

## **AUTHOR ACCEPTED MANUSCRIPT**

"Online resources supporting workers with chronic episodic disabilities: an environmental scan"

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## **Abstract**

### **Purpose**

To conduct an environmental scan describing publicly available resources focused on working with an episodic disability and providing information and advice about communication and accommodation to support working people living with episodic disabilities.

### **Methodology**

We conducted an environmental scan of English language, freely available, online resources relevant to episodic disabilities in the workplace. We used Google™ to conduct structured keyword searches. Resources were reviewed and data extracted about episodic health condition(s) addressed, intended audience(s), resource format, and content about health, legal rights, workplace issues, and accommodation and communication needs.

### **Findings**

Searches yielded 5300 links to websites which was supplemented by 101 links identified by partners. Screening for relevance found 210 resources for which data were extracted. Of them, 158 addressed specific episodic disabilities or episodic disabilities generally. Most resources provided useful information addressing communication and accommodation of episodic disability. However, information specific to the episodic nature of disability was not consistently available. The resources generally lacked interactivity which could potentially limit users in applying the information to their personal circumstances.

### **Originality**

This is one of few studies that examined publicly available resources relevant to working with episodic disabilities.

### **Practical implications**

Our findings suggest there are good resources to help workers and managers/supervisors navigate accommodations for episodic disabilities. Research should aim to improve the interactivity of information to personalize resources to worker and workplace needs, as well as formally evaluate resources and their outcomes. Practitioners may wish to recommend resources that specifically address workplace challenges for their clients.

## **Introduction**

For the majority of people with disabilities in Canada, the limitations they experience due to their health are not stable but are dynamic and can change over time; these have been described collectively as “episodic disabilities” (Morris *et al.*, 2019; Standing Committee on Human Resources Skills and Social Development and the Status of Persons with Disabilities, 2019).

Conditions associated with episodic disability are often highly prevalent and can include mental health disorders like depression and anxiety, rheumatic diseases like arthritis and lupus, Crohn’s and colitis, multiple sclerosis, migraine and epilepsy. Improved treatments for previously life-threatening diseases like some types of cancer and HIV/AIDS have resulted in these also being experienced as chronic, episodic disabilities (Canadian Working Group on HIV and Rehabilitation, 2011). A recent survey of disability in Canada found that while 39% of persons with disabilities 15 years old and over experienced continuous limitations, 61% reported that limitations due to their health changed over time, including both those with progressive limitations and those who experienced periods of good health or well-managed disease interrupted by periods of illness and disability (Morris *et al.*, 2019). In addition, many conditions causing episodic disabilities are labelled as invisible or hidden disabilities. That is, signs and symptoms of the conditions may not be apparent to others until symptoms are severe (Gignac *et al.*, 2012; Prince, 2017).

There is also increasing recognition of the personal, social and financial impact of chronic, episodic disabilities on employment (Gignac *et al.*, 2020; Morris *et al.*, 2019; Prince, 2017; Standing Committee on Human Resources Skills and Social Development and the Status of Persons with Disabilities, 2019). Although chronic conditions resulting in episodic disabilities differ in their etiology, they often share similar impacts on work, including increased

absenteeism, presenteeism (reduced productivity while at work), and unpredictable impacts on the amount or type of work performed (Galarneau and Radulescu, 2009; Gignac *et al.*, 2008; Jetha *et al.*, 2015; Morris *et al.*, 2019; Public Health Agency of Canada, 2000). The Public Health Agency of Canada (2000) estimates that among the most common chronic diseases (e.g., rheumatic diseases, mental health conditions, respiratory conditions, cardiovascular diseases, diabetes), 60-80% of the total costs are related to lost productivity or forgoing work (Public Health Agency of Canada, 2000). Employment costs for two of the most prevalent diagnostic categories in Canada – arthritis and mental health – are estimated to each be about \$4.4 billion per year making the indirect costs of these conditions 2-4 times greater than their direct health care costs (Caveen *et al.*, 2007; Clarke *et al.*, 1997; Dewa *et al.*, 2004; Government of Canada, 2006; Li *et al.*, 2006; Public Health Agency of Canada, 2010; Sanderson and Andrews, 2006; Stephens and Joubert, 2001; Yelin *et al.*, 2004).

The intermittent, uncertain and invisible nature of episodic disabilities creates unique challenges for implementing accommodations, workplace planning, and for communication and disclosure of episodic disabilities at work (Feuerstein *et al.*, 2010; Gignac *et al.*, 2008; Gignac *et al.*, 2015; Gignac *et al.*, 2012; Jetha *et al.*, 2015; Jetha *et al.*, 2014; Karpur *et al.*, 2014; Lindbohm and Viikari-Juntura, 2010; McDowell and Fossey, 2015; Mehnert, 2011; Stergiou-Kita *et al.*, 2016; Tremblay, 2011). Studies find that many individuals with episodic disabilities choose not to disclose health information or accommodation needs or they delay disclosing until workplace problems are consistent and severe (Bishop and Allen, 2001; Fesko, 2001; Gignac and Cao, 2009; Gignac *et al.*, 2011; Greene, 2000; MacDonald-Wilson, 2005; Munir *et al.*, 2005; Munir *et al.*, 2007; Vickers, 1997). This can mean that accommodation needs are not addressed or that individuals give up employment temporarily or permanently. The invisibility of many

episodic disabilities can also result in misperceptions or stigma about a worker's abilities or motivation. Even when a worker discloses an episodic disability, supervisors may be unsure how to initiate conversations about worker performance and accommodations or be concerned about doing more harm than good (Brouwers *et al.*, 2020; Gignac *et al.*, 2012; Gignac *et al.*, 2020; Norstedt, 2019; Toth and Dewa, 2014).

