and wham!

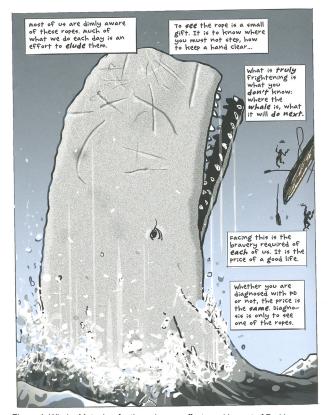


Figure 4. Whale: Metaphor for the unknown effects and impact of Parkinson disease (PD). 10

Reprinted from: Dunlap-Shohl P. My degeneration: A journey through Parkinson's. University Park, PA: The Pennsylvania State University Press; 2015.

For participants, the expressive visual elements used by the author clarified the information being conveyed and helped them understand what it feels like to live with this chronic disorder.

Theme 2: The Comic Form Engages Clinicians in Ways that Differ from Other Mediums

Participants uniformly found the book engaging and indicated that, particularly because of the vivid visual depictions, it captured their attention more than a text-only reading would have done. Even so, the experience of reading a comic was different than expected for some participants. As one person said: Here you can't, you can't just look at words. You can't just look at the comic. You need to look at them both together to get what he was trying to put through, in the story.

A few readers concluded that simultaneously assimilating visual and verbal messages complicated the reading: Yeah, I stopped sometimes. I had to go back and read just the words because sometimes the pictures were a little overwhelming.... there was a lot going on. You're trying to match the actions about what's going on with the words.... [It was] a little distracting because your eyes were going all over the page, trying to follow.

In this way, some participants found that reading comics required more time and effort than a regular textbook or narrative might. Others, however, noted pleasure in reading holistically: I liked it because, I mean, the illustrations, I could argue, are equal with the words and—reading the words, look at the picture and just take it all in as a whole.

Participants also felt that Dunlap-Shohl's skill in combining word and image made information more accessible and that My Degeneration might help clinicians better explain clinical findings or treatments to patients. As 1 participant expressed: [D]yskinesia and all that stuff, and I thought that those explanations that they gave were really good. Because sometimes I find even as a therapist, sometimes it's hard to describe [symptoms] in words that people are going to understand. Likewise, another participant said: The description of the DBS [deep brain stimulation] surgery ... it was, like, dark, and yeah when he's in the surgery ... the explanation of that surgery [and] the explanation of what happened after ... was very clear and accurate but also low enough [readability] level that it didn't feel overwhelming, like it would be understandable to a lot of people.

Of note, clinicians in the study found Dunlap-Shohl's description of DBS—and other technical matters—to be accurate and informative. One participant commented: It's actually amazingly accurate because the way he goes into DBS, he uses a few doctors' names. They are the persons ... who do [this] work. He mentions the name Dr Starr [H]e is THE person on DBS It's just amazingly accurate in that sense, you know.

Theme 3: Benefits of the Book May Extend beyond the Clinical Team

In addition to the book's usefulness for the clinical team, participants emphasized the potential value of *My Degeneration* to patients, particularly for helping them cope with physical, social, and psychological symptoms of PD. There was broad agreement that one particular passage, in which the author describes the common experience of freezing in place and being unable to walk, was especially useful (Figure 5).



Figure 5. Walk This Way: Example of Dunlap-Shohl's advice for episodes of abasia. ¹⁰ Reprinted from: Dunlap-Shohl P. My degeneration: A journey through Parkinson's. University Park, PA: The Pennsylvania State University Press; 2015

One reader said: As a physical therapist, I utilize a lot of those tricks but, easy for me to say as an able-bodied person ... "Oh, just do this!" ... I marked that page because I felt like ... patients will really understand ... the whole walking backwards thing.

Participants were resolute in their view that such images could be directly used with patients and were excited to try this in their own practices. One participant commented: You know, if someone was just diagnosed, what are they going to do? They're ... probably not going to hear everything you're telling them. They're blanking out ... they're going to go on the Internet; they're going to find all the stuff, and they're going to find definitions of tremor, rigidity, bradykinesia—what these words mean And they're going to get a very clinical definition That, coupled with this [book] is much more effective without a doubt. I think it's a great way of [describing] dyskinesia [I]t's much more effective.

Although using My Degeneration with patients was uniformly viewed as potentially helpful, a number of participants cautioned that clinicians should choose carefully the patients with whom to share the book, as it might not be appropriate for all patients, particularly those with a recent diagnosis of PD: But if you give it to someone who just got the diagnosis for the first time ... it might be a little bit difficult to take. "Oh, is that gonna be me in the wheelchair? Is that gonna be me with the festination?... Is that gonna be me?"

Similarly, participants felt that clinicians should consider carefully if and when to provide this resource to family members and friends, as it could be frightening or alarming if presented at the wrong time.

Finally, an unexpected finding was that some participants thought that this book could be helpful to patients with chronic illnesses other than PD: So, I think you can kind of generalize it to ... other chronic diseases like MS ... because they're going to have the depression and all those things and kind of go through the disease process like Parkinson's.

Joint Display

Study participants in this mixed-methods study indicated that they gained insight into patient and family experiences of living with PD by reading *My Degeneration*. Participants also reported changes in attitudes toward the medium of comics.

