

The Lived Experience of Parkinson’s Disease: A Content Analysis of Parkinson’s Patients’ Blogs

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ABSTRACT: **Background:** Blogs have become a major venue of information sharing and emotional release for people worldwide. Illness blogs are a specific type of blog in which patients describe their experience with illness and coping with disease. Illness blog research has been conducted on several disorders; however, blogs by Parkinson’s disease (PD) patients have been neglected.

Objectives: To categorize the characteristics of PD patients from blogs and explore whether we can learn about the medical issues with which they are most concerned, as conveyed through their blog posts.

Methods: Using located PD patients’ blogs, we analyzed the contents of 78 blogs, and employed thematic analysis of eight arbitrarily selected blogs.

Results: The majority of blog authors in our sample (N=78) were from the United States (42%). The number of blogs written by male and female authors was fairly similar: 49% and 44%, respectively, while gender was unknown for 7%. Blogs were written by both early- and late-onset PD patients. The thematic analysis revealed five major themes: diagnosis, symptoms, treatment, coping mechanisms, and information.

Conclusions: Thematic analysis of blogs by PD patients provided considerable information and insight regarding the experience of these patients, which is significant to other patients and their families, as well as to medical professionals. Further qualitative studies of larger blog samples utilizing data mining techniques are needed to further explore the subjective experiences of patients.

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KEY WORDS: blogging, illness blogs, internet, Parkinson’s disease (PD)

We attempted to gauge medical issues raised by PD patients spontaneously in a non-medical setting by accessing blogs they wrote. These blogs are freely available, and although they have several limitations, they may provide important insight into patients’ concerns, which may then be studied systematically. To investigate the feasibility of this approach, we studied a selected sample of blogs. Although a similar method has been used to study other disorders [2-13], to the best of our knowledge, this is the first report on neurological disorders, and specifically PD.

An internet blog consists of web pages in which entries are listed by date [14]. Illness blogs are unique in that they provide information on many different aspects of disease and treatment as shared by patients, often starting from the time of diagnosis and continuing through the various stages of illness. Fox and Purcell [15] estimated that 12% of adults with a chronic health condition maintain their own illness blog, and 28% read illness blogs written by others.

Unlike other online health resources and social media, illness blogs revolve around one person’s experience, which is described freely without being restricted by a specific format. Blog posts are dated and others can add comments. As readers become involved in the blog and add their comments to posts, a small community is created around the blog author and his or her illness [10].

In this content analysis of blogs by PD patients, we investigated whether it was possible to locate blogs by PD patients, evaluate author characteristics, and analyze writer reports of experiences of illness, by applying thematic analysis as a qualitative research tool while exploring the medical issues with which the writers are most concerned.

PATIENTS AND METHODS

DATA

For our internet search of blogs written by PD patients, we used the following sources:

- Google search engine
- Google blogs search engine
- Specific blog search engines [Table 1]
- Websites of PD organizations and associations [Table 1]

Patient’s quality of life (QoL) is accepted as a major, perhaps predominant, issue for the quality of care, and several instruments have been developed to evaluate QoL in patients with Parkinson’s disease (PD) [1]. While helpful, these instruments have several limitations. They are typically based on responses to closed questionnaires presented during a busy hospital clinic visit with limited time available, and may be subjected to patients’ attempts to impress or satisfy the clinician or investigator.

Table 1. Data search information

| Blog search resources | | Search strategies and terms by language [‡] | |
|----------------------------------|---|--|--------------------------|
| Blog search engines | PD organizations and association websites | English | Hebrew |
| Technorati | Parkinson's ^{UK} (https://www.parkinsons.org.uk/) | blog* Parkinson's disease | In url: בלוג פרקינסון |
| blograma | National Parkinson's Foundation (http://www.parkinson.org/) | In lp: parkinson's disease+blog | בלוג פרקינסון |
| Parkinson's Disease Blog Network | European Parkinson's Disease Association (http://www.epda.eu.com/) | In title: parkinson's blog | |
| | Northwest Parkinson's Foundation (https://nwpf.org/) | Parkinson's disease blog | |
| | Michael J. Fox Foundation (https://www.michaeljfox.org/) | Living with Parkinson's disease blogs | |
| | Davis Phinney Foundation for Parkinson's (https://www.davisphinneyfoundation.org/) | Parkinson's patients blogs | |
| | APDA national young onset center (https://www.apdaparkinson.org/what-is-parkinsons/early-onset-parkinsons-disease/) | | |
| | Parkinson's Australia (https://www.parkinsons.org.au/) | | |

