

The impact of the episodic nature of chronic illness: A comparison of fibromyalgia, multiple sclerosis and human immunodeficiency virus

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ABSTRACT

The purpose of this narrative review was to describe and compare the characteristics and episodic nature of disability among three chronic illnesses: multiple sclerosis (MS), HIV and fibromyalgia (FM). Searches were performed in electronic databases using a combination of keywords including episodic, relapse, remission, and fluctuation. We included articles published between 2004–2014 that described health challenges and the episodic nature of the illness. Data were extracted from selected articles, including the authors, date of publication, study population, the aims of the study, outcome measures and main study findings, and then were charted and collated to the dimensions of disability in the episodic disability framework. The descriptive words

about symptoms/impairments, difficulty in day to day functioning, challenges to social inclusion and uncertainty were compared across illnesses to identify similarities and differences. We reported findings as a narrative summation. Forty-seven articles were included in this review. The comparison of the three chronic illnesses demonstrated that some of the symptoms/impairments such as pain, fatigue, sleep disturbance, depression, stress, and anxiety were reported commonly across illnesses. Similarly, difficulty with day to day functioning, challenges to social inclusion and uncertainty were reported across illnesses. On the other hand, factors influencing the symptoms, difficulties in daily functioning, challenges to social inclusion and uncertainty were found to be different. The episodic nature of the illness was identified among the three chronic conditions. People living with FM or MS or HIV, experience some common dimensions of disability that may be similarly experienced as episodic in nature. These similarities may not be exclusive to these three chronic illnesses, but could apply to individuals living with other chronic and episodic illnesses. Pursuing ways to enhance rehabilitation services among the conditions that experience similar episodic disability may help collectively to address disability and improve the overall health of people living with chronic illnesses.

Keywords: Chronic illness, Episodic disability, Fibromyalgia, Multiple Sclerosis, Rehabilitation

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INTRODUCTION

Episodic disability is defined as the health-related consequences of living with an illness characterized by fluctuating periods of good and ill health [1]. Episodic disability may be experienced by people living with multiple sclerosis (MS), chronic fatigue syndrome, fibromyalgia (FM), lupus, epilepsy, arthritis, diabetes, human immunodeficiency virus (HIV), and some mental health conditions [2]. These fluctuating periods of illness and wellness can affect a person’s health, employment stability, and quality of life [2].

Although evidence on episodic disability is evolving in Canada, to our knowledge no statistics exist on the exact number of people living with episodic illnesses [3]. However, the number of people living with chronic illnesses that may be episodic in nature is increasing. For example, in Canada, an estimated 63,000 individuals are living with HIV [3], 55,000–75,000 living with multiple sclerosis [4] and 900,000 affected by fibromyalgia [5]. Thus, it is important to understand the episodic nature of disability across chronic illnesses, so that rehabilitation services can be tailored to improve health-related quality of life. Rehabilitation can be defined as any service or health provider that may help to address the health-related challenges experienced by an individual [6].

Episodic disability has multiple dimensions affecting physical, mental, emotional and social life domains [7]. There are several frameworks that describe disability including the International Classification of Functioning, Disability, and Health (ICF) [8], but none were developed to address the episodic nature of disability [1]. The episodic disability framework (Figure 1) was derived from the experiences of individuals living with HIV [9]. It consists of three components – dimensions of disability (symptoms and/or impairments, difficulties carrying out day-to-day activities, challenges to social inclusion, and uncertainty), contextual factors (social support, stigma, living strategies and personal attributes) and triggers of disability [9]. The episodic disability framework conceptualizes disability as a consequence of HIV, its treatments and associated co-morbidities that may fluctuate over time. This framework not only portrays the episodic nature of disability, but also emphasizes the complex interaction between contextual factors which may exacerbate or alleviate different dimensions of disability over time [9]. Hence, the episodic disability framework is

an ideal framework to guide the consideration of episodic disability in the context of chronic illness (Figure 1).

Rehabilitation services including physiotherapy, occupational therapy, and speech-language pathology can assist adults living with episodic disability [10]. Fluctuations in health and the severity of episodic disability pose challenges to rehabilitation professionals in setting short-term and long-term treatment goals [11, 12]. Hence, it is important for rehabilitation professionals to understand the characteristics of episodic disability, because this will help to educate patients about the triggers of episodes, inform self-management techniques and assist in developing strategies for individuals to help deal with episodes of illness [6]. Rehabilitation professionals also need a thorough understanding of the complex changing needs of people living with episodic disability so that services can be tailored accordingly [6].

