Online tools for individuals with depression and neurologic conditions

A scoping review

Sara Lukmanji, MPP; Tram Pham, BHSc; Laura Blaikie, BA; Callie Clark, MSc; Nathalie Jetté, MD, MSc; Samuel Wiebe, MD, MSc; Andrew Bulloch, PhD; Jayna Holroyd-Leduc, MD; Sophia Macrodimitis, PhD; Aaron Mackie, MD; Scott B. Patten, MD, PhD

Abstract

Background: Patients with neurologic conditions commonly have depression. Online tools have the potential to improve outcomes in these patients in an efficient and accessible manner. We aimed to identify evidence-informed online tools for patients with comorbid neurologic conditions and depression.

Methods: A scoping review of online tools (free, publicly available, and not requiring a facilitator) for patients with depression and epilepsy, Parkinson disease (PD), multiple sclerosis (MS), traumatic brain injury (TBI), or migraine was conducted. MEDLINE, EMBASE, PsycINFO, Cochrane Database of Systematic Reviews, and Cochrane CENTRAL Register of Controlled Trials were searched from database inception to January 2017 for all 5 neurologic conditions. Gray literature using Google and Google Scholar as well as app stores for both Android and Apple devices were searched.

Self-management or self-efficacy online tools were not included unless they were specifically targeted at depression and one of the neurologic conditions and met the other eligibility criteria. **Results:** Only 4 online tools were identified. Of these 4 tools, 2 were web-based self-management programs for patients with migraine or MS and depression. The other 2 were mobile apps for patients with PD or TBI and depression. No online tools were found for epilepsy. **Conclusions:** There are limited depression tools for people with neurologic conditions that are evidence-informed, publicly available, and free. Future research should focus on the development of high-quality, evidence-based online tools targeted at neurologic patients.

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From the University of Calgary Cumming School of Medicine, Canada.

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Correspondence to: Nathalie.Jette@albertahealthservices.ca

Depression is common in neurologic conditions such as epilepsy, multiple sclerosis (MS), Parkinson disease (PD), traumatic brain injury (TBI), and migraine.^{1–6} Depression in neurologic patients also has distinct features. For example, depression in epilepsy patients often goes untreated due to fear of increasing the risk of seizures.⁷ There are many barriers to accessing mental health resources for patients with neurologic conditions including barriers related to geography, available human resources, mobility, stigma, and cost.

Online tools can help reduce barriers⁸ and mediate adverse events related to depression in these patients, such as reduced treatment adherence^{9,10} and worsened quality of life.^{11–14} A randomized control trial found that MoodGYM, a general cognitive behavioral therapy program for depression, improved participants' dysfunctional thinking and their scores on a depression scale.¹⁵ However, patients with MS and depression using MoodGYM reported worsened physical symptoms and expressed a need for such programs to recognize the interaction between their MS and their depression.¹⁶ Therefore, online tools are important and effective; however, the unique nature of depression in neurologic patients emphasizes the need for resources targeted specifically towards these patients.

The availability of web-based programs for depression has been studied.¹⁷ However, the extent and type of online tools for patients with neurologic conditions and depression is unknown. Therefore, we conducted a scoping review to identify evidence-informed self-management tools available online for patients with 1 of 5 major neurologic conditions (epilepsy, MS, PD, TBI, and migraine) who also have depression.

METHODS

A scoping review of online tools relating to depression in those with neurologic conditions was conducted using the 6-stage framework provided by Arksey and O'Malley¹⁸ as well as the subsequent recommendations made by Levac et al.¹⁹

Research objectives

The 5 neurologic conditions of interest were epilepsy, PD, MS, TBI, and migraine. The objective was to summarize the types of online tools that are available to inform future research and health policy in this area.

Identification of relevant studies

The search strategy was developed with the help of a librarian with systematic and scoping review experience. The search strategy included terms related to each neurologic condition (and their synonyms), depression, self-management, patient education, and the Internet. The search was not limited by date, language, or study design. The searches for each of the 5 conditions were conducted using databases that index peer-reviewed literature (MEDLINE, Embase, PsycINFO, Cochrane Database of Systematic Reviews, Cochrane CENTRAL Register of Controlled Trials), mobile app stores (iTunes and Google Play Store), as well as Google and Google Scholar. The mobile app stores were searched in December 2016 while the rest of the search strategy was run in January 2017 for all 5 neurologic conditions (appendix e-1 at Neurology.org/cp).