List of blog search engines and websites for PD organizations and associations in which blogs of PD patients were searched as well as a list of strategies and search terms in English and Hebrew utilized during the blog search

PD = Parkinson's disease, APDA = American Parkinson Disease Association

[‡]The * is used to truncate (or stem) a word while searching a text (i.e., using the search term "blog*" will enable the system to retrieve not only "blog" but also "blogs" and "blogging")

- PD disease forums and patient networks featured on the website PatientsLikeMe
- Blogrolls (a list of links on PD patients' blogs leading to other blogs written by PD patients)

The search using Google's search engine and Google's blog search engine was conducted in both Hebrew and English utilizing various strategies and search terms [Table 1]. We found 81 blogs written by PD patients. Manually locating illness blogs is not a straightforward and linear process as they are spread across the internet without a major repository [10,16]. The majority of the blogs we found were identified through blogrolls of blogs we located via PD patient blogs. We conducted two separate analyses: an author characteristic analysis and a thematic analysis.

INCLUSION CRITERIA FOR ANALYSIS OF AUTHOR CHARACTERISTIC

To qualify for our analysis, the blog authors had to specifically state that they have PD and write the blog entries themselves. They had to include content that revolves specifically around their experience as a PD patient. We excluded the following contributions: a blog written by a Parkinsonism-plus patient, one written by an author who does not have PD, and a third that included posts unrelated to PD. The remaining 78 blogs (N=78) were sorted according to patient gender, age, number of blog authors, geographic location, type of PD (either late- or young-onset), and the presence of co-morbidities.

INCLUSION CRITERIA FOR THEMATIC ANALYSIS

To be included for thematic analysis a blog had to meet the following criteria:

- Have at least three posts
- Be written by a single author whose gender was known
- Be easy to navigate and follow via a blog archive

Based on these criteria, we excluded 23 blogs. We arbitrarily selected eight blogs (n=8) for the thematic analysis: two blogs by females with young-onset Parkinson's disease (YOPD), two blogs by females with late onset of PD, two blogs by males with YOPD, and two by males with late onset of PD.

We employed thematic analysis [17] to explore major themes within the blogs. Thematic analysis is conducted by searching for themes that describe the phenomenon under study. The process consists of a pattern of recognizing certain data, which become the categories for analysis and are designated as a "theme" [18]. We applied an innovative tool [16] that utilizes a blog platform that enables researchers to store the blog posts being analyzed, assign themes to each blog post using the tag feature, and highlight the content that expresses the chosen theme. We used Blogger, a free blog publishing service owned by Google, to create a blog as a research platform, and adjusted its privacy settings to remove it from Blogger's listed blogs to block search engines from finding it. We set ourselves as the only people permitted to read and edit the blog. Figure 1 describes the theme assignment process.

By assigning themes to posts using the tag feature, similarly themed posts were grouped together. Posts were regarded inappropriate for analysis if their content was not related to the author's life as a PD patient. A total number of 855 posts by these eight bloggers (i.e., blog writers) were tagged for thematic analysis. Following the tagging process, the main themes were grouped into categories.