The nature of episodic disability can pose difficulty for individuals engaging in the workforce or school, which can make them dependent upon health and disability benefits [13, 14]. Since individuals living with episodic disability are not entirely well and not entirely unwell, they often find it difficult to access disability support programs [14]. A continuum of rehabilitation care can help to prevent the occurrence of episodes and help individuals living with episodic illnesses engage in work and improve their quality of life [6].

Recognition of the impact of the episodic nature of disability for people living with chronic illnesses is relatively recent. Several studies have reported the multiple dimensions of episodic disability experienced by people living with HIV [9, 10, 15–18]. However, episodic disability is not unique to HIV [11]. Chronic illnesses such as FM and MS are characterized by fluctuations in pain, fatigue and muscle weakness which can worsen activities of daily living and increase uncertainty or worrying about future health [19, 20]. This suggests that both FM and MS may demonstrate similarities in the nature and type of disability experienced over time. However, an absence of literature exists that comprehensively compares the characteristics of episodic disability across illnesses.

A comparison of the characteristics and understanding of the differences and similarities across chronic and episodic illnesses will help rehabilitation professionals



Figure 1: Dimensions of disability in the episodic disability framework.

[O’Brien KK, Bayoumi AM, Strike C, Young NL, Davis AM. Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Health Qual Life Outcomes*. 2008;6:76].

to understand the unique needs related to episodic disability and better provide patient-centred care [2, 11, 21]. Informing policy makers about the collective needs of people living with episodic disabilities may also help to make flexible policies [13, 14]. Hence, the purpose of this paper is: (1) to describe the characteristics of disability across three chronic illnesses (MS, HIV and FM) by mapping health-related challenges to the dimensions of the episodic disability framework (2) to understand the episodic nature of FM, MS, and HIV and (3) to describe the similarities and differences in episodic disability across the three illnesses.

METHODS

We conducted a narrative review to understand the episodic nature of illness in FM, MS, and HIV. A narrative review is a comprehensive synthesis of previously published information [22]. Specifically, we were interested in reviewing literature that described the health challenges and fluctuations (episodic nature) of the three chronic illnesses. We conducted a literature search of the following databases: PubMed, Google scholar, CINAHL and OVID to identify relevant data sources published between 2004 and 2014. No restrictions were made on the methodological quality of the studies. The search terms included: ‘fluctuation’, ‘relapse’, ‘remission’, ‘flare-ups’, ‘exacerbation’, ‘triggers’, ‘episodic disability’ AND multiple sclerosis; AND rehabilitation; AND HIV; AND fibromyalgia; episodic illness OR chronic illness OR multiple sclerosis; OR rehabilitation; OR HIV; OR fibromyalgia. The search was limited to publications that were written in English. One reviewer (SV) screened titles and abstracts of citations to confirm inclusion criteria outlined below.

Articles were included if authors described the health-related challenges (or disability) experienced among people with HIV, MS or FM and/or the potential fluctuation or episodic nature of any of these three chronic illnesses. All types of research methods were included. Studies of pharmacological interventions, surgical interventions and those conducted on animals were excluded. As this review was exploratory in nature and available literature was limited we did not consider the methodological quality of the studies.

Charting, collating and summarizing

We extracted data from each included article such as the authors, date of publication, the aims of the study, study population, outcome measures and main findings. The findings related to the documented health-related challenges of each chronic illness were mapped onto the dimensions of disability in the episodic disability framework. Once charted, the findings were collated to compare the similarities and differences as these related

to dimensions of disability and the episodic nature of disability across the illnesses. Descriptive words about the symptoms/impairments, difficulties in day to day activities, challenges to social inclusion and uncertainty across illness were used to identify the similarity and differences. The results were then reported as a narrative summation (Figure 2).

RESULTS

The literature search yielded 298 articles, of which 47 peer reviewed articles were included in the review. Among them, 13 articles were about FM, 17 articles were about MS, and 17 articles were about HIV. This section explains the characteristics of disability and episodic nature of each condition based on the dimensions of the episodic disability framework including symptoms/impairments, difficulty in day to day activities, challenges to social inclusion and uncertainty.

Symptoms /Impairments

For the purposes of mapping the study findings, symptoms/impairments were defined as physical, cognitive, mental or emotional health-related consequences of disease [1]. A summary of the data mapping is outlined in Table 1.

