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# Assessing the availability and quality of online self-help videos: A pilot study with a focus on Parkinson's disease

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## Abstract

**Objective:** The Internet and other electronic media may provide one part of a solution for reducing disparities in availability of medical services. From a patient-centred perspective, an individual with a chronic, degenerative condition may ask what information is available that I can use to manage changes in my functional capacity over time, and how effective is this? The purpose of this study was to assess the availability and quality of a sample of online self-help videos which address common functional problems ubiquitous among individuals living with one such condition: Parkinson's disease.

**Design:** Cross-sectional survey.

**Setting:** Internet.

**Method:** An Internet search was conducted to identify self-help videos offering instruction on how to manage changes in function, and each video was assessed using 17 factors relevant to instructional quality.

**Results:** Of 295 videos, 14 (4.7%) provided self-help instruction for three chosen skills. The quality of instructional presentation averaged 2.75 on a 5-point scale, where 1 was poor and 5 was excellent.

**Conclusion:** The identified self-help videos that addressed maintaining functional outcomes for individuals living with Parkinson's disease varied significantly in quality, and few met accepted standards of instructional design. Future research into effective presentation modes and patient functional capacity needs might usefully develop a patient-centred curriculum that can be delivered utilising multiple platforms. This area of research is critical in rehabilitation and other health settings to enhance assistance for individuals living with chronic health conditions and their families and caregivers.

## Keywords

Chronic conditions, Parkinson's disease, self-help, social media, tele-health

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## Introduction

The majority of health-care activities undertaken by any individual are self-directed. Indeed, individual decisions about diet, exercise and lifestyle are the primary drivers of health and well-being (Illich, 1976). When people can no longer adequately manage their own health, they have a number of options. Often, they may seek medical treatment and become medical patients. Even as patients, however, they may seek out self-help materials and other information to supplement their medical treatment. In these situations, patients may often want to know, 'What information is available that I can use to manage changes in my functional capacity over time, and how effective is it?' (Patient-Centered Outcomes Research Institute [PCORI], 2013). This strategy of self-help may be particularly important for those with long-term chronic conditions and/or those who experience health disparities, such as those living in rural areas (Cosby et al., 2008).

Self-help involves an individual acting on his or her own (VandenBos, 2007) to cope with, adjust to and manage changes associated with ageing or the onset of various health conditions. Self-help can be enhanced by using written information and instruction (Tagliati et al., 2011) or information shared in the context of a group (Attard and Coulson, 2012). From a service provider's perspective, many health system planners and providers view self-help as an important supplement to medical treatment (e.g. Davison et al., 2000). From a patient's perspective, both self-help and traditional medical service providers represent supplementary options to their ongoing efforts to maintain their health and cope with changes in their health status.

Research has focused on the quality of online health information for consumers for many years (Eysenbach et al., 2002), and the Internet has become an important resource for health information (Mazanderani et al., 2013). For example, online instructional videos regarding consumer health appear omnipresent – addressing topics from pregnancy vitamins (e.g. <http://www.webmd.com/vitamins-and-supplements/lifestyle-guide-11/vitamin-expert>) to changing an adult diaper (<http://www.youtube.com/watch?v=736yqzfn1oE>).

Indeed, some online instructional videos offer a means to support self-help. These videos may provide insights about adjustment or demonstrate key skills and techniques for negotiating critical situations of daily living. Self-help materials attempt to increase knowledge and facilitate skills that will ameliorate the difficulties faced by the user (Williams, 2003).

Although research-based criteria exist to enhance the instructional content of videos (e.g. Beaudin and Quick, 1996) and to increase learning via a multimedia presentation based on the cognitive processing abilities (e.g. Mayer and Moreno, 2003), online self-help video vignettes may be difficult to find or be of poor quality. For example, although the US National Institute of Health Senior Health provides informative videos for a variety of health conditions and topics such as depression and physical activity (<http://nihseniorhealth.gov/videolist.html>), there is no video with specific content for Parkinson's disease (PD).

Research exists on the effectiveness of electronic communication to deliver self-help and mutual aid to underserved populations (e.g. Shigaki et al., 2008); yet, no assessment has been conducted on the availability or quality of electronic-based communication for individuals living with chronic health conditions. Yet, from the patient-centred perspective, this may be an important source of information for this population. Thus, researchers should gather information to assess the availability and quality of online instructional self-help videos to address the functional changes due to specific health conditions.