To address these issues, organizations, especially those representing individuals living with various chronic conditions causing episodic disabilities, have produced resources such as pamphlets, guide-books, videos, tools, and/or training that are directed towards supporting the employment of people living with chronic, episodic health conditions. They are often freely available, found online, and include resources for mental health conditions, cancer, arthritis, MS and HIV/AIDS. They represent substantial investments of time and money, particularly by governments and non-profit organizations. But while these resources continue to proliferate, we know little about the types of resources available across episodic disabilities, which workplace audience was targeted, the content, or level of interactivity employed.

Our objective was to conduct an environmental scan (ES) to identify and describe existing, publicly available English-language resources that focused on working with an episodic disability and that provided information and advice about accommodation and communication about support needs for a person working with an episodic disability. We sought to investigate: 1) the characteristics of resources (e.g., health condition(s) and audiences addressed); 2) the content of the resources (e.g., information about accommodation and communication); and 3) whether resources offered interactive content that allowed a user to engage with or personalise the information provided. An ES is an appropriate method to identify and describe these types of resources as it is a method typically used in business contexts for needs assessment and

collecting program development data. Environmental scans have recently been used in public health contexts (Rowel *et al.*, 2005; Wilburn *et al.*, 2016), healthcare quality improvement (Sibbald *et al.*, 2013) and for patient decision-making resources to aid in healthcare (Mahmoodi *et al.*, 2018).

## **Methods**

Our methods for conducting the environmental scan (ES) were consistent with ES methods conducted for similar purposes and described in the literature (Fajardo *et al.*, 2019; Mahmoodi *et al.*, 2018; Wilburn *et al.*, 2016).

### *Resource selection criteria and internet search strategy*

Our selection criteria for the environmental scan were English language, freely available, online resources relevant to communication and accommodation of episodic disabilities in the workplace. We considered resources that could be used by various workplace audiences such as people living with an episodic disability or who provided support in a workplace to someone living with an episodic disability (e.g., supervisors, managers, human resource professionals, disability managers, union representatives, co-workers). Resources were excluded if they were about privacy and accommodation legislation or high-level policies (e.g., duty to accommodate laws, disability standards, implementation of strategic plans); were media stories (e.g., newspaper articles, social media comments, blog posts); academic articles and reports on research findings; and were not aimed at workplaces (e.g., targeted health professional awareness).

Our methods to find relevant resources were built upon systematic searching methods for scoping reviews (Arksey and O'Malley, 2005; Colquhoun *et al.*, 2014; Tricco *et al.*, 2016) and grey literature searching (Farkas *et al.*, 2015; Mahood *et al.*, 2014). We conducted a series of

structured key-word searches using Google between November 2016 and January 2017. One set of searches combined terms about episodic disabilities with terms referring to both workplace audiences and communication. A second set of searches combined terms for ‘disclose’ or ‘reveal’ with workplace terms and terms for specific chronic conditions that can cause episodic disability (See Appendix 1 for examples of the search terms). In all searches, if websites provided links to other potentially relevant websites, the new sites were added to our search yield.

The first 100 links resulting from each of 53 searches (considering all terms and synonyms) were scanned for potential relevancy by an information specialist at the Institute for Work & Health. If the resources did not meet inclusion and exclusion criteria (e.g., excluding conditions such as learning disabilities which are longstanding and not prone to interruption by variable periods of limitation), they were excluded in this initial screen; duplicates were also removed at this point. As this scan is part of a larger partnership grant to develop new tools and resources related to communication and accommodation where gaps exist, we also engaged with our partners and other experts broadly involved in episodic disability (including representatives from diverse health charities, human resource professionals and disability managers) and asked them to identify known relevant resources and/or organizations which may produce these types of resources. Resources identified by our partners and other experts were included in the scan. All links/sites identified as potentially relevant from the Google searches and/or by partners and experts were screened for relevance by one of the authors (JB) by exploring the websites in detail to determine if inclusion and exclusion criteria were met (see Figure 1 for details).

Resources were catalogued by country of origin and organization. Resources were also grouped where appropriate. For example, a video with a companion booklet were considered a



single resource. Resources that were distinct, that is they had no apparent connection even if they were from the same organization, were kept separate.

### *Data charting*

The research team created a data charting form to meet study objectives and capture details about the content presented in the resources. The form captured what episodic health condition(s) was addressed, the intended audience(s), and the format(s) or medium(s) of the resource. It also contained sections for the reviewers to chart details about resource content in five areas: health issues, legal rights, workplace issues, workplace accommodation and communication about accommodation needs, including disclosure. Information about interactive aspects of the resource was also charted. This included whether the resource provided the user an opportunity to engage with or personalise the information provided (e.g. a workbook or online course) or consisted of a one-way flow of information (e.g. a webpage, podcast or video).