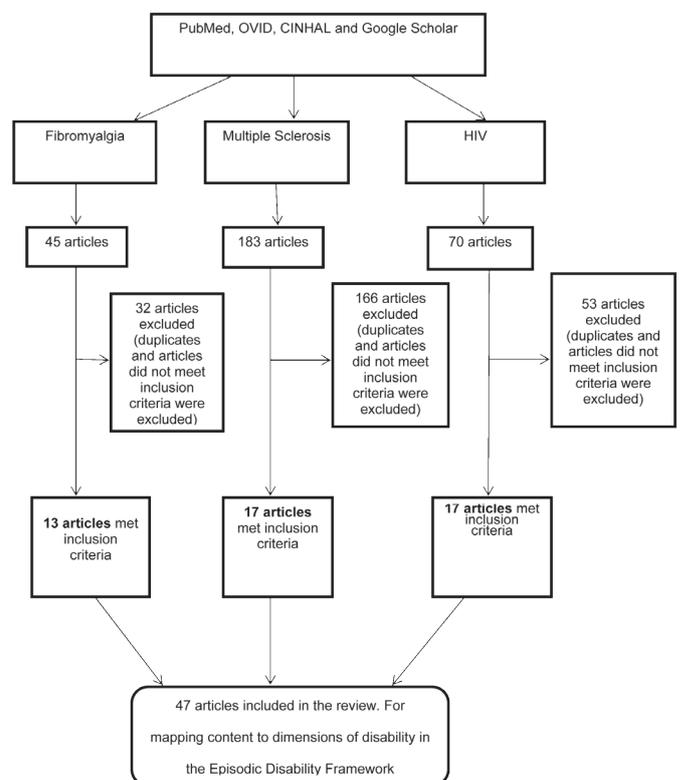


Figure 2: Flow diagram of search strategy and article inclusion.

Table 1: Mapping the symptoms across the chronic illnesses to dimensions of disability in the episodic disability framework

	Fibromyalgia	Multiple sclerosis	HIV
Major similarities	Pain:* Musculoskeletal [23, 24]	Pain:* Neuralgia [30]	Pain: *[41] Musculoskeletal Neuralgia
	Muscle weakness [23]	Muscle weakness* [39]	Muscle weakness *[41]
	Fatigue [23]	Fatigue * [34]	Fatigue *[41, 45]
	Sleep disturbance [24]	Sleep disturbance [34]	Sleep disturbance *[41]
	Depression [25–27]	Depression [34]	Depression *[41, 44]
	Stress [28]	Stress [34]	Stress *[41, 45]
Major similarities	Anxiety [28]	Anxiety [34]	Anxiety *[41]
	Cognitive problems: [23, 29] Working memory Verbal fluency Episodic memory Semantic memory	Cognitive problems:[36–38] Working memory New learning memory Episodic memory Information processing speed	Cognitive problems:*[42, 48–51] Working memory Verbal fluency Prospective memory Episodic memory Information processing speed
	Joint stiffness [24]	Spasticity [30]	Joint pain *[41]
	Migraine [26]	Bladder& bowel incontinence[39]	Lipodystrophy * [41]
	Tender points [24]	Muscle spasm [30]	Peripheral neuropathy* [41]
Differences	Decreased pain threshold [23]	Loss of balance [30]	Decreased muscle mass*[41]
			Other complications: [41] Side effects of medication:*
			Diarrhea Nausea Vomiting
			Premature onset of diseases:[41] Heart disease Obesity Metabolic disorders Stroke
			Multiple sclerosis Osteoporosis Osteoarthritis Inflammatory arthritis Cancer

(*Indicate symptoms which have been as fluctuating or episodic)

Fibromyalgia

Fibromyalgia (FM) can be characterized by the presence of widespread musculoskeletal pain [23], stiffness in joints and multiple tender points [24]. In addition to pain, individuals living with FM can experience fatigue and sleep disturbances [24]. A case study conducted with a woman living with FM for 10 years, noted that sleep disturbances were often due to chronic pain and a repetitive collapse of the pharynx during sleep [24]. Further, the study suggested that due to disturbed sleep, individuals may experience fatigue and daytime sleeping [24].