The purpose of this study was to assess the availability and quality of a sample of online self-help videos that address common functional problems ubiquitous to individuals living with one such condition – PD. We approached this study from a patient-centred perspective; thus, we utilised practical search strategies and focused on functional skills that are relevant to individuals

living with PD. Ultimately, this research will benefit practitioners and patients by eliminating wasted time and effort required to sort through online resources that are not of adequate quality. Furthermore, this research holds the potential to identify standards for future production of online self-help instructional videos to support individuals living with similar chronic conditions.

## Methods

### Sample

PD is a neurological disease that affects over 500,000 individuals in the USA (National Institute of Neurological Disorders and Stroke, 2013). A range of strategies for managing the consequences of changes in function have been established (e.g. Tagliati et al., 2011), and this area of research is critical in rehabilitation and other medical settings to enhance assistance for individuals living with this disease.

In a review of the themes expressed in a recent online support group for individuals living with PD, Attard and Coulson (2012) noted that the 'most prominent subtheme in the study was the exchange of information on diverse topic related to Parkinson's disease' (p. 405). Thus, it is apparent that individuals with this condition who are using online resources are in need of accessible and useful information. From the patient's perspective, video vignettes that provide insights about adjustment and demonstrate key skills and techniques for negotiating critical situations of daily living offer a solution to this need for information.<sup>1</sup>

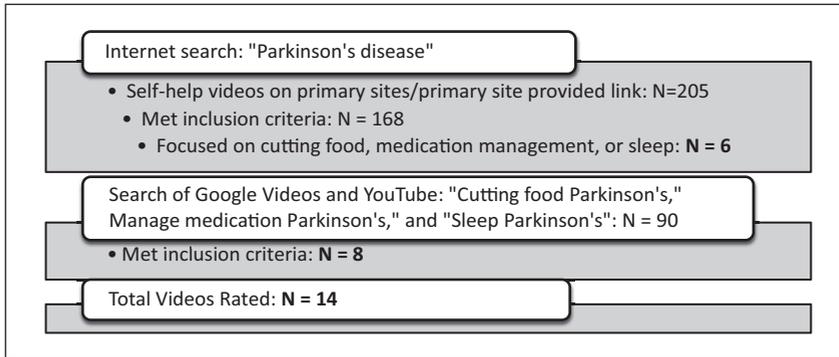
### Procedure

The present research involved an iterative process of exploring website content. First, we used the Google search engine to search for the term 'Parkinson's disease'. This provided an overview of the online information available. Second, we excluded sites advertising products or services. Third, we identified primary sites of information as sites containing a broad range and depth of information rather than a limited range of topics or minimum amount of information on multiple topics. The primary sites identified included the American Parkinson's Disease Association, the Parkinson's Disease Foundation, The National Parkinson's Disease Foundation and the Michael J. Fox Foundation. Fourth, we identified self-help videos on these primary sites or to which these primary sites provided a link. Fifth, we reviewed these videos and excluded advertisements and videos exceeding 15 minutes in length.<sup>2</sup>

Finally, we selected a convenience sample from the selected videos that focused on three functional self-help or self-management skills (cutting food, medication management and sleep) to examine in detail. In accordance with the limitations of this pilot study, we chose to focus on these three skills as offering a sample of functional limitations that individuals living with PD experience. These skills are consistently mentioned on relevant websites (e.g. lifeskills.com and everydayhealth.com).

As the primary sites contained few videos addressing the selected functional skills, we conducted additional searches of Google Video and YouTube specifically for 'Cutting food Parkinson's', 'Manage medications Parkinson's' and 'Sleep Parkinson's'. We selected items from the first 10 links returned for each search, as users are far less likely to view content beyond the first page of results (Eysenbach and Kohler, 2002).<sup>3</sup>

Overall, we identified 205 videos for review on primary sites or to which a primary site provided a link. Six (4%) of these met the inclusion criteria (not an advertisement and less than 15 minutes in length) and addressed the selected functional skills. The search of Google Videos and



**Figure 1.** Online self-help video selection process.

YouTube produced 90 links to instructional videos, of which 8 (8.9%) met the inclusion criteria and addressed the selected skills. The 14 videos that met the inclusion criteria and addressed the functional skills were then rated for instructional quality. The entire process is shown in Figure 1.