For this ES, we were interested in content related to communication about limitations with job tasks and whether any accommodations might be helpful, including content not only for workers with a disability but also for supervisors, managers, HR or other workplace parties who may need to initiate this conversation. The details extracted from content for all workplace parties included whether the resource contained advice about who should be involved, when discussions should take place, where and how to start a conversation, what to say and what not to say. For content aimed at workers with an episodic disability, we also extracted details on advice about disclosure, including information about whether the resource presented a view in favour of disclosure, was against disclosure, did not take a particular perspective, or emphasized individual circumstances and choice related to sharing personal health information. We charted whether the resource offered information regarding the pros and cons of disclosure, suggestions about whom

to speak with, how much to disclose, and information about whether to revisit disclosure at later date. The review team also noted whether tools to aid communication were provided and whether the advice and/or tools were aimed at a one-time conversation or addressed the need to follow-up at a later date.

In the final section of the charting form, reviewers were asked to provide their assessment or judgement about whether the resource was: useful; concrete / applied; engaging; interactive. Reviewers were also asked to judge the resources on: usability; production quality; fit with current evidence; and overall quality. Reviewers were asked to make their best judgements based on the data charting for each resource relative to others and on a team discussion about each of these areas.

A team of reviewers (n=9) completed the data charting. The team included researchers, graduate students, and project coordinators with research experience in episodic disabilities. An initial pilot was conducted on two resources using the data charting form developed by the authors. Reviewers met as a team to discuss and refine the form and the instructions for charting, including coming to consensus on the operational definitions on the form items. Resources were each reviewed by a single reviewer to chart the data; one reviewer (JB) checked all charting forms. This check ensured that one of the team had a view of all resources and ensured that the charting forms were complete.

## **Results**

Google searches yielded 5300 links to websites. Partners and experts provided another 32 links and an additional 69 links were found in the websites identified by the Google search or partners/experts. The initial screening identified 453 potentially relevant links/websites; the second more in-depth screening found a total of 189 links/websites containing 210 resources

produced by 149 organizations which were included in the data charting (see Figure 1). The largest number of resources were from Canada (33.8%), the United States of America (27.1%), and the United Kingdom (20.5%). The remaining resources were from Australia (10%), Ireland (4.3%), New Zealand (1.9%) or other jurisdictions (1.9%).

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Figure 1

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*Conditions addressed:*

Of the 210 resources identified and included in our scan, the majority (75.3%) addressed a chronic condition or family of conditions causing episodic disabilities. The largest group addressed mental health conditions (28.1%) followed by HIV/AIDS or Hepatitis B/C, epilepsy and cancer. Only a small number (2.4%) addressed the broader category of “episodic disabilities” (see Table 1). A further 48 resources (22.9%) addressed disability in general and 4 resources (1.9%) focused on “invisible” or “hidden” disabilities. As these would include most episodic disabilities, they were included in the scan.

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Table 1

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*Target audiences:*

The resources most commonly targeted employees with episodic or other disabilities. Approximately 70% of all resources either entirely or in part addressed a worker with a disability (see Table 1). Although fewer resources targeted supervisors/managers, HR, disability managers or co-workers to support interactions with a worker with a disability, there were approximately

50% of resources with some material appropriate for supervisors handling employee issues, and approximately 20% of resources contained some material relevant for co-workers. Target audiences did not differ a great deal across conditions.

*Format/Medium:*

All resources were obtained from online sources. Over half had components which were optimized for offline usage such as pdf books and pamphlets. In addition, about 15% consisted of dedicated websites, linking webpages and other documents to form one coherent resource. The format/medium did not differ greatly across conditions or audiences.

*Resource Content:*

As our objective was to describe resources for episodic disabilities, the following results are focused on the 158 resources that addressed chronic conditions causing episodic disability, as well as the resources that discussed episodic disabilities more generally (see Table 1).

*Health issues content:* Just under half of the resources for episodic disabilities mentioned common symptoms or activity limitations (48.7%) related to a health condition or provided basic condition/disease information (46.8%). There was some variability across chronic conditions with more than half of resources related to mental health conditions and about a third or less of cancer and MS resources providing disease or symptom information.

*Legal information content:* A majority of resources had some information about discrimination or human rights (72.8%) and accommodation rights (71.5%). Many resources provided information about privacy legislation related to disclosing health information (48.7%), but fewer (29.1%) described health & safety regulations. There was some variability across conditions regarding legal information with more resources specific to HIV/Hepatitis, epilepsy, multiple sclerosis and cancer covering discrimination/human rights and accommodation rights

than others. A majority of HIV/Hepatitis resources had information about privacy legislation whereas less than half of the resources for other conditions provided this information. Of note is that a majority of epilepsy resources described health and safety regulations while a third or less of the resources for other conditions did so.

*Workplace and work-life balance content:* A majority of resources (72.2%) provided information or examples of ways to provide workplace support to individuals living with episodic disabilities with little variation across chronic conditions. Supports described in resources included being empathic, emotionally supportive and providing help or assistance. Just over half of the resources (58.2%) described potential performance issues (e.g. absenteeism or difficulty with job activities) that may be linked to chronic conditions and episodic disability. Fewer than half (44.9%) discussed the timing of support and accommodation conversations (e.g. proactive or reactive). In addition, about 35.4% of resources mentioned broader work-life issues (such as balancing the demands of work, health and one's personal life).