A narrative review suggested that presence of chronic pain, fatigue, poor sleep patterns, fear and anxiety predispose individuals with FM to depression [25]. Similarly, authors from two studies suggested that depression can also be associated with episodic migraines and increased body weight in FM [26, 27]. Factors such as physical or emotional stress also could aggravate symptoms [28]. Interestingly, authors of a review article on FM noted that the relationship between stress, anxiety, fatigue and depression may be due to the fact that the same central mechanism that drives pain, fatigue and sleep drives mood [25].

In addition to physical and emotional symptoms, studies have shown that individuals with FM can experience a decline in cognitive function and mental alertness [23]. More precisely, they can experience trouble with working memory (cognitive resource available in a given situation), episodic memory (ability to remember specific events) and verbal fluency (ability to access stored knowledge about words) [29]. Further, authors suggested that people living with FM can have difficulty with semantic memory (ability to remember facts and information that are not tied to specific events) [29].

In terms of the episodic nature of disability, fluctuations are primarily reported in physical symptoms. The intensity of pain was frequently identified as fluctuating over time and may be exacerbated by stress [20, 28]

Multiple sclerosis

Multiple sclerosis (MS) is a demyelinating disease of the central nervous system (CNS) in which physical and neurological functioning progressively deteriorates over time [30, 31]. Multiple sclerosis (MS) is characterized by patchy inflammation, gliosis, and demyelination within the CNS [30]. The most common type of MS is characterized by the relapse and remission of the neurological symptoms [32, 33]

A cross-sectional study with 101 participants with MS reported that individuals may experience acute and chronic pain [30]. Acute pain is due to the acute inflammatory process, whereas chronic pain is due to the progression of the disease, spasticity, neuralgia, poor musculoskeletal postures and gait abnormalities [30]. Though the underlying mechanism is unclear, pain associated with MS has been linked to damage of the pain pathways associated with the CNS lesion which causes increased neuronal activity in the spinal cord [30]. Authors also reported that pain often becomes an everyday occurrence in individuals which can affect their quality of life [30, 32]. In addition, headaches were found to be secondary to MS disease [30].

Depression is commonly reported in individuals living with MS [30]. Authors of a cross-sectional study demonstrated that pain was the major source of depression [30]. Depression, anxiety and remission status have been reported as predisposing factors of fatigue in MS [33, 34]. Authors of a case study also suggested that fatigue often is the only symptom of relapse in some individuals living with MS [33, 35].

Individuals living with MS can also experience cognitive impairments. For example, a case control study conducted with 51 individuals with MS and 68 healthy individuals demonstrated that those living with MS experienced greater cognitive impairment affecting new learning memory, working memory and information processing speed [36]. Compared to healthy individuals, new learning memory and processing speed are affected

to a greater extent than working memory [36]. Authors of a study conducted with 426 participants claimed that during the early stages of MS episodic memory is most frequently affected [37]. In a comparison of 24 individuals with MS to 24 healthy individuals, a strong association between dysarthria and cognitive linguistic deficit was revealed [38]. Further, authors of a case control study found that in the chronic progressive type of MS with dysarthria, episodic memory, and linguistic expressions also may be affected [38].

Finally, one review identified that sexual dysfunction in MS is due to the lesion affecting neural pathways involved in physiological function [39]. Sexual dysfunction in MS may also be a result of the side effects of medication, pain, muscle weakness, bladder and bowel incontinence, which further affects quality of life [39].

In terms of the episodic nature of disability, neurological symptoms are considered to be fluctuating in MS [40]. In addition, one qualitative study suggested that unexpected episodes of pain can affect the illness experience [32].

HIV

People living with HIV often report physical and mental health impairment which affects their activities and participation [41]. Due to the HIV infection and the side effects of the medication, people living with HIV often have fatigue, diarrhea, nausea, muscle weakness, decreased muscle mass, stress, depression, lipodystrophy, and peripheral neuropathy [42]. Authors of a cross-sectional study identified that individuals aging with HIV often have high prevalence of comorbidities such as diabetes, heart disease, obesity, metabolic disorders, stroke, osteoporosis, osteoarthritis, inflammatory arthritis and cancer [41]. Further, a focus group study reported that these comorbidities can lead to more symptoms and impairments [1].