RESULTS

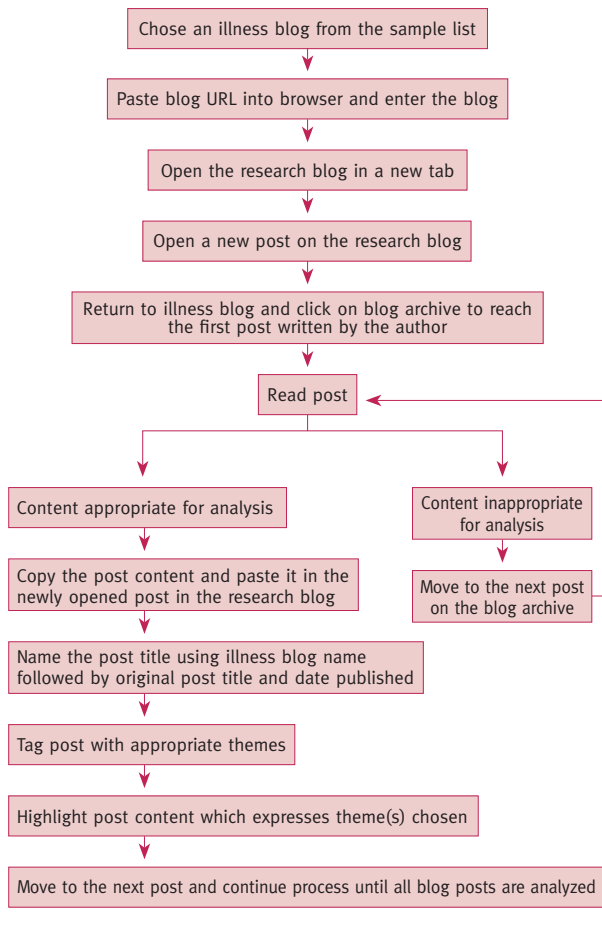
BLOG AUTHOR CHARACTERISTICS

The number of blogs written by male and female authors was fairly similar: 39 (49%) and 34 (44%), respectively. The gender of five authors was unknown. The geographic distribution included 33 authors (43%) from the United States, 9 (12%) from England, 4 (5%) from Canada, and 3 (4%) from Israel. Spain, Australia, New Zealand, and Malaysia were each represented by one blog (1%). In 25 cases (32%), the author's location was unknown. Finally, co-morbidity was mentioned in 11 blogs (14%). Table 2 presents characteristics of all blog authors that we analyzed.

THEMATIC ANALYSIS

Five primary themes were identified in the eight blogs analyzed: diagnosis, symptoms, treatment, coping mechanisms, and

Figure 1. Theme assignment process



information. The themes, treatment, and information were further subdivided into sub-themes, that is, information provision (sharing information with readers who have similar interests) and recommendations (designated mainly for patients newly diagnosed) [Figure 2].

DIAGNOSIS

All bloggers mentioned some aspect of their diagnosis. The main sub-themes related to diagnosis were the diagnosis itself, delayed diagnosis, and reaction to diagnosis. Two bloggers commented about how their doctor delivered their diagnosis. One writer felt that the physician was very blunt, while the other was described as being more sensitive. The rest of the bloggers who wrote about their diagnosis reported being diagnosed, but not the way in which the diagnosis was delivered. Four bloggers reported experiencing symptoms long before a diagnosis was given, some for as long as 9 years. Reactions to diagnosis varied from devastation and denial (1) to acceptance (2), indifference (1), anger (1), and relief (2) as the long uncertainty regarding the writer’s condition was finally resolved.

Table 2. Blog author characteristics

| Characteristic | Frequency | Percentage |
|---|-----------|------------|
| Author | | |
| Single author | 75 | 96% |
| Single author + contributing author/authors | 2 | 3% |
| Two authors | 1 | 1% |
| Gender | | |
| Male | 39 | 49% |
| Female | 34 | 44% |
| Gender unknown | 5 | 7% |
| Age at time of data collection | | |
| 20s | 3 | 4% |
| 30s | 1 | 1% |
| 40s | 5 | 7% |
| 50s | 4 | 5% |
| 60s | 6 | 7% |
| 70s | 1 | 1% |
| 80s | 1 | 1% |
| Age unknown | 57 | 74% |
| Stated young onset | 18 | 23% |
| Location | | |
| United States | 33 | 43% |
| England | 9 | 12% |
| Canada | 4 | 5% |
| Israel | 3 | 4% |
| Spain | 1 | 1% |
| Australia | 1 | 1% |
| New Zealand | 1 | 1% |
| Malaysia | 1 | 1% |
| Location unknown | 25 | 32% |
| Co-morbidities | 11 | 14% |

A list of blog authors’ major identity indicators by frequency and percentage

SYMPTOMS

Mainly motor symptoms were mentioned, particularly tremors, rigidity, and bradykinesia.