*Accommodation content:* Nearly three quarters of resources (72.8%) gave examples of types of workplace accommodations possible for episodic disabilities such as flexible hours, work from home options, assistive devices or ergonomic workstations (see Table 2). Resources varied in whether examples were linked to specific limitations. For example, nearly half of the resources (46.2%) noted accommodations that may be useful for specific limitations, but this varied across condition with about a third of mental health resources (32.2%) providing accommodation examples to 80.0% of multiple sclerosis resources that provided example accommodations. In general, fewer than a quarter of resources discussed the need to monitor needs over time (24.7%) or safety issues at work (22.2%) with a considerable range across health conditions. Only 8.2% of resources had sample accommodation plans.

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Table 2

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*Communication and disclosure content*

Over half of the resources provided advice on who should be involved in a communication about accommodations (58.9%), when the communication should take place (54.4%) and what should be discussed during these communications (51.9%) (see Table 3). About a third of the resources provided information or tips about ways to start a conversation about accommodation needs (36.1%) and what should not be discussed (33.5%) (e.g., jurisdictional requirements regarding need to disclose a specific diagnosis). Just under a quarter (23.4%) of the resources provided a specific tool (such as a decision aid (8.9%) example script (8.2%), or template (7.6%)) to help workers. About a third of the resources (30.4%) mentioned that more than one conversation about an episodic disability at work might be necessary. A small number of resources (4.4%) described multiple communication opportunities including: disclosure at different phases (e.g., job search, interview, following job commencement), keeping in touch when off work, conversations about leaving work issues, or continuous communication. About a quarter of the resources indicated where the conversation should take place (24.1%) (e.g., in a comfortable, yet private area). The findings about communication did not differ greatly across health conditions.

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Table 3

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Within the content that was aimed specifically towards workers with an episodic disability, about half of the resources provided information about the advantages and disadvantages of disclosure

(49.4%); advantages included access to supports or accommodations, increased awareness of the condition, or being proactive to avoid crises, while disadvantages listed included concerns about personal privacy, negative job ramifications (e.g., forgoing a promotion), or gossip by others. A similar number of resources provided advice on who an employee could disclose to (46.8%), and how much to disclose (43%). Very few resources provided information about revisiting disclosure (7%) or addressed issues about past experiences with disclosure (8.9%) (see Table 4).

Although communication trends were largely similar across resources for specific conditions, there was variability. For example, 30-40% of mental health resources discussed different aspects of disclosure compared to 65-70% of epilepsy resources and 50-60% of resources devoted to HIV-hepatitis, cancer, and MS.

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Table 4

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Overall, two-thirds of the resources (61.4%) had what we termed a ‘balanced approach’ to disclosure, stressing that it was a personal decision and providing no specific recommendation for or against disclosure. A small percentage of resources (9.5%) recommended disclosure of a health condition; these resources included resources aimed at mental health conditions, arthritis, epilepsy, and cancer. More than a quarter of HIV/hepatitis resources (26.1%) advised against disclosing health information, as did 3.4% of mental health resources; none of the resources for other episodic conditions advised against sharing health information.

#### *Interactive content*

We also examined whether the resources had any interactive features to engage users and increase the potential to apply the information presented. Most resources did not provide any

interactive or personalisable content (82.9%). Very few resources provided decision aids or self-assessment tools to assist users with the decision whether or not to disclose (3.2%), how much to disclose (1.9%), and to whom to disclose (1.9%) any personal health information or its impact on work. A few more resources provided interactive accommodation planning resources regarding the specific nature of job (7.6%), current job difficulties (5.7%), or potential accommodations for specific limitations (5.7%). We also found that a small number of resources (3.8%) provided interactive training or practice exercises (e.g. through scenarios about issues of communication or accommodation) to employees with disabilities (2.5%), supervisors/managers (1.9%) or others in the workplace (0.6%).

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Table 5

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*Overall reviewer quality assessment ratings:*

Finally, reviewers were asked to rate various attributes of the resources they reviewed. The overall quality assessment across all resources was 6.1 (out of 10). In general, the reviewers rated the resources as adequate in their usefulness (6.7), in being concrete and applicable (6.1), and in their fit with current evidence (6.4). However, the resources were typically not judged to be particularly engaging (4.9 out of 10) or interactive (2.4 of 10). The scores for the resources were reasonably consistent across reviewers with standard deviations between 1.6 and 2.2. We did not calculate a kappa as resources were not reviewed by two reviewers.

**Discussion**

We conducted an environmental scan of publicly available English-language resources aimed at helping individuals living with episodic disabilities navigate working with a health condition.