Depression was commonly reported in individuals living with HIV [43]. This may be due to decreased immune function, accelerated HIV disease progression and non-adherence to HIV medication [43]. A randomized controlled trial (RCT) conducted with 249 HIV positive adults, in which 123 participants received specialized intervention for depression, and the 126 control participants received usual care, found that depression was more commonly reported in the control group [43]. In addition, authors of a prospective observational study claimed that individuals with HIV experiencing depression, stress and traumatic life experiences reported fatigue levels that were influenced by income and employment status [44]. Higher income and employment were associated with low fatigue levels, whereas low income or unemployed were associated with chronic fatigue [44].

Neurocognitive impairment is a growing area of concern among people living with HIV. This may be due

to the HIV virus which crosses the blood brain barrier affecting most parts of the brain including cerebral white matter [45]. Authors of a cohort study suggested that though cART medication decreases the incidence of dementia, milder forms of asymptomatic or mild neurocognitive impairment may persist, increasing the burden of illness [45]. More specifically executive memory (e.g., planning, multitasking, prioritizing, and paying attention), working memory, episodic memory, and prospective memory (ability to execute future intentions, such as remembering to remember) may be affected [46–51].

In terms of episodic disability, among these symptoms, authors reported that episodes of illness in HIV may be influenced by the side effects of medication, comorbidities, intrinsic and extrinsic factors and triggers [1, 9]. In addition, aging with HIV, stigma and discrimination further exacerbate the episodes of illness [9].

Difficulties with day to day activities

For the purposes of mapping the study findings, difficulties with day to day activities were defined as any difficulty in performing routine activities that people tend to do every day [1]. A summary of the data mapping is outlined in Table 2.

Fibromyalgia

People with fibromyalgia reported decreased physical activity levels which limited their daily functioning [52]. A study conducted with 55 women demonstrated that a decrease in physical activity in individuals with FM may be due to a decreased pain threshold, reduced muscle strength and decreased muscular flexibility leading to progressive deconditioning and a sedentary lifestyle [52]. Similar results were reported by authors of a case-control study, who found that decreased quadriceps muscle strength seen in women with FM could predispose them to a sedentary lifestyle [53]. Further, authors of two reviews reported that the sedentary life style in people

living with FM may be attributed to fear of movement and avoidance behavior towards physical activity which can exacerbate their symptoms [28, 54].

A cross sectional study that compared 19 women with FM with 20 healthy women demonstrated that women with FM had low functional capacity and an exacerbation of pain during their six-minute walk test compared to the healthy women [55]. This finding suggested that physical activity (difficulty with day-to-day activities) and exacerbation of pain (symptoms and impairment) in FM are directly linked to each other [55]. Authors of studies also claimed that exacerbation of pain may limit daily functional activities and predispose individuals living with FM to a more sedentary lifestyle and progressive deconditioning [28, 54, 55].

Multiple sclerosis

Among people living with MS, day to day activities are reported to be primarily affected by neurological dysfunction [56]. Apart from the steady deterioration in neurocognitive functioning, episodes of relapse and remission can further affect day to day functioning [19]. Individuals with MS may experience muscle weakness and decreased walking endurance which increases the likelihood of falls [57, 58]. Similarly, authors of an RCT suggested that the incidence of falls increases with MS disease progression. This finding is further supported by a retrospective cross-sectional study conducted with 27 participants with MS where authors claimed that impaired cognitive processing speed in MS was associated with an increased incidence of falls [59].

The day to day functioning of people living with MS is further affected by pain and neurocognitive functioning which can also affect adherence to medication and driving [32]. A prospective cohort study conducted with 156 people with MS reported that during the early stages of MS the neurological deficits may be relatively minor and cognitive function unaffected, but daily functioning may still be limited [56]. Though the reasons are unclear, fatigue, depression and uncertainty about work and social environment could predispose individuals to early

Table 2: Mapping the difficulties with day to day activities across illness to dimensions of disability in the episodic disability framework

Fibromyalgia	Multiple Sclerosis	HIV
Exacerbation of pain * : affects the activities of daily living [28, 52–55, 66, 67]	Neurological problems*: affect walking. Cognitive problems affect: - Driving - Adherence to medication [32, 56–60]	Cognitive problems affect*: [42, 47, 48, 50, 51] - Organizing appointment - Remembering medication - Paying bills - Driving - Vocational functioning - Exerting self control - Learning alternate or new coping skills

(*indicate episodic factors that affect day to day activities)

limitations in daily functioning [56].

Further, a study conducted with 18 individuals with MS suggested that processing speed impairment in MS could affect activities in their everyday life such as finding a number from a phone book, counting change, locating an item on a shelf or reading directions in the medicine bottle [60]. Authors also reported that sexual dysfunction and bladder and bowel incontinence in MS can further affect day to day activities and quality of life [60].

