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Adults with ME/CFS report surprisingly high rates of youth symptoms: A qualitative analysis of patient blog commentary

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Abstract.
BACKGROUND: Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a debilitating chronic illness that impacts pediatric populations.
OBJECTIVE: The current study aimed to better understand adult perceptions of their experiences leading up to their diagnosis of ME/CFS.
METHOD: Patients provided data regarding symptoms of ME/CFS they may have experienced during childhood through a popular community blog forum, with participants interacting via blog comments in real-time and across various geographical locations.
RESULTS: Descriptive analyses indicated that roughly 43% of adult survey participants reported having developed ME/CFS prior to age 18. A standard content analysis of patient blog commentary revealed several themes, such as poor mental health, family pattern/history, healthy childhood preceding sick adulthood, feeling misunderstood, lack of clarity until adulthood, sharing of resources, poor school functioning, isolation/poor social supports, and coping mechanisms.
CONCLUSION: There are unique benefits and insights that can be used by investigators who collaborate with patient organizations as a means of better understanding ME/CFS illness severity, presentation, and lived experiences.

Keywords: Chronic fatigue syndrome, myalgic encephalomyelitis, web blog, qualitative research

1. Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a debilitating chronic illness characterized by symptoms such as post-exertional malaise, cognitive difficulties, and sleep impairments [1]. According to pre-pandemic estimates, it affects 1.5 million people throughout the United States, causing economic dislocation, financial burden, and job loss [2]. ME/CFS studies investigating etiology and prevalence report inconsistent outcomes. According to the IOM, rates of ME/CFS in childhood occur anywhere from 0.03 to 1.29 percent of the population [1], with a recent community-based sample reporting 0.75% had pediatric ME/CFS [3]. Such discrepant findings are likely due to several factors, such as varying methodologies, sampling biases, and lack of consensus on a research case definition [3, 4].

In regard to ME/CFS symptom presentation, youth display many similarities to their adult counterparts (e.g., headaches, gastrointestinal symptoms, orthostatic intolerance, light sensitivity, and pain) [5]. However, children are far more likely to complain of symptoms that fluctuate in frequency and severity [6], come on gradually, or present in clusters that mimic the standard flu (i.e., stomach bug, sore throat, swollen glands, etc.) [1, 7]. Unfortunately, many children are ill for years before receiving a diagnosis of ME/CFS, which can be attributed to lack of knowledge on the part of primary care physicians [8].

Functional limitations and stigma further exacerbate these hardships for youth with ME/CFS. For children and adolescents with this illness, social,

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emotional, and educational development is often interrupted by efforts to cope with symptoms. Many studies have identified school absence as significantly increased in youth who have ME/CFS [1]. For example, one study found that nearly 90% of youth with ME/CFS missed a "considerable" amount of school, with attendance records indicating anywhere from 15 to 50 percent of school days missed [9]. Repeated school absences not only increase stress due to improper curriculum exposure, but also impede social development. Similarly, unfair bias, stigma, and bullying can disrupt social and emotional functioning for youth with this illness [10, 11]. This sense of being misunderstood is further aggravated by physician misdiagnoses [12]. There is a clear need for more comprehensive understanding of ME/CFS illness experiences among youth in order to better address long-term impacts of the illness across physical, social, occupational, and emotional domains that may extend into adulthood.

Parslow et al.'s [13] ME/CFS qualitative literature review revealed four themes central to the pediatric ME/CFS illness experience, including 1) disruption and loss: physical, social, and the self; 2) barriers to coping: suspension in uncertainty, problems with diagnosis and disbelief; 3) facilitators to coping: reducing uncertainty, credible illness narratives, diagnosis and supportive relationships; and 4) hope, personal growth, and recovery. These authors documented the lived experiences of the severe impact of ME/CFS on social and educational functioning.

Unfortunately, there remains a scarcity of studies evaluating pediatric ME/CFS and how early symptoms of the illness can lead to negative outcomes throughout the lifespan. For those that do exist, few contain analyses of long-term outcomes, and instead evaluate children at a single time-point [13]. Only a few studies have evaluated long-term outcomes in youth, and those that have suggest that many symptoms do remain over time [14]. For an illness that often fluctuates in symptom presentation and severity, long-term analysis of patients is crucial to understanding the course of ME/CFS. Additionally, it is important for researchers and medical professionals to seek out pediatric patient experiences, as qualitative research serves an important role in understanding chronic illness and improving patient outcomes within vulnerable populations [15].