Our aim was to examine the conditions described, the workplace audiences targeted, the content of resources (particularly related to communication and accommodation) and the level of interactivity. As online searches are increasingly common as a way that the public seeks health and employment advice, it is important to better understand the availability of resources and the content and quality of information they contain. One of the benefits of this study is that it synthesizes information to help people living with chronic health conditions, workplaces, health professionals and other groups to understand the availability and potential applicability of large amounts of information without having to search for that information on their own. Our findings yielded 158 publicly available resources to help workers with episodic disabilities and/or other workplace parties address issues related to communication and support. However, comprehensive information specific to the episodic nature of disability related to various health conditions was not consistently available. The resources we found generally lacked interactivity which could potentially limit users in applying the information to their circumstances. Research should aim to improve the interactivity of information to personalize resources to worker and workplace needs, as well as formally evaluate resources and their outcomes.

Most of the resources were targeted toward specific health conditions, which would make it relatively easy for individuals living with those conditions to start to find information. However, there are also disadvantages to condition-specific resources. While content may be applicable across diverse health conditions, it is unlikely that individuals with a particular health condition (e.g., diabetes) would search for information related to other health conditions (e.g., cancer). Condition-specific resources also have privacy implications if a worker wishes to share any of the resources with someone else in the workplace as this would disclose their diagnosis. Employers also express a preference for non-condition specific resources that may be more

widely applicable among their employees regardless of diagnosis (Gignac *et al.*, 2020). Going forward, it would be helpful if work-related information could be targeted more broadly and if researchers, employers, and the public developed a shared lexicon as a means of sharing information relevant to multiple episodic disabilities.

In addition to information aimed at workers with a disability, many resources also provided information for supervisors/managers and other workplace parties who may need to support a worker with an episodic disability. Workers and supervisors/managers are important audiences and likely to have questions about disability and/or accommodation and work (Brouwers *et al.*, 2020; Jetha *et al.*, 2019; Karpur *et al.*, 2014; Norstedt, 2019). However, it is not clear whether individuals within a workplace who provide support and accommodation are aware of these resources. Additional research is needed to better understand how to reach workplace audiences and increase uptake of information to support employees with episodic disabilities.

The resources we found often provided useful content including disease and symptom information to build awareness, suggestions for seeking treatment and management of health, accommodations, and legal and legislative information. At the same time, resource developers need to be cautious about including treatment or legislative information as this information can change over time or it may not be relevant to individuals living in different regions or countries. Importantly, very few resources included in this scan included information about when the resource or content had been created or last updated. In cases when information was available, some resources were several years old.

A majority of resources provided accommodation examples, but many resources did not link these accommodations to specific job limitations. Advice about monitoring changes in needs over time, safety issues, and evidence evaluating the success of accommodations was not

provided in most resources. Specific information and guidance about what types of supports, self-management and accommodations are important and often sought by employees as well as supervisors/managers (Gignac *et al.*, 2015; Gignac *et al.*, 2018; Gignac *et al.*, 2020; Hielscher and Waghorn, 2015; Jetha *et al.*, 2019; Von Schrader *et al.*, 2014). To be more practical and relevant to the needs of workers and organizations, resources should improve the breadth and applicability of example accommodations they provide. An additional challenge for those with episodic disabilities is that only 35% of the resources in our scan described the episodic nature of the conditions. The intermittent and recurring nature of many health conditions is relevant to how workplaces manage and support employees with these conditions (Gignac *et al.*, 2012; Gignac *et al.*, 2020; Karpur *et al.*, 2014; Lindbohm and Viikari-Juntura, 2010; McDowell and Fossey, 2015). In particular, advice about accommodations and accommodation planning for workers with episodic disabilities needs to take into account that accommodation needs can change over time.

Disclosure and communication about episodic disabilities and work was acknowledged in the resources as being a sensitive and challenging issue for all concerned, as highlighted in research (Brouwers *et al.*, 2020; Gignac *et al.*, 2012; Norstedt, 2019; Toth and Dewa, 2014). Many resources provided content related to communication and disclosure, including information about potential advantages and disadvantages to communicating personal health information at work (Jones and King, 2014). Yet, despite the importance and challenges of disclosure, very few resources provided tools like decision aids to help their target audience negotiate the sensitivity and challenges they face. Given the potential for stigma and uncertainty surrounding disclosure, the low number of resources providing tools is a concern. Research in this area show that workers often delay communication and seeking support until problems are

severe (Gignac and Cao, 2009; Karpur *et al.*, 2014; Williams *et al.*, 2006). This may make providing support more challenging. Recent research suggests that proactive use of accommodations may be more helpful than delaying accommodation use until there is a problem (Gignac *et al.*, 2018).

There also were few resources that had interactive content or ways to tailor the content to individual needs. Although many resources were available in different formats to make them more user friendly, they rarely provided opportunities to interact with or individualize the information provided. Elements that engage the audience enhance learning and retention and are more relevant to users (Kirkpatrick, 1996; Kulik and Kulik, 1991; Parker *et al.*, 2018; Wong *et al.*, 2010). Future resource development should strive to include interactive elements to increase engagement. Research needs to monitor uptake in resources when they are more passive versus active (Kirkpatrick, 1996; Wong *et al.*, 2010) and evaluate their usefulness in terms of work outcomes like satisfaction, absenteeism and productivity.