TREATMENT

All bloggers wrote about treatments. Six treatment types were identified: medication, exercise, supplements, nutrition, complementary therapies, and surgery.

Medication

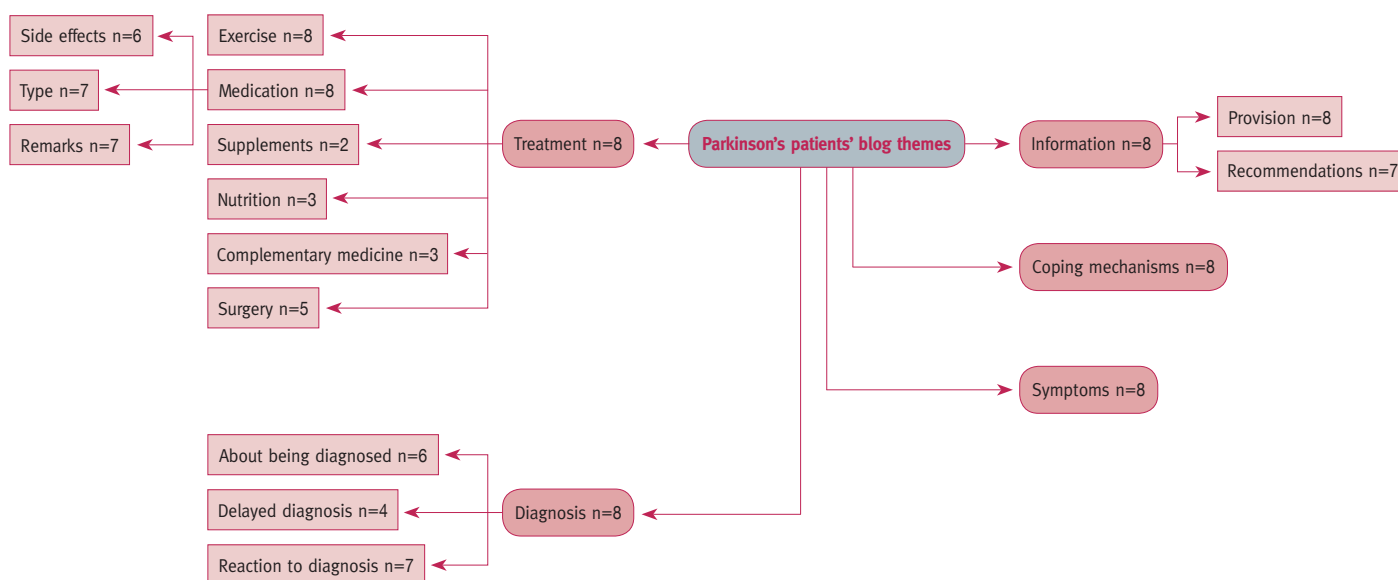
The sub-treatment theme of medication was further divided into three sub-themes:

Medication type

All but one blogger mentioned a medication type in their blog. The most common medication mentioned were levodopa combinations (7) followed by rasagiline and selegiline (5).

Medication side effects

Interestingly, bloggers rarely mentioned experiencing medication side effects. Medication side effects were mentioned primarily by one blogger. The most frequent side effects mentioned were dyskinesia and diuresis.