### *Rating instructional quality*

After the 14 self-help videos had been selected for review, a rating system was utilised to provide a standard and efficient method to rate their instructional quality. In a review of the literature, we found no examples of rating scales used specifically to assess the quality of self-help videos. However, this review did point to a 17-item rating scale developed to assess the quality of instructional content of videos (Beaudin and Quick, 1996). Although a rating scale for each sub-component of the scale was provided, the dimensions of each item were undefined. Accordingly, we modified this instrument by adding specific anchors and detailed, objective descriptions for each identified presentation component. We also incorporated other general principles of effective learning (Astleitner, 2005) and principles of cognitive load (Mayer and Moreno, 2003) into the identification of the anchors. Specifically, we anchored questions with criteria reflecting concepts such as reflexive learning (e.g. participants had time to reflect), opportunity to evaluate content (e.g. competing ideas or non-applicable content) and sustaining interest (e.g. presenting the problem, varying delivery). Table 1 presents a sample of the rating scale for one of the 17 items.<sup>4</sup>

## **Results**

Our search identified a total of 14 online instructional videos that met the inclusion criteria and addressed the identified functional skills: cutting food, medication management and sleep. Table 2 shows the distribution of the search results across the three main sources.

Utilising the modified rating scale, the mean rating across 17 dimensions of quality reported on a 5-point scale was calculated ('1' reflected poor quality and '5' reflected excellent quality; supplementary materials were not applicable). The overall average rating across the 15 applicable dimensions was 2.75, including 3.14 for content, 2.41 for instructional plan and 2.98 for technical production. Table 3 presents these results. The reliability of this scale was not established due to the limitations of this pilot study and will be the focus of subsequent research.

In general, the content of the videos was accurate and bias-free, and the presentations clearly stated the problem to be addressed and presented the proposed content. The audio quality and relationship between the audio and video were good, although speed, music and sound effects

**Table 1.** Sample rating scale and anchors for dimensions of learner application.

Rating	Anchor
1	No applications apparent
2	Action steps present
3	Motivation provided or problem presented
4	Action steps presented clearly and sequentially
5	Action steps easily carried out with the guidance of the video

**Table 2.** Source and distribution of online instructional videos for three patient-centred self-management skills.

Patient-centred question	Search terms	Number of videos identified		
		Google	YouTube	Primary sites
How do I cut my food	Cutting food Parkinson's	4	1	0
How do I keep track of medications	Manage medications Parkinson's	0	0	2
How do I cope with sleep problems	Sleep Parkinson's	0	3	4

**Table 3.** Mean ratings of quality of online instructional self-help videos.

Effective presentation components		Mean rating (1–5)	Percent rated excellent (5)
Content	Accurate	3.07	7%
	Useful	2.86	7%
	Bias-free	3.50	7%
Instructional plan	Stated the objectives	3.29	7%
	Content presentation	3.43	0%
	Learner application	2.36	0%
	Learner reflection	1.79	0%
	Met the objectives	2.14	7%
	Learner interaction	1.57	0%
	Integration into the learning environment	2.29	0%
	General video and design characteristics	2.21	14%
Technical production	Focused on intended content	4.07	43%
	Visual quality	1.71	7%
	Audio quality	3.64	14%
	Audio–visual relationship	3.29	14%
Supplementary materials	Provided introductory information	N/A	N/A
	Clarified and summarised the content	N/A	N/A

were rarely optimised. Furthermore, none of the videos used a visual portrayal of the task being addressed, even when specific skills or strategies were described. That is, the videos consisted of ‘talking heads’ (Ellis and Childs, 1999) telling viewers what to do rather than showing them how to do it.

No videos included supplementary material or were explicitly integrated into a broader learning or instructional framework. Furthermore, few used special effects or other video-specific techniques to show the learner relevant behaviours, places, techniques or procedures. Indeed, few clearly stated a target audience, offered opportunities to reflect, provided summary statements or presented concrete steps or directions for further action.

In addition, few of the videos reviewed appear to have taken the particular cognitive characteristics of many individuals living with PD into consideration, especially those in more advanced stages of the disease. For example, few videos seem to have taken cognitive load into consideration by reducing working memory demands, off-loading information to separate processing channels, pre-training or strategically allowing time between the presentation of different pieces of information.

## Discussion

This pilot research utilised search strategies that patients might use. We found few self-help videos that addressed the identified sample of functional limitations faced by individuals living with PD. The videos we did find varied significantly in quality, with few meeting standards of instructional design. However, the information presented in the videos was rated as being accurate, and many videos involved experts in the field. In addition, many of the available videos avoided jargon and provided appropriate descriptions at various levels of detail.