HIV

Neurocognitive impairment such as deficits in memory and attention can impact activities of daily living in people living with HIV [46, 47, 51]. Cognitive impairment can affect a wide variety of skills, including driving, vocational functioning, exerting self-control and learning alternate or new coping skills [50]. Authors of a case-control study demonstrated that difficulty with multitasking such as organizing an appointment, remembering medication and paying bills are seen in individuals with HIV [48]. A qualitative study conducted with 12 men with HIV reported that cognitive challenges fluctuate and that these fluctuations were predictable and mostly triggered by fatigue or anxiety [46].

Despite the fact neurocognitive impairment is commonly seen in individuals with HIV, a survey reported that adults over the age of 50 were less likely to report cognitive symptoms and were more adherent to treatment when compared to young adults living with HIV [61]. This may be due to the fact that older adults used coping strategies to remember their daily routine in order to overcome their difficulty in executing their intentions [47, 51]. An RCT conducted with 220 young adults (< 30 years) demonstrated that neurocognitive deficits are seen in HIV-positive young adults and can affect their day to day functioning [50]. Apart from cognitive impairments and the episodic nature of illness, other factors such as concurrent health conditions and side effects of medications can further compromise day to day activities for adults with HIV [62].

Challenges to social inclusion

A third source of comparison across studies relates to the impact on social participation. Challenges to social

inclusion exist when an individual experiences difficulty interacting with others or engaging in social roles such as taking part in leisure activities, personal relationships, employment, education, adequate housing, health care, and training [1]. A summary of the findings is outlined in Table 3.

Fibromyalgia

Individuals living with fibromyalgia can face challenges to social inclusion due to a decline in cognitive function and mental alertness [23]. Authors of a review article claimed that due to cognitive deficits, people with FM report having trouble remembering and difficulty in performing work that requires high cognitive and technical demands [23]. Due to deficits in episodic and semantic memory, individuals with FM face challenges in remembering specific events such as appointments, phone numbers or even certain words which might affect their personal, social and work environment [23]. In addition, a sudden exacerbation of pain could affect participation in personal, social and work activities [20].

Multiple sclerosis

Neurocognitive deficits in processing speed, working memory and new learning memory could affect the social inclusion of people living with MS [38, 60]. Cognitive functioning is essential for planning, organizing and executing an activity; hence, cognitive deficits in MS can affect a wide range of activities such as work, personal relationships, and social integration [32]. Further, a cross-sectional study conducted with 149 individuals with MS reported that those with neurocognitive deficits experienced depression and physical and mental fatigue which further affected their social participation [34]. This finding was supported by a review which claimed cognitive function deficits were a clear indicator of disease progression which leads to deterioration in social functioning [63]. Apart from the deficits in cognitive function, relapse of neurological problems could eventually affect their personal, social and work participation.

Table 3: Mapping the challenges to social inclusion across illness to dimensions of disability in the episodic disability framework

Fibromyalgia	Multiple Sclerosis	HIV
Cognitive problems affect: [23] - Work - Personal and Social participation Sudden exacerbation of pain*: affects social participation	Neurocognitive problems* affect: [32, 34, 63] - Work - Personal and social participation	Fluctuation in health, stigma and discrimination* affecting social role, including: [62] - Work - School - Attending social events

(*indicate the challenges to social inclusion affected by the episodes)

HIV

Physical and mental health impairments and HIV stigma can affect the social inclusion of people living with HIV [7]. A qualitative study conducted with 20 women reported that rigorous medication regimes, stress, and fatigue significantly affected their participation at work [62]. Authors also reported that individuals often worry about HIV disclosure fearing rejection, discrimination and stigma in the workplace [62]. Stigma and discrimination can affect social roles such as engaging in work, school and attending social events [7, 62].

In addition, concurrent health issues, neurocognitive impairments and side effects of medications can severely compromise social participation of people living with HIV [7]. Authors of a focus group conducted with 38 participants living with HIV reported that apart from health challenges, extrinsic (social support and stigma) and intrinsic contextual (living strategies and personal attributes) factors may exacerbate the episodes eventually affecting the social role [9]. Further, authors of a phenomenological study claimed that due to lack of workplace recognition and understanding of the episodic nature of illness people living with HIV are often unable to continue to work [62].