Study selection

Prior to the initial screening, the research team discussed and agreed on the inclusion and exclusion criteria. For the purpose of this review, tools were defined as self-management/assessment tools or social support/interventions offered online or downloadable as a mobile app. Tools were included if they were for at least 1 of the 5 neurologic conditions of interest (epilepsy, PD, MS, TBI, or migraine) and depression. They were also required to be evidence-based (tested in a prior study), offered online, publicly available, free, and in English or French. Online tools were excluded from the review if they required a live facilitator. Self-management or self-efficacy online tools were not included unless they were specifically targeted at

Supplemental Data

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The online tools found for migraine and MS were both web-based self-management programs while the online tools found for patients with PD and TBI were both mobile apps.

depression and one of the neurologic conditions and met the other eligibility criteria. Editorials, abstracts, posters, and pediatric studies were also excluded.

The online resources and tools were reviewed by 2 study authors. The final inclusion decisions were made in consultation with senior study authors. Any disagreement was discussed among the research team until a consensus was reached.

Charting the data

The variables to be abstracted for each article were determined in consultation with the research team and a standardized data abstraction form was created. The data abstraction form was pilot tested prior to abstracting data from all of the full-text articles. All data abstraction was done by 2 study authors.

Collating, summarizing, and reporting the results

Results were descriptively summarized and categorized as a mobile app or a self-management website.

Consultation

The research team provided expert consultation throughout the process as well as on the final article.

RESULTS

Four online tools pertaining to depression among the 5 neurologic conditions were found through our search. One tool each was identified for migraine,²⁰ MS,²¹ PD,²² and TBI,²³ while no tools were identified for epilepsy (figure). The online tools found for migraine and MS were both web-based self-management programs while the online tools found for patients with PD and TBI were both mobile apps (table 1).

Figure Flow diagram

* In addition to all 100 Google search results for each condition. MS = multiple sclerosis; PD = Parkinson disease; TBI = traumatic brain injury.

We found few publicly available and free online tools that do not require facilitators relating to depression among the 5 neurologic conditions despite our broad search strategy.

The web-based self-management program identified for migraine patients with depression is known as painACTION.²⁰ This program was developed based on a self-management education model and comprises 5 core components relating to the self-management of migraine. One of these core components is emotional coping, which is meant to address issues such as negative thinking and catastrophizing,²⁴ both of which are important elements in the cognitive-behavioral management of depression. This program provides tailored content and is delivered in several different formats including lessons, tools, self-assessments, and user-generated content.²⁴

The other web-based self-management tool identified in this scoping review is Overcoming MS (OMS), which is for patients with MS with depression.²¹ This program promotes lifestyle modification through resources such as a website and social media sites, which deliver similar content and are updated based on new research evidence.²⁵ The website includes videos, a community forum, blogs, and podcasts, and some of the topics addressed for improving mood and MS symptoms are meditation and exercise.²⁵ This program also includes a 5-day physician-led retreat; however, this component of the program is not free.²⁵

A mobile app called uMotif for people with PD and depression was also found.²² uMotif is a tracking app that allows users to record measures such as mood and energy. uMotif also allows patients to set up medication reminders, and includes physical responsiveness games as well as disease-related information.²²

The other mobile app found in our search is the T2 Mood Tracker, which is for people with TBI and depression.²³ This mobile app is specifically targeted towards veterans and, similar to uMotif, it is a tracking app that allows users to record their emotions and depressive symptoms and compare it to their TBI symptoms over time. This app developed to track deployment-related behavioral issues (e.g., depression, anxiety, posttraumatic stress disorder) employs movable rating scales and allows users to add custom rating categories beyond behavioral issues, such as pain and sleep.²³ Though apps like uMotif and the T2 Mood Tracker can be a component of self-management of depression, or a means of informing measurement-based care, they are not in themselves an intervention for depression. We also found several mobile apps that were mood trackers for individuals with neurologic conditions (appendix e-2). However, unlike the uMotif and T2 Mood Tracker, these apps did not specify depression or were not evaluated in a study; therefore, they were not included in this scoping review.

The 4 online tools included in this scoping review have each been evaluated in a study. In addition to depression outcomes, which are summarized in the discussion, other outcome measures were also examined in these studies and can be found in table 1.

DISCUSSION

We found few publicly available and free online tools that do not require facilitators relating to depression among the 5 neurologic conditions despite our broad search strategy. As a result, this scoping review demonstrates an important gap in the availability of online tools to help persons with neurologic conditions manage their depression, in addition to standard in-person mental health care. We also found a lack of representation of tools developed in non-Western countries. To elaborate, of the 4 online resources and tools identified, 2 were from North