The current study aimed to evaluate adult participants reporting retrospectively on illness experiences as they progressed from childhood to adulthood. This approach might provide insights into an understanding of pediatric issues that may provide further insight into ME/CFS in adulthood as research has documented burden of illness in adults including significant physical limitations and barriers to maintaining employment [16]. This exploratory analysis will serve to provide insights about how adults perceive their earlier illness experiences.

2. Methods

2.1. Procedure

The current study utilized a mixed methods approach, where qualitative and quantitative data were abstracted from a post on *Health Rising*, a popular ME/CFS-related blog. The blog posting, titled "Childhood ME/CFS Prevalence Takes a Hike – Plus Take the Childhood Poll," was published on February 12th, 2020 by Cort Johnson [17]. The post highlighted findings from a large-scale community-based epidemiological study of pediatric ME/CFS by Jason and colleagues that found nearly 0.75% of youth are affected, with African American and Latino groups being affected the most [3]. Items in the current survey included "How old were you when you came down with ME/CFS?" and "Please check any of these events that you experienced during childhood (0–18 years old) prior to the start of your ME/CFS," with response options containing various symptoms and illness triggers.

2.2. Participants

Survey participants included a purposive sample of 617 patients who had ME/CFS. Comments from 70 participants provided the basis for qualitative analysis. Participants who completed the single survey poll ($n = 617$) and those who provided blog commentary ($n = 70$) were analyzed and reported on separately. It is assumed that those who provided survey data or blog comments were of adult age (i.e.,>18) due to the survey item's request for patients to report *retrospectively* on childhood experiences. However, no explicit information on age, location, or gender were collected. The authors' Institutional Review Board was consulted via email regarding informed consent and study procedures. Due to the public nature of the blog commentary and poll, it was deemed unnecessary for review. Regarding anonymity, usernames and/or other identifying information associated with verbatim qualitative responses were omitted in this

manuscript. While usernames and/or other identifying information can be found on the host's website, Eldh and colleagues suggest that using verbatim quotes more effectively captures the informant's emotions and experiences, especially in regard to limited data sets [18].

2.3. Data analysis

Qualitative analysis of survey items was conducted by computing standard frequencies, as survey items required participants to select as many answer options as applied. Qualitative analysis of survey comments was conducted using a summative approach to content analysis [19]. That is, comments ($n = 70$) were coded according to perceived themes or patterns, and the frequency of theme occurrence within comments was counted prior to performing a literature review. Coders initiated this process by reading comments individually to identify key themes and sub-themes. Afterwards, each coder met to compare similarities and differences in coding schemes. Themes inconsistent between coders were either eliminated due to low occurrence or combined within a larger theme. Those themes that showed up consistently for each coder were assigned a code name for which all comments associated with this theme would belong. After reaching a consensus, each coder individually re-coded the comments a final time to test for interrater reliability, using Cohen's kappa ($K = 0.94$ averaged across all codes). All coding and analysis of major themes was conducted using NVivo 12 software [20].

3. Results

3.1. Survey analysis

Five hundred eighty-two respondents indicated their age when they developed ME/CFS (Table 1). The most frequently reported age of onset was 11–18 ($n = 170$). Roughly 43% of survey participants reported having developed ME/CFS prior to age 18. 617 participants checked events that they experienced during childhood (0–18 years old) prior to the start of their ME/CFS (Table 2). Participants were instructed to select as many of the items that applied to themselves, with options including a range of illness triggers (physical or social/emotional) and symptoms. Among the most commonly endorsed (i.e.,>25%) childhood symptoms/events were gut problems ($n = 246$), tonsillitis/strep throat ($n = 226$), difficulty going to sleep ($n = 200$), frequent colds ($n = 191$), depression or anxiety ($n = 188$), infectious mononucleosis ($n = 170$), frequent headaches ($n = 166$), sensitivity to heat or cold ($n = 166$), turbulent or traumatic family environment ($n = 164$), frequent antibiotics use ($n = 156$), and overnight stay(s) in a hospital ($n = 154$) (Table 2).