Figure 2. Primary identified themes and sub-themes that were identified in the eight blogs analyzed

Medication remarks

Most bloggers shared their experience of consuming medication. The main sub-themes related to medication remarks were: problems related to medication, humor related to medication, and changes related to medication use. Six bloggers reported problems related to medication, ranging from unfavorable effects of missing a dose or taking a dose too late, the lengthy time it takes for a medication to 'kick in,' being over medicated, the ineffectiveness of a medication, inappropriate or insufficient medication dosage, and the uncertainty of how long a medication will remain effective. Humorous remarks regarding medication were made primarily by one blogger. Seven bloggers remarked on adjusting to a new medication or a dose change.

Exercise

All bloggers reported exercising regularly, some even daily. Exercise was perceived as a way of fighting aging, treating symptoms such as insomnia, keeping in shape, postponing medication dose increase, preventing falls, and improving one's function during a medication 'off period.' The most common exercise regimes mentioned in blog posts were jogging, special exercise programs for PD patients, and yoga.

Supplements

The use of natural supplements for treating PD symptoms was mentioned primarily by one blogger who wrote extensively and comprehensively about his research, experience, and experimentation with consuming natural supplements, including 5-Hydroxytryptophan, curcumin, and coconut oil.

Nutrition

Three bloggers mentioned the effects of nutrition and nutritional modification on their condition and on the efficacy of their medication. They described experimenting with a vegan diet, fasting, and lowering sugar and protein intake to treat their symptoms.

Complementary therapies

Complementary therapies were minimally mentioned in the blogs analyzed and were mostly referred to by three bloggers who mentioned Reiki, acupuncture, and therapeutic gemstones.

Surgery

Deep brain stimulation (DBS), which has become an important surgical intervention for PD patients [19], was the surgical treatment option mentioned by five bloggers. Only one writer underwent the procedure. This blogger documented the events leading to the procedure, including his hesitations, as well as the complications following the procedure, and the rehabilitation period. Two bloggers mentioned contemplating undergoing the procedure and two shared their doubts and fears regarding this approach.

COPING MECHANISMS

Bloggers found different coping mechanisms to deal with PD. Some were explicitly addressed while others could be inferred from the posts. The three most common coping mechanisms found included participating in PD support group or PD society/conference, fundraising for PD, and being involved with hobbies. Almost all bloggers (7) participated in PD support groups, societies, or conferences. Four bloggers mentioned

regularly fundraising for PD, and five bloggers mentioned engaging in hobbies such as gardening, traveling, meditation, and art as means of coping.

Using humor and a positive outlook as a way of dealing with PD was mentioned by six bloggers, and three mentioned meditation and mindfulness as coping mechanisms. Two bloggers in the thematic analysis published books about their experience as PD patients. Five other bloggers in our larger sample of 78 blogs also published books relating to PD. Four bloggers expressed their active effort to fight the disease while two admitted that a mechanism of denial sometimes worked for them. Maintaining an illness blog in itself is obviously a coping mechanism, but four bloggers explicitly expressed this in their writing, along with internet research.

INFORMATION

One of the fundamental aspects of blogging is information sharing, as information in posts can be read and others can comment on them. Two major sub-themes related to information were identified: information provision and recommendations.

Information provision

The three major information provision sub-themes we found were medical research, PD and PD research, treatment, complications, and diseases in general. Information about medical research was provided by five bloggers. Another five bloggers provided information about PD, its complication, and treatment as well as research. Two blogs provided information about diseases in general. The major research information provider was one of the male bloggers with late onset PD who regularly shared the findings of his daily internet searches. We noted that a vast majority of information provided was medical and disease related.

Recommendations

The sub-themes identified under recommendations were: PD resources, PD medication and treatment, and interaction with a neurologist. The recommendations were mainly aimed toward newly diagnosed patients. Five bloggers recommended resources such as online PD resources, relevant smart phone applications, and books about PD.

Three bloggers supplied tips regarding medication and treatment, which revolved around medication reminders, promoting medication uptake, carrying reserves when traveling and outdoors, and promoting Eastern therapies such as Reiki. Three bloggers shared recommendations regarding interaction with a neurologist. They strongly recommended selecting a knowledgeable neurologist, and believed that choosing a movement disorder specialist was preferable. They also promoted an active management approach, which included questioning the suitability of methods and recommendations of their physicians and other medical profes-

sionals about their care and condition as well as asking for a second opinion when they felt the need.