Finally, the reviewers subjectively rated the quality of all the resources. They considered the usefulness of the resource, how engaging it was, the degree of interactivity and whether it contained specific and concrete information, was relevant to user needs, and fit with current evidence. Overall, reviewers rated the average quality of the resources as moderate (6.1 on a 10-point scale ranging from low to high). In particular, the resources did not rate well on engagement and interactivity. In addition, it was often challenging for the reviewers to determine if the content of a resources was evidence-based. Because the research team may have different perceptions than users living with a chronic episodic health condition, additional research needs to be conducted from the perspective of potential users assessing what their needs are in a

resource, what type of content they would find most useful, and what ways they would find information most engaging to meet their needs.

This research has some limitations that should be acknowledged. We tried to adopt a search strategy that would most closely match that used by the general public and used Google searches. Despite conducting the searches from the same computer to minimize different search results based on history, it is possible that we missed some resources using this search method. We also included only English language resources. Future studies need to include resources in other languages. We limited our scan to those resources that were publicly available and omitted proprietary resources that required memberships or other payments to access. This may mean that higher quality content and more interactive tools like decision aids exist. However, we believe that many individuals with chronic episodic health conditions frequently seek freely available resources and may not look for other sources of information. Future research needs to explore resources that are available from disability management companies, health and human resource professional associations, or other groups and compare them to publicly available resources.

Despite some limitations, our environmental scan methods were guided by a systematic approach based on scoping review methods. A key strength to this research was the use of a comprehensive search strategy, guided by an information specialist with experience in grey literature searches. We also searched for a variety of health conditions that result in episodic disabilities and our data charting incorporated a standardized form. Our findings highlight that there are a number of good resources that are freely available to help workers and managers/supervisors navigate accommodations for episodic disabilities. Although room for

improvement exists, many resources acknowledge the complexity of living and working with an episodic health condition and aim to ensure breadth and depth to the information they provide.

Our findings show there are a number of resources available that are relevant for workers with episodic disabilities, therefore there are implications for practitioner and researchers. Health and occupational health practitioners may wish to suggest such resources for those with chronic episodic conditions to aid in return to work or stay at work. Our findings suggest that it would be helpful to recommend resources not solely based on health condition but also to consider resources that more specifically address the workplace challenges their clients might be experiencing and to tap the resources of a range of conditions. Most resources were not difficult to find using basic internet searches (i.e. Google), and although practitioners have limited time available, reviewing and suggesting a few different resources could provide meaningful assistance to those with episodic disabilities. Studies, such as this one, are also helpful as they can provide practitioners with a high-level synthesis and evaluation of information available.

There are also implications of this study for additional research. We identified areas for improvement of resources to better address the needs of workers with episodic disabilities. We noted that new research is needed to go beyond a single condition and to target multiple episodic disabilities, that dissemination needs to be improved, that accommodations need to be linked to specific job demands, and that there needs to be interactive tools and resources that are personalized to a person's health and work demands. Studies evaluating resources also need to be conducted. There is a need for accommodations to be flexible and adaptable over time, and research conducted to guide how accommodation policies and practices could be best implemented in order to maximize their value. To do this, there is a need for developers to engaged or partner with researchers in the development process. In addition, future research on

interactivity to better understand how to engage individuals when they use these resources would be valuable. Principles from adult education and design (Kirkpatrick, 1996; Wong *et al.*, 2010) apply here along with research to improve current resources.

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Figure 1. Search and review results