Table 1
Age of ME/CFS onset

	($n = 581$)
	% (n)
0–10 years	13.3 (82)
11–18 years	27.6 (170)
19–25 years	11.8 (73)
26–40 years	23.7 (146)
41–55 years	17.3 (107)
56–70 years	00.2 (1)
>70 years	00.3 (2)

3.2. Qualitative analysis of blog commentary

Seventy participant comments were analyzed for recurring patterns or themes. Following careful analysis and discussion, nine separate yet interrelated themes emerged: 1) Feeling misunderstood, 2) Mental health challenges, 3) Family pattern/history, 4) Illness in adulthood despite healthy childhood, 5) Poor school functioning, 6) Prolonged lack of illness clarity, 7) Sharing of resources, 8) Isolation/poor social supports, and 9) Coping mechanisms. Participants were able to comment on any matter they deemed appropriate after reading the blog post.

3.2.1. Feeling misunderstood (n = 14)

Many participants recorded comments indicating overwhelming feelings of being misunderstood, with judgment stemming from family, friends, or medical professionals. Common descriptions included symptom dismissal despite clear and consistent experiences, inappropriate treatment recommendations, and overall lack of understanding regarding disease etiology. One participant, in an effort to describe what appears to be orthostatic intolerance, a common symptom of ME/CFS, described denial of symptom legitimacy; they stated, "*I remember in secondary school trying to explain to my father that it was difficult standing upright because I felt all droopy. He told me it was backache. I said it was not an ache but droopiness.* '*Yes, that's what back ache is.*"' Many others complained of the near constant rejection from medical practitioners, providing comments such as

Table 2
Events experienced during childhood prior to ME/CFS onset

	($n = 617$)
	% (n)
Gut problems	39.9 (246)
Tonsillitis/strep throat	36.6 (226)
Difficulty going to sleep	32.4 (200)
Frequent colds	31.0 (191)
Depression or anxiety	30.5 (188)
Infectious mononucleosis	27.6 (170)
Frequent headaches	26.9 (166)
Sensitivity to heat or cold	26.9 (166)
Turbulent of traumatic family environment	26.6 (164)
Frequent antibiotics use	25.3 (156)
Overnight stay(s) in a hospital	25.0 (154)
Heavy menstrual bleeding	24.6 (152)
Difficulty exercising	24.3 (150)
Sensitivity to smells/foods/chemicals	23.3 (144)
Seasonal allergies	23.3 (144)
Surgery (ies)	22.9 (141)
Frequent ear infections	22.4 (138)
Food sensitivities	22.4 (138)
Fainting or dizziness	21.7 (134)
Unrefreshing sleep	21.7 (134)
Experienced significant illness or death in immediate family	21.4 (132)
Prolonged colds	20.9 (129)
Parents divorced	20.7 (128)
Experienced something similar to post-exertional malaise	20.4 (126)
Difficulty paying attention	20.4 (126)
Non-seasonal allergies	18.3 (113)
Broken bone(s)	17.5 (108)
Dizziness	17.3 (107)
Concussion(s)	16.0 (99)
Mentally tired after little effort	15.9 (98)
Irregular periods	15.6 (96)
Chronic pain	15.4 (95)
Problems remembering things	15.1 (93)
Traumatic birth	13.3 (82)
Need to take frequent naps	13.0 (80)
Physical abuse (often kicked, slapped, hit)	12.0 (74)
Frequent urination	11.3 (70)
Sexual abuse	10.7 (66)
Tick bite	10.5 (65)
Premature birth	9.7 (60)
Negative response to vaccines	9.1 (56)
Messy bowels	8.8 (54)
Underweight birth	7.9 (49)
Herpes simplex rash (usually around lips/genitals)	7.9 (49)
Serious car or other accident(s)	7.5 (46)
Caesarean birth	5.5 (34)
Unexplained weight loss	0.3 (2)
Exposed to Giardia	0.2 (1)
Intensive care stays in a hospital	0.2 (1)

"*I'm 58 now, I just get new Diseases diagnosed with me all the time.*" Several indicated improper treatment protocols or recommendations, such as one that stated "*The KidsHealth link at the beginning of this post still recommends GET for pediatric ME patients*! *When will stigma give way to actual science?*" Regardless of context, comments related to this theme seemingly reflected memories of estrangement or loss of hope in response to misunderstanding.