DISCUSSION

Illness blogs provide a new and extensive information source for learning about patient experience through online illness narratives, otherwise gleaned from medical records or patient interviews, shedding light on the lived experience of disease. Internet ethnography, the underpinning methodological approach of our study, is a fairly new form of naturalistic inquiry gaining importance in these times of closer attention to patient-centered outcomes and quality of life in regard to medical research. This approach is reliable and strong for several reasons: it is not restricted by geographical boundaries, participant burden is low, and recall bias is absent. In addition, as authors write about their experience in “real time,” it enables researchers the unique opportunity to study the disease experience longitudinally, starting with diagnosis [20].

The scientific validity of the present study deals with data extraction from a relatively novel source which, as yet, has little validated research data. It cannot be compared with data collection in clinical studies, nor even from patient interviews, because there is no direct interaction with the patient in any form. In self-written blogs, the data source is free text written by the patients. We trust that as this field expands more data will become available, which will enable a comparison with the information presented here, and qualification and classifications can be established.

Our study provides a proof of concept of the feasibility of useful data mining from blogs. The database we used was limited, but the method can be easily expanded based on similar and additional sources and using this, or more sophisticated data mining techniques. The results obtained are not surprising, and most of the identified results could have been predicted, supporting the validity of method. Additional observations, such as the use of unconventional therapies and the reliance of bloggers’ ideas for coping mechanisms, as well as discussions on engaging in physical exercise to improve function during off periods and delaying the need for medication dose increase, are important issues not frequently addressed in traditional studies.

The use of publicly available internet data during internet ethnography challenges privacy, confidentiality, and informed consent [21] and is a source of debate among researchers. Some claim that if internet data is freely accessible it can be used for research without prior approval [7], while others call for a more cautious approach until standard methods for granting approval of internet-based observational studies are formed [20]. As stated, we practiced caution during our thematic analysis by blocking our blog platform, which included the internet addresses of all the patient blogs under analysis, from being exposed publicly for reasons explained previously.

Illness blog content analysis turns out to be a valid method of obtaining information concerning medical issues raised by PD patients in a non-medical setting. Our study expands illness blog research to the field of neurological disorders and demonstrates the feasibility of collecting data about the personal experiences of dealing with the disease. This information contributes an additional aspect to the holistic management of the Parkinsonian condition.

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Capsule

Cryo-electron microscopy structures of tau filaments from Alzheimer's disease

Alzheimer's disease is the most common neurodegenerative disease, and there are no mechanism-based therapies. The disease is defined by the presence of abundant neurofibrillary lesions and neuritic plaques in the cerebral cortex. Neurofibrillary lesions comprise paired helical and straight tau filaments, whereas tau filaments with different morphologies characterize other neurodegenerative diseases. No high-resolution structures of tau filaments are available. Fitzpatrick and co-authors presented cryo-electron microscopy (cryo-EM) maps at 3.4–3.5 Å resolution and corresponding atomic models of paired helical and straight filaments from the brain of an individual with Alzheimer's disease. Filament cores are

made of two identical protofilaments comprising residues 306–378 of tau protein, which adopt a combined cross-β/β-helix structure and define the seed for tau aggregation. Paired helical and straight filaments differ in their inter-protofilament packing, showing that they are ultrastructural polymorphs. These findings demonstrate that cryo-EM allows atomic characterization of amyloid filaments from patient-derived material, and pave the way for investigation of a range of neurodegenerative diseases

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Eitan Israeli

“Listen to the mustn'ts, child. Listen to the don'ts. Listen to the shouldn'ts, the impossibles, the won'ts. Listen to the never haves, then listen close to me... Anything can happen, child. Anything can be”

Shel Silverstein, (1930–1999), American poet, singer-songwriter, cartoonist, screenwriter, and author of children's books