Overall, this pilot study identified a low proportion of videos focused on teaching strategies and techniques to deal with common functional problems experienced by individuals living with PD. Indeed, we were surprised by what appeared to be a paucity of relevant, patient-centred self-help and disease management supports of any kind. The online videos reviewed presented information at a relatively superficial level (e.g. statements of goals or tasks without details of how to perform the skill). The videos typically showed individuals simply talking about experiences, situations and recommendations (e.g. talking heads) and did not use visual portrayal of how to perform a skill or task.

These findings need to be considered with caution, however, as this was a pilot study designed to assess only a small sample of functional limitations experienced by individuals living with PD. The process used to search for relevant videos may have missed some videos that exist. Although the target skills in this study are prominent functional limitations for individuals living with PD, there may be higher quality online self-help instructional videos to address other functional limitations. Nonetheless, the process necessary to find quality online self-help videos for other functional skills is likely similar. Furthermore, the third (T.S.) and fourth authors (D.O.) are both individuals diagnosed with PD and contributed to the study procedures. As such, these procedures represent how others with the condition might search for the information.

The video rating system used in this pilot research was developed based on Beaudin and Quick's (1996) instructional video rating system, which was grounded in research on video instructional materials; yet, our research team determined that anchors were necessary to standardise ratings. Thus, the results of this study must be viewed as preliminary. While the rating system used in this research has face validity, future research should further analyse the reliability and validity of this rating tool (e.g. comparing the results of this rating scale with the findings of a content expert). Future research should also apply this rating system to online self-help instructional videos for individuals living with other chronic medical conditions and their families and caregivers.

As highlighted earlier, many of the videos identified through user-generated content and leading research, treatment and dissemination organisations received low-to-medium ratings of essential

qualities of effective video training and instruction. Yet, many strategies are available to accomplish these goals, such as reducing working memory demands or providing pre-training for participants, and these strategies have been shown to significantly increase learning when using multimedia (Mayer and Moreno, 2003). Such strategies may be especially useful for individuals with PD, as cognitive domains such as memory, visual–spatial learning and attention can be negatively compromised (Nazem et al., 2009).

This study benefits both patients and caregivers by potentially reducing the time and energy required to sort through the vast amount of online information. The future use of this scale will enhance the quality of online self-help resources from a patient-centred perspective; this tool can be used to create high-quality videos and to identify existing videos that effectively meet patients' needs. As such, primary websites – such as government agencies and private foundations – might use these procedures to evaluate the content and structure of their video programmes to more effectively deliver information and support to those living with PD and their caregivers.

These procedures to assess the availability and quality of online self-help videos are also applicable to individuals living with other chronic health conditions, such as diabetes, developmental disabilities or traumatic brain injury. Such assessments should also consider the response requirements of accessing the information, including both physical requirements (e.g. typing) and cognitive load requirements (e.g. time-intensive webinars or written passages).

With the advent of social technology, Merolli, Gray and Sanchez (2013) have suggested that

Attention and refinement to the affordances of social media in an illness context must be considered alongside or in place of platform specific studies. Further research is thus suggested using systematic and thoughtful study designs to investigate how the particular affordances of social media are best suited to addressing different patient needs. (p. 11)

It is important to emphasise quality research in this area to address and surmount barriers that currently exist in using evidence-based practices of social media to enhance rehabilitation and other medical services (Merolli Gray and Sanchez, 2013). Furthermore, as suggested by Mazanderani O'Neill and Powell (2013) in a study focused on the use of YouTube by patients with multiple sclerosis, researchers and practitioners should engage with social media to better understand what type of information is significant to patients; in turn, this may minimise the gap between patients and professionals.

Finally, online video supports should address the concerns that individuals experience with change over time. Thus, research should involve individuals with chronic health conditions, and their families and caregivers, to construct socially valid curricula and interventions (Seekins and White, 2013). In turn, these evidence-based interventions may help ameliorate functional and psychological problems occurring across the lifespan. Current technology provides many options to meet the social and informational needs of this population, and now research and service providers should proceed to further examine, create and utilise these important supports.

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## Notes

1. The third (T.S.) and fourth (D.O.) authors are both individuals diagnosed with Parkinson's disease and participate in a self-help support group.
2. Ellis and Childs (1999) suggested that instructional videos not exceed 15 minutes to avoid loss of interest by the viewer.
3. A review of subsequent pages suggested that the proportion of relevant links declined precipitously.
4. Please contact the corresponding author for a copy of the full rating scale used to assess the self-help videos.

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