3.2.2. Mental health (n = 13)

This theme represented a large group of participants who described struggles with deteriorating mental health, either as a result of illness burdens

or as a factor that they believe triggered their symptom onset. One participant commented "*I think you need to have CEN or childhood emotional neglect in your list – I would think that is important. Also emotional abuse and/or narcissist parent,*" while another described a traumatic upbringing filled with persistent emotional abuse and an unbearable pressure to succeed in school, both of which affected their general health. Most other participants described the development of anxiety or depression as a result of the many limitations imposed on them by their illness. These limitations often took the form of difficulties with education, relationship maintenance, and functional limitations that prevented them from engaging in preferred activities. Another subset of participants described experiences of poor mental health as a result of social stigmatization or disbelief of illness experiences. In referencing their parents, one participant described how "*impatient they became w/me. Maybe that's when my anxiety & depression began followed by OCD/hair pulling. No one could figure out what was wrong w/me.*"

3.2.3. Family pattern/history (n = 12)

Several participant comments documented a history of ME/CFS or some suspected version of an ME/CFS-like illness within their immediate family. In describing the course of their illness, one participant mentioned "*it hit again when I was 32 after having my daughter . . . been ill ever since. My 8 year old is now ill too . . . she's never recovered . . .* " Others seemed to connect older relative's experiences to their own, such as one participant who stated "*I have since wondered if he too had ME, because of a number of other issues. My mother just says that he was lazy*!" Similarly, few participants described this familial pattern as a method of uncovering their own diagnosis, thus facilitating treatment.

3.2.4. Healthy childhood preceding sick adulthood (n = 11)

This theme reflected a group of participants who detailed particularly healthy childhoods leading up to the onset of ME/CFS in adulthood. Comments falling under this theme were often mentioned in tandem with a specific time-period or illness-triggering event. For example, one participant stated, "*I did not get ME until a car accident at age 32 & I was extremely healthy & athletic until that pt,*" while another described themselves as "*the ultimate healthy person with zero allergies . . .* " who "*developed this crap in my 50's and I manage it pretty well with the diet from hell*." Several other participants described definite time-periods in childhood when they believed they were ill, only to recover then relapse after years of remission.

3.2.5. Poor school functioning (n = 10)

Comments belonging to this theme indicated a trend of decreased school attendance or difficulty engaging in academic material as a result of functional limitations. Many comments mentioned cognitive difficulties as a hindrance to academic success, such as one participant who stated, "*Math was my most difficult subject followed by reading comprehension, test-taking, excessive fatigue, & sensitive to cold temperatures, easily distracted, confusion & word pronouncing.*" Others were simply unable to cope with their symptoms in the school setting, such as one who described the following: "*got sent home a lot in grade school because I'd get migraines and throw up until high school when I started my period which was horrible.*" Yet another mentioned "*[A] lot of pressure on me at school to perform well*," either as a stress factor triggering the onset of symptoms, or as an unrealistic expectation imposed upon them due to illness stigma.

3.2.6. Lack of clarity until adulthood (n = 6)

A handful of participants detailed a lifelong battle of fighting illnesses or symptoms that they later understood to be ME/CFS. Participant comments belonging to this theme reflected a sense of confusion regarding illness experiences in younger years, either due to lack of proper treatment or information, only to 'connect the dots' later into adulthood. Nearly all comments related to this realization described a series of events of illnesses that occurred either as a trigger to their ME/CFS, or as an indicator of predisposition. One participant described a host of illness experiences and bouts of treatment leading up to a diagnosis, with no clear triggering event: "*I was 8 yrs. old when I believe I "got" CFS, which started as constant/recurring flu-like illness mixed with severe allergic rhinitis . . . I was not formally diagnosed with CFS until 39 yrs old . . . In retrospect I think these "dry allergies" were PEM.*"

3.2.7. Sharing of resources (n = 6)

Comments belonging to this theme reflected the interactive and community-based nature of *Health Rising,* the blog we used in the current study. Within the comments, many took the time to write about newly uncovered information, studies, or resources

Table 3
Summary of themes from qualitative analysis (N = 70)