Uncertainty

Uncertainty can be defined as a state of being worried about the future living with a chronic or episodic illness [1]. A summary of the comparative data is outlined in Table 4.

Fibromyalgia

Individuals with fibromyalgia can experience low coping efficacy, more depression and poor quality of life leading to illness uncertainty [20]. A cross-sectional longitudinal study conducting weekly interviews of 51 women for 12 weeks demonstrated that pain, stress, and pain helplessness were key factors that increased uncertainty related to illness [64]. This was further supported by authors of a qualitative study, who claimed that pain exacerbation and difficulty coping with symptoms were a major cause of illness uncertainty [20].

Multiple sclerosis

In people with MS, severe pain, fatigue, depression, neurocognitive deficits and unpredictability of illness were cited as major causes of uncertainty [32]. Authors of a qualitative study using focus groups reported that unexpected episodes of pain and unpredictability of illness were the major sources of uncertainty [32]. A prospective cohort study conducted with 144 participants with MS demonstrated that following a relapse, physical improvements could take 2 -12 months to restore. This prolonged periods of illness and increased the unpredictability of living with MS [40].

HIV

Uncertainty is a key health related challenge for some people living with HIV [65]. Emotional distress, anxiety, fear and depression were primary sources of uncertainty [65]. A focus group conducted with 38 adults with HIV demonstrated that people living with HIV often have new uncertainties due to their limitations related to work, finances, housing, medication, and insurance, hence they often have to negotiate their life priorities [1]. Similarly, authors of a qualitative study reported that older adults living with HIV experienced uncertainty related to their aging, long term housing and transition to retirement [65]. In addition, people living with HIV may also have uncertainty related to side effects of medication and the inability to plan their future due to the episodic nature of their illness [1].

DISCUSSION

To our knowledge, this is the first study to use the episodic disability framework to explore the concept of episodic disability across three chronic illnesses. The review of health challenges in FM, MS and HIV using dimensions of disability in the episodic disability framework enabled us to understand the types of disability and the episodic nature of illness across the three chronic illnesses. We describe an overview of the similarities and differences across the three illnesses.

Table 4: Mapping uncertainty across illness to the dimensions of disability in the Episodic Disability Framework

Fibromyalgia	Multiple Sclerosis	HIV
Uncertainty related to:[21] Illness * Work * Income *	Uncertainty related to: [32, 40] Illness * Work * Income *	Uncertainty related to:[65] Illness * Work * Income * Housing * Medication * Insurance * Related to aging*

(*indicate uncertainty due to the episodes)

Cognitive impairments such as impaired working memory and episodic memory were described across the three illnesses [23, 38, 46] and were identified as a major factor affecting day to day activities and social inclusion. These findings highlight the importance of cognitive assessment and identify cognitive problems to facilitate the early introduction of interventions to improve activities of daily living in these conditions.

Illness uncertainty was commonly reported among individuals with MS, HIV, and FM and is a hallmark of episodic disability [32, 40, 65]. However, people living with HIV experienced uncertainty in different ways, related to work, finance, housing, rigorous medication regime and aging [65]. The prominence of uncertainty in HIV may be due to its association with stigma and discrimination, which can make it difficult for individuals to obtain employment, find secure housing and predispose them to uncertainty. It may also be due to uncertainty having been more widely studied in the context of HIV in comparison to the other two illnesses. Regardless, giving its contribution to episodic disability rehabilitation professionals should not only consider the course of illness but also address the psycho-social aspects related to uncertainty for people living with HIV, FM and MS.

In HIV, studies made explicit reference to the episodic nature of disability [1, 7, 9, 13, 17]. However, in FM and MS, the episodic characteristics of the illnesses were not explicitly addressed. This may be due to the fact that the term episodic disability was first established in the context of HIV [1]. Further understanding of the consequences of episodic disability in other chronic conditions and the impact of uncertainty will help to identify strategies to alleviate episodes of disability for people with chronic illness.

Episodic disability is a relatively new term used to identify individuals living with unpredictable fluctuations in health [1]. If symptom/impairments, difficulties in day to day activities, challenges to social inclusion and uncertainty fluctuate due to illness then it can be considered as episodic disability [1]. This review identified that the episodic nature of the illness was apparent in the HIV literature and to some extent addressed in FM and MS literature. Though the underlying cause of the episodes were different in the FM, MS, and HIV, difficulties in daily functioning, challenges to social participation and uncertainty were described among the three illnesses. These similarities may also apply to other illnesses that share a similar episodic nature. There may be advantages to bringing more episodic health conditions under one broad concept of episodic disability. The Canadian Working Group on HIV and Rehabilitation (CWGHR) a national, charitable organization provides leadership, vision and co-ordination of endeavors related to HIV, disability and rehabilitation [66]. Under the leadership of CWGHR, the episodic disability network was established

to bring together a variety of disability communities to work on the shared issues [67].