Table 1 Included online tools

Title of online tool	Creator	Study authors and design	Year	Condition	Country of origin	Target user	Type of tool/resource	Summary of tool/resource	Study outcomes measured	Link to resource
T2 Mood Tracker	The US Defense Department's National Center for Telehealth & Technology	Bush et al.; cross-sectional observational	2013	TBI	United States	Patients, caregivers	Mobile app	Mobile app, originally created for veterans, to track TBI and depression-related symptoms over time	Mixed methods survey regarding app usability and benefits	t2health.dcoe.mil/apps/t2-mood-tracker
uMotif	uMotif	Lakshminarayana et al.; open-label multicenter randomized controlled trial	2017	PD	United Kingdom	Patients	Mobile app	Mobile app to track PD and depression-related symptoms; also includes games and information	Adherence to treatment ^a ; quality of life; quality of consultation ^a ; nonmotor symptoms; belief about medications; depression and anxiety	umotif.com/
Overcoming Multiple Sclerosis	Founder: George Jelinek	Hagkiss et al.; cross-sectional observational	1999	MS	Australia	Health care providers, researchers, patients, and caregivers	Web-based program	Online lifestyle management program with videos, a community forum, blogs, and podcasts	Depression ^a ; fatigue ^a ; physical health ^a ; mental health ^a	overcomingms.org/
Pain Action	Principal investigators: Emil Chiauzzi, Jonas Bromberg, and Lynette Menefee Pujo	Bromberg et al.; randomized trial	2011	Migraine	United States	Patients	Web-based program	Online intervention that involves cognitive-behavior therapy and self-management principles through lessons, tools, self-assessments, and user-generated content	Psychological distress (anxiety, depression, ^a and stress ^a); use of coping strategies ^a ; self-efficacy ^a ; pain catastrophizing ^a ; migraine-related disability; locus of control; patient global impression of change ^a	painaction.com

Abbreviations: MS = multiple sclerosis; PD = Parkinson disease; TBI = traumatic brain injury.

^aStudy found significant improvement.

America,^{20,23} while 1 was from the United Kingdom,²² and the other was from Australia.²¹ A scoping review of web-based interventions for depression reported similar results as it found that most interventions are targeted toward the general adult population rather than special populations (i.e., patients with neurologic conditions) and that most interventions are in English.¹⁷ It is possible that these gaps exist because the development of high-quality online resources and tools for people with neurologic conditions and depression is a resource-intensive process and there may be limited funding to support the development of not-for-profit tools.

However, the development of such resources is a worthwhile endeavor, as the 4 online tools we did identify were associated with several positive effects. A randomized trial of painACTION, which assessed depression outcomes using the Depression Anxiety and Stress Scales (DASS-21), found clinically significant differences in depression between the experimental and control group, with painACTION users reporting improvements in depression as well as other psychological outcomes.²⁴ In addition, a study of OMS found that people who participated in all 3 aspects of the program were 89.8% less likely to screen positive for depression.²⁵ However, the authors did not find that participants who solely used the website (the freely available component) had a reduced odds of screening positive for depression.

In terms of the apps, based on a study of veterans, the T2 Mood Tracker was reported to be useful for tracking depression-related symptoms and sharing them with health care providers.²⁶ In addition, a multicenter randomized control trial of uMotif found several positive effects, such as improved treatment adherence. App users also perceived their consultations to be of higher quality. However, there was no significant improvement in outcomes relating to depression after using uMotif.²² Improvements in depression outcomes for patients using these apps may be more modest than web-based programs because both apps are primarily tracking devices rather than interventions.

A potential limitation of our scoping review, which is a limitation of evidence synthesis in general, is that some resources or tools may have been missed. This limitation is especially relevant for the gray literature search (Google) as it is only feasible to go through a portion of these results. However, it is unlikely that we missed any tools because the number of relevant results was low and the relevancy of results on a Google search is presented from highest to lowest. Similarly, since content on the Internet is constantly evolving and changing, it is possible that searches run at a later date would retrieve different results. Another possible limitation is that we did not include tools that required a live facilitator or involved any user costs. Tools including these components may be beneficial for people with neurologic conditions and depression. We have included a list with examples of excluded tools with reasons for exclusion (table 2); however, they are likely not as accessible as the resources and tools that met our criteria as they involve access barriers.

Although there are guidelines and standards that have been published on the management of depression in neurologic conditions, these are primarily targeted at health care professionals rather than persons with neurologic conditions.^{27–31} According to an investigation of patient and caregiver perspectives on Internet interventions for long-term conditions, patients and caregivers value Internet interventions that do not use excessively complicated information or medical terminology.³² Patients and caregivers also want practical information that would help them, or their friends and family, plan day-to-day activities.³² As a result, resources and tools targeted towards health care professionals are unlikely to meet patients' needs in terms of both clarity and utility. In addition, most of these standards are not based on high-quality evidence (i.e., randomized controlled trials).