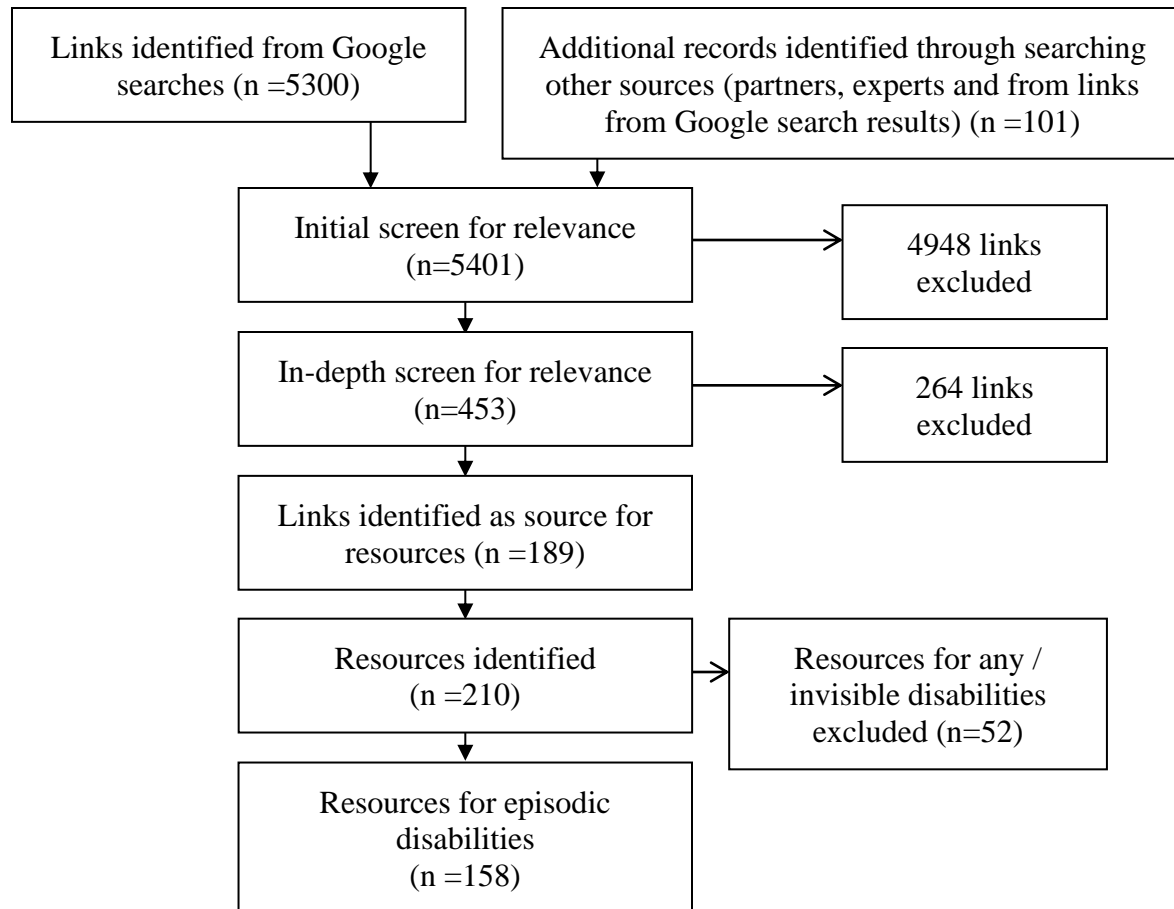




Table 1: Conditions, audience and format/medium of identified resources

<u>Characteristics</u>	<u>Categories</u>	<u>Number</u>	<u>Percentage</u>	
<i>Conditions Addressed</i>	<i>Resources for Episodic Disabilities</i>			
		Mental Health conditions	59	28.1%
		HIV/AIDS or Hepatitis B/C	23	11.0%
		Epilepsy	17	8.1%
		Cancer	16	7.6%
		Multiple Sclerosis	15	7.1%
		Arthritis and related conditions	10	4.8%
		Crohn's & colitis	4	1.9%
		Parkinson's Disease	4	1.9%
		Diabetes	3	1.4%
		Migraine	2	1.0%
		“Episodic” disabilities	5	2.4%
		<i>General resources (not specific to episodic conditions)</i>		
	Any disability or health condition	48	22.9%	
	“Invisible” or “Hidden” disabilities	4	1.9%	
<i>Audience(s) Addressed<sup>1</sup></i>		Employee(s) with a disability	145	69.0%
		Employers, managers and/or supervisors	107	51.0%
		Human resources and/or disability management professionals	35	16.7%
		Co-workers of a person with a disability	20	9.5%
		Other audiences (e.g. students, job seekers, service providers)	13	6.2%
		Audience unclear	1	0.5%
	<i>Format/Medium<sup>1</sup></i>	<i>Primary use offline</i>		
		Book or pamphlet	125	59.5%
		Workbook or Worksheet (something to fill out)	22	10.5%
		Template (something to copy and personalize)	11	5.2%

Online Resources Supporting Workers with Episodic Disabilities – Figure and Tables

<u>Characteristics</u>	<u>Categories</u>	<u>Number</u>	<u>Percentage</u>
	Other (e.g. slides, questionnaires, infographics)	3	1.4%
	Intended to be edited, then printed (e.g. a fillable PDF)	4	1.9%
	<i>Primary use online</i>		
	Single webpage (one page, part of a larger website)	69	32.9%
	Dedicated Website (several webpages interlinked, forming one coherent resource)	32	15.2%
	Video (non-interactive, e.g. videos)	26	12.4%
	Interactive (online training or exercises requiring input, decision aids, etc.)	8	3.8%
	Podcast or Webinar	3	1.4%

<sup>1</sup> Coding is not exclusive; resources could address more than one audience or use more than one format or medium

Table 2: Accommodation content by condition (percentages)

	<b>All Episodic (n=158)</b>	<i>Mental Health</i> (n=59)	<i>HIV- Hepatitis</i> (n=23)	<i>Epilepsy</i> (n=17)	<i>Cancer</i> (n=16)	<i>Multiple Sclerosis</i> (n=15)	<i>Arthritis &amp;c.</i> (n=10)	<i>"Episodic"</i> (n=5)	<i>Other</i> (n=13)
<i>Examples given</i>	<b>72.8%</b>	66.1%	65.2%	70.6%	75.0%	86.7%	80.0%	100.0%	84.6%
<i>Examples linked to specific limitations</i>	<b>46.2%</b>	32.2%	43.5%	58.8%	50.0%	80.0%	50.0%	60.0%	46.2%
<i>Monitoring needs over time</i>	<b>24.7%</b>	28.8%	8.7%	29.4%	12.5%	40.0%	30.0%	20.0%	23.1%
<i>Safety issues addressed</i>	<b>22.2%</b>	10.2%	30.4%	58.8%	25.0%	33.3%	10.0%	-	15.4%
<i>Evaluating success</i>	<b>13.9%</b>	18.6%	8.7%	11.8%	12.5%	13.3%	10.0%	20.0%	7.7%
<i>Sample accommodation plan(s)<sup>1</sup></i>	<b>8.2%</b>	13.6%	-	5.9%	12.5%	-	-	20.0%	7.7%