Table 2 shows integration of the quantitative and qualitative results for the 2 constructs—empathy/understanding of the lived experience of PD, and 2) attitudes toward comics—in a joint

Table 2. Joint display of convergent mixed-methods data analysis							
Construct	Quantitative results	Qualitative results	Convergence and divergence	Conclusion			
Empathy and understanding of the lived experience of PD	12-point increase in self-efficacy scores (p = 0.001); items related to understanding lived experience of patients with PD No change in items related to clinical knowledge of PD No change in clinicians' views on what patients with PD worry about	Theme 1: The book provides a meaningful way for clinicians to learn about the lived experience of patients with PD Fostered self-reflection about communicating with patients with PD Enhanced empathy for patients with PD with PD	Convergence	Book is helpful for promoting empathy and understanding of the patient experience and/or perspective Clinicians learned new things about the PD experience			
Attitudes toward comics	0.5-point increase in positive descriptions about comics on the semantic differential scale (p = 0.029) No change in scores on Attitudes toward Comics questionnaire Significant increase in Net Promoter Score from -50 to +77 (scaled -100 to +100), suggesting participants very likely to recommend the comic	Theme 2: The comic form engages clinicians in ways that differ from other mediums. Recognized value of images Comic provides more accessible descriptions	Convergence	More positive attitudes about comics after experiencing their power firsthand			

PD = Parkinson disease

display. When combining the datasets in this way, the findings are largely convergent, meaning that they support one another's conclusions.

DISCUSSION

This mixed-methods study confirmed our hypothesis that reading *My Degeneration* would improve clinicians' confidence in understanding the lived experience of patients with PD, as demonstrated by a significant increase in self-efficacy scores and favorable qualitative comments. We found no change in participants' scores on a test of clinical knowledge or their perceptions of patients' attitudes toward potential consequences of PD after they read the book. However, the results of the qualitative analysis revealed that clinicians did believe they gained new insights from *My Degeneration*, primarily with regard to the psychosocial effects of the disease on patients and their family members. In facilitating deeper reflection about potential patient experiences, this study suggests that reading *My Degeneration* fosters empathy on the part of clinicians.

We also found that reading *My Degeneration* led to more positive views of comics in general (as measured by the Semantic Differential Scale) and increased the likelihood that participants would recommend the book to others (as measured by the NPS). Qualitative results supported these findings, with participants commenting specifically on the value of the visual imagery in comics and noting that the images provided more accessible descriptions of the issues faced by patients with PD than do other mediums. This finding reflects current comics scholarship, which identifies how comics promote empathic responses to the subject matter by combining words and images to promote a narrative that is understood via emotions as well as through reason.⁸

A major strength of our study lies in the consistent, convergent findings that emerged between quantitative and qualitative data, but there are limitations. Most importantly, the sample size was small, and the study was conducted at a single site

without control group comparisons. Additionally, given the relationships of participants to the researchers, and the fact that the discussion groups were held at the home of the head of the movement disorders clinic at our institution, there was a risk of social desirability bias (ie, wanting to please the researcher), which could have positively skewed the results. Relatedly, the discussion itself may have altered participants' views on the book, which is an inevitable feature of any group discussion. Further research is needed to confirm our findings, and replicating the study at multiple sites using a randomized controlled trial (perhaps comparing comics with more traditional educational materials) would be useful.

CONCLUSION

To our knowledge, this study is the first of its kind: Combining qualitative and quantitative data to better understand the use of comics in clinical medicine. Specifically, we found that using a disease-specific comic with clinicians might increase awareness of, and empathy for, the patient's experience of illness. Future work in this area might compare the use of comics with the use of movies (such as "Awakenings"), StoryCorps (stories narrated by people in their own words, at www.storycorps.org), self-help manuals, or support groups. Additionally, subsequent studies might measure empathy directly (via observation of clinic visits before and after the intervention), and/or by surveying the patients/family caregivers as to the empathy of the clinicians. Our team is presently conducting similar studies with patients and family caregivers to better understand how comics may be used in conjunction with conventional treatment. We encourage a broader evidence-based implementation of comics in different fields of medicine—for example, mental illness, cancer, and eating disorders—to help identify how best to use this medium to assist patients, clinicians, and caregivers to navigate the emotional and informational components of illness with greater confidence and hope. �

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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Kathleen Louden, ELS, of Louden Health Communications performed a primary copy edit.

Authors' Contributions

Kimberly R Myers, MA, PhD, designed and conceptualized the study, analyzed and interpreted the data, and drafted and revised the manuscript. Daniel R George, MSc, PhD, analyzed and interpreted the data, and drafted and revised the manuscript. Xuemei Huang, MD, PhD, designed and conceptualized the study, and analyzed and interpreted the data. Michael D F Goldenberg, MA, analyzed and interpreted the data. L J Van Scoy, MD, analyzed and interpreted the data, and revised the manuscript. Erik Lehman, MS, analyzed qualitative data. Michael J Green, MD, MS, designed and conceptualized the study, analyzed and interpreted the data, and drafted and revised the manuscript. All authors have given final approval to the manuscript.

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