The results from our scoping review identified a gap in the evidence surrounding online tools for managing depression in neurologic conditions. Based on the importance of evidence-based tools targeted at patients and the increasing number of Internet users worldwide, future research should be aimed at developing such online tools for these patient groups. Tool development for patients with epilepsy and depression in particular should be a priority,

Table 2 Examples of excluded online tools

Title of online tool	Creator	Year	Condition	Country of origin	Target user	Type of tool/resource	Summary of tool/resource	Link to resource	Reason for exclusion
UPLIFT	Epilepsy Foundation	2010	Epilepsy	United States	Patients	Program delivered online or on the phone	An 8-week cognitive therapy and mindfulness program aimed at reducing depressive symptoms and improving patient self-management for patients with epilepsy	epilepsy.com/get-help/managing-your-epilepsy/self-management-programs/uplift	Resource requires a live facilitator for both the online and phone sessions
Deprexis^{a,b}	Gaia AG	2009	Epilepsy	Germany	Patients	Web-based program	An online depression program that includes 10 interactive modules	deprexis.com/	Resource is not free to use; resource is not specific to people with epilepsy
iPerform	HARI Lab	2014	TBI	United States	Patients	Mobile app	A mobile app that allows TBI patients to track their depressive symptoms using biweekly mood assessments	apkpure.com/iperform/edu.pitt.hari.IPerform	Resource requires a live facilitator
Problem-Solving Treatment Program (PST)	Boeschoten et al.	2012	MS	The Netherlands	Patients	Web-based program	A 5-week online self-help intervention program for patients with MS and depression	ncbi.nlm.nih.gov/pmc/articles/PMC3493307/	Resource requires a live facilitator; resource not publicly available
Deprexis^{a,b}	Gaia AG	2009	MS	Germany	Patients	Web-based program	An online depression program that includes 10 interactive modules	deprexis.com/	Resource is not free to use; resource is not specific to people with MS
Mood Gym^b	Australian National University	2004	MS	Australia	Patients	Web-based program	An interactive online cognitive-behavioural therapy program consisting of 5 modules	moodgym.anu.edu.au/welcome	Resource is not specific to people with MS
Beating the Blues^b	Ultrasis Ltd.	2004	MS	United Kingdom	Patients	Web-based program	An 8-session online cognitive-behavioral therapy program	beatingtheblues.co.uk/patients/	Resource is not free to use; resource is not specific to people with MS
MS Invigor8	Moss-Morris et al.	2012	MS	United Kingdom	Patients	Web-based online program	An 8-session web-based interactive cognitive-behavioral therapy program	ncbi.nlm.nih.gov/pubmed/22516321	Resource is not publicly available

Abbreviations: MS = multiple sclerosis; TBI = traumatic brain injury.

^a Same resource.

^b A study evaluated these tools in the neurologic condition they are categorized under, even though the tool was not created specifically for that condition, and these tools were therefore excluded.

seeing that this scoping review did not retrieve any online tools for this patient group. In addition, when developing such tools, it is important to create content tailored to patients specifically. As mentioned, based on patient and caregiver perspectives on Internet interventions for long-term conditions, language and tone are important quality metrics, as well as including content that is relevant to daily living.³² Therefore, developing patient-targeted tools is important for meeting patients' needs in terms of both clarity and utility.

Once the number of available high-quality resources for people with depression and neurologic conditions grows, the development of an eHUB, which is an online portal that links to various online resources and tools, could be a useful next step. An eHUB is attractive because it can update its vetting (e.g., it can remove out-of-date sites) and it is scalable as it can grow in relation to the number of available tools and resources. Also, based on the findings from the OMS program, the more resources participants used (e.g., a book and retreat in addition to the website), the less likely they were to screen positive for depression. Since an eHUB pools together various resources, it is possible that it will have a similarly improved effect.

An existing eHUB, known as the Beacon website, currently provides links to vetted online mental health resources.³³ However, this website does not outline resources specific to neurologic patients with depression. Online resources and tools targeted to this group are important because the optimal course of treatment for depression can be affected by a patient's neurologic condition.¹⁶ Therefore, once the resources specific to neurologic patients with depression are developed, an eHUB is a promising way to facilitate much-needed access to high-quality, credible, and up-to-date tools and information on diagnoses, treatment, and self-management for this patient population.

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AUTHOR CONTRIBUTIONS

S. Lukmanji contributed to the acquisition and interpretation of the data, prepared the initial draft of the manuscript, and contributed to the revisions. T. Pham contributed to the acquisition and interpretation of the data and the revisions of the manuscript. L. Blaikie contributed to the acquisition and interpretation of the data and the revisions of the manuscript. C. Clark contributed to the acquisition and interpretation of the data and the revisions of the manuscript. N. Jetté obtained study funding and contributed to the conceptualization and design of the study, the interpretation of the data, preparation of the initial draft of the manuscript, and the revisions of the manuscript. S. Wiebe obtained study funding and contributed to the conceptualization and design of the study, the interpretation of the data, and the revisions of the manuscript. A. Bulloch obtained study funding and contributed to the conceptualization and design of the study, the interpretation of the data, and the revisions of the

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