<sup>1</sup>(i.e. something that can be adapted to make your own plan, rather than just examples)

Table 3: Communication advice by condition (percentages)

	<i>All Episodic (n=158)</i>	<i>Mental Health (n=59)</i>	<i>HIV- Hepatitis (n=23)</i>	<i>Epilepsy (n=17)</i>	<i>Cancer (n=16)</i>	<i>Multiple Sclerosis (n=15)</i>	<i>Arthritis &amp;c. (n=10)</i>	<i>"Episodic" (n=5)</i>	<i>Other (n=13)</i>
<i>Who should be involved in the conversation?</i>	<b>58.9%</b>	54.2%	65.2%	64.7%	62.5%	73.3%	50.0%	40.0%	53.8%
<i>When should you speak?</i>	<b>54.4%</b>	54.2%	47.8%	76.5%	62.5%	53.3%	30.0%	40.0%	53.8%
<i>What should be said?</i>	<b>51.9%</b>	61.0%	47.8%	52.9%	56.3%	60.0%	40.0%	20.0%	23.1%
<i>How should you start the conversation?</i>	<b>36.1%</b>	47.5%	21.7%	41.2%	31.3%	53.3%	20.0%	20.0%	7.7%
<i>What should NOT be said<sup>1</sup></i>	<b>33.5%</b>	39.0%	43.5%	29.4%	37.5%	33.3%	10.0%	-	23.1%
<i>Where should you speak?</i>	<b>24.1%</b>	28.8%	21.7%	23.5%	37.5%	26.7%	-	20.0%	7.7%

<sup>1</sup>(e.g. what should not be asked, or told to other employees, etc.)

Table 4: Disclosure advice for employees with a disability by condition

	<b>All Episodic (n=158)</b>	<i>Mental Health (n=59)</i>	<i>HIV- Hepatitis (n=23)</i>	<i>Epilepsy (n=17)</i>	<i>Cancer (n=16)</i>	<i>Multiple Sclerosis (n=15)</i>	<i>Arthritis &amp;c. (n=10)</i>	<i>"Episodic" (n=5)</i>	<i>Other (n=13)</i>
<i>Pros &amp; cons of disclosure</i>	<b>49.4%</b>	40.7%	52.2%	70.6%	50.0%	60.0%	50.0%	20.0%	53.8%
<i>Whom to disclose to</i>	<b>46.8%</b>	28.8%	60.9%	70.6%	75.0%	46.7%	60.0%	-	46.2%
<i>How much to disclose</i>	<b>43.0%</b>	30.5%	60.9%	64.7%	50.0%	53.3%	20.0%	20.0%	46.2%
<i>Addresses past experiences (negative or positive)</i>	<b>8.9%</b>	6.8%	13.0%	5.9%	12.5%	13.3%	10.0%	-	7.7%
<i>Revisiting disclosure at a later date</i>	<b>7.0%</b>	3.4%	4.3%	5.9%	18.8%	13.3%	10.0%	20.0%	-
<i>Other</i>	<b>10.8%</b>	6.8%	13.0%	5.9%	37.5%	6.7%	10.0%	-	7.7%

Table 5: Interactive content by condition (percentages)

	<b>All Episodic (n=158)</b>	<i>Mental Health (n=59)</i>	<i>HIV- Hepatitis (n=23)</i>	<i>Epilepsy (n=17)</i>	<i>Cancer (n=16)</i>	<i>Multiple Sclerosis (n=15)</i>	<i>Arthritis &amp;c. (n=10)</i>	<i>"Episodic" (n=5)</i>	<i>Other (n=13)</i>
<i>No interactive content</i>	<b>82.9%</b>	74.6%	95.7%	94.1%	75.0%	73.3%	90.0%	100.0%	92.3%
<i>Interactive decision aid addressing</i>									
<i>whether to disclose or not</i>	<b>3.2%</b>	3.4%	-	-	6.3%	13.3%	-	-	-
<i>how much to disclose</i>	<b>1.9%</b>	1.7%	-	-	-	13.3%	-	-	-
<i>whom to disclose to</i>	<b>1.9%</b>	3.4%	-	-	-	6.7%	-	-	-
<i>Interactive accommodation planning addressing</i>									
<i>specific nature of job</i>	<b>7.6%</b>	6.8%	-	5.9%	25.0%	13.3%	-	-	7.7%
<i>current job difficulties</i>	<b>5.7%</b>	5.1%	-	-	18.8%	13.3%	-	-	7.7%
<i>potential accommodations for specific limitations</i>	<b>5.7%</b>	6.8%	-	5.9%	12.5%	6.7%	-	-	7.7%
<i>other:</i>	<b>4.4%</b>	5.1%	-	-	6.3%	13.3%	-	-	7.7%
<i>Interactive training aimed at:</i>									
<i>employee with a disability</i>	2.5%	3.4%	-	-	12.5%	-	-	-	-
<i>supervisor</i>	1.9%	3.4%	-	5.9%	-	-	-	-	-
<i>other(s):</i>	0.6%	1.7%	-	-	-	-	-	-	-