One potential benefit of grouping episodic disabilities is in the area of policy. The variations in definitions of disability used by the health care system, insurance companies, and government benefit programs lead to a lack of clarity and may create barriers in accessing income support, drug coverage assistance and housing support for people living with episodic disability. For example, Ontario Ministry of Community and Social Services defines a person with disability as one living with a substantial mental or physical impairment that is continuous or recurrent and is expected to last more than a year [68]. However, this does not apply to all individuals living with disability. Since an episodic illness does not necessarily lead to an episodic disability, there is a need to provide a uniform definition for episodic disability. Clarification of the difference between episodic illness and episodic disability could bring more health conditions under one broad concept and facilitate policy makers to make flexible policies for people living with episodic conditions. However, it is important to be mindful that policies that group heterogeneous illnesses have the potential to detract from flexible approaches and hence need to be monitored and evaluated.

This review also identified differences in disability among the illnesses. Factors influencing physical symptoms, day to day functioning, social participation, and uncertainty were unique to each illness. For example, pain is the major impeding factor in FM, whereas neurocognitive deterioration is the major factor in MS. On the other hand, side effects of medication, stigma and discrimination impede HIV. This reinforces the importance for rehabilitation professionals to understand the nuances of chronic illnesses and tailor treatment, according to the individual needs of the person.

This review also identified a strong relationship between physical symptoms and day to day functioning of individuals living with chronic illness. For instance, fatigue and depression impeded the daily function of individuals with FM, MS, and HIV [25, 33, 44]. Similar observations were reported by O'Brien et al. who demonstrated that physical symptoms directly influence day to day functioning [7]. This suggests that if rehabilitation professionals target interventions to alleviate physical symptoms that this might then subsequently improve the daily functioning of individuals living with chronic illnesses.

This mapping exercise supports the conceptualization that episodic disability is multi-dimensional, involving symptoms, difficulty with day to day activities, challenges to social inclusion, and uncertainty. This reinforces the importance of adopting a multidisciplinary approach (including physical therapy, occupational therapy, and speech-language pathology) for individuals living with episodic disability.

A possible limitation of this review was the use of the episodic disability framework as it was developed based on the experiences of people living with HIV. However, we were able to easily map the characteristics of FM and MS to the dimensions of disability. Hence, there is utility in using the episodic disability framework in other chronic illnesses which are episodic in nature.

Results from this review indicate a dearth of literature exists that addresses the episodic nature of chronic illnesses. Though the concepts of relapse and remission were addressed in MS, the episodic characteristics of disability were not described. Similarly, authors of included studies tended to describe impairments more extensively compared to the other dimensions of disability that may be a result of impairments, such as challenges to social inclusion. This may be a reflection of our search strategy which more specifically targeted the level of impairment. Nevertheless, further research is needed to understand the experience and implications of episodic disability in FM, MS and other episodic illnesses. Further, understanding the influence of demographic factors such as gender, age and race on episodic disability is an important area for future research. Additionally, studies evaluating the impact of interventions to prevent or mitigate episodes of disability are warranted.

This review is not without limitations. We searched a limited number of databases and search terms. The words to describe the episodic nature of illness may vary; hence, there was a possibility of missing relevant articles. In addition, we did not examine reference lists of included articles to identify other potentially relevant studies.

CONCLUSION

People living with fibromyalgia or multiple sclerosis or HIV, experience some common dimensions of disability that may be similarly experienced as episodic in nature. These similarities may not be exclusive to these illnesses, and could apply to individuals living with other chronic and episodic illnesses. Increased understanding of the disability resulting from episodic illness can assist rehabilitation professionals in developing interventions to prevent or mitigate disability and episodes of disability.

Author Contributions

Saipriya Vajravelu – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Kelly O’Brein – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising

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Sandra Moll – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Patricia Solomon – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Guarantor

The corresponding author is the guarantor of submission.

Conflict of Interest

Authors declare no conflict of interest.

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