		(*n* = 70)
Themes	Central meanings	% (*n*)
Feeling misunderstood	Comments related to being misunderstood, dismissed, or not believed by peers, educators, and medical practitioners	20.0 (14)
Mental health	Descriptions of poor or adverse mental health experiences, either as a trigger for ME/CFS, or as a result of the unique burden of this illness	18.6 (13)
Family pattern/history	Mention of a family history of ME/CFS or related chronic illness	17.1 (12)
Healthy childhood preceding sick adulthood	Descriptions of being previously very healthy, active children before illness onset in adulthood	15.7 (11)
School attendance	Descriptions of poor school attendance or problems functioning in a school setting	14.3 (10)
Lack of clarity until adulthood	Descriptions of being ill for most of the patient's life, and not having received a formal diagnosis or understanding the cause of illness until much later in life	8.6 (6)
Sharing of resources	Attempts to share valuable resources or information related to illness experiences with fellow blog participants	8.6 (6)
Isolation/poor social supports	Feelings of loneliness or isolation as a result of functional limitations or stigmatization	5.7 (4)
Coping mechanisms	Methods that patients used to deal with their illness, either in terms of symptom management or the mental/emotional toll brought about by illness challenges	2.9 (2)

used in their own daily lives. For instance, a few participants shared studies that revealed interesting or related findings, while others noted suggestions for future polls or recorded interviews to explore. Several others expressed a deep sense of gratitude for the blog host's work to disperse ME/CFS-related information, stating "*THANK YOU for everything you do for this community- a LOT of energy goes into this*! *I have learned so much from your articles and am finally gaining some direction as to what steps I need to take next.*"

3.2.8. Isolation/poor social supports (n = 4)

Several participants spoke of the impact that ME/CFS had on their ability to foster and maintain relationships in childhood and beyond. Similarly, others mentioned poor support or understanding of their illness from others as a factor leading to increased feelings of isolation. In reference to the burden of symptom management and functional limitations, one participant noted "*[I] Remember being so tired & napped even when my siblings & peers were playing,*" while another mentioned "*Being misunderstood is (I believe) extremely isolating – which just makes everything so much more difficult*." One participant described the intermingling of illness experiences as a factor contributing to their daughter's isolation, stating, "*It has been very difficult for her in so many ways – education, isolation, friendships and anxiety.*"

3.2.9. Coping mechanisms (n = 2)

Only a couple participants provided comments in alignment with this theme. These comments included accounts of how lack of diagnostic clarity triggers feelings of confusion and lack of hope for those affected by this illness. As a result, the ability to implement proper coping mechanisms, either regarding mental or physical health, is necessary for those living with ME/CFS. Participant comments belonging to this theme described several coping mechanisms, such as one mother whose daughter is "*having therapy at the moment, aged 25, to help her come to terms with the limitations imposed on her life by this horrible disease.*" Another described the role of enjoyed hobbies in creating a sense of stability, stating "*My safe & comforting haven, spiritual, & most constant companion in life – art, music, & photography.*"

4. Discussion

Roughly, 43% of survey participants reported developing ME/CFS prior to age 18. It was surprising that such a high percentage of adult patients with ME/CFS would retrospectively trace symptom experiences to their youth. However, this finding aligns with previous research finding a high percentage of those with ME/CFS having onset of symptoms during adolescence, specifically for ages 10 to 19 [21]. It is

possible these findings were influenced by selection bias as the survey may have been of particular interest to those with this childhood experience. Still, with a reported 1.5 million cases with ME/CFS [2], it is also possible that a far higher percentage of adults developed symptoms earlier than had once been thought.

Stomach aches are one of several symptoms that commonly occur in children but have a scarcer presence in adults [22]. It is not surprising that gut problems were a frequently endorsed survey event for those ill with ME/CFS in childhood. Similarly, headaches, sleep disturbance, and cognitive difficulties are among the most reported pediatric ME/CFS symptoms [23], and both headaches and difficulty going to sleep were frequently endorsed in the current survey. In contrast, survey items relating to cognitive difficulties (e.g., difficulty paying attention, mentally tired after little effort) were among the least endorsed survey items despite evidence of being a hallmark symptom in both pediatric and adult populations [1].

Qualitative analysis of blog commentaries revealed numerous themes related to illness non-recovery and patient lived experiences throughout the lifespan. Several of these themes detailed the systemic nature of ME/CFS and included descriptions of symptom profiles or onset patterns, as well as biophysiological etiologies of ME/CFS. For example, it was not surprising that many patients mentioned a family history of ME/CFS or related illnesses, as several studies have indicated significant increased risk of ME/CFS among close relatives, thus suggesting a heritable component to predisposition [24, 25]. For example, work by Albright and colleagues [24] found significantly higher association for diagnosis of ME/CFS for first-, second-, and third-degree relatives of those with ME/CFS, which aligns with findings from the present analysis in which participants reported family members such as siblings or children having or being suspected of having ME/CFS as well. Several other participants described previously healthy and active childhoods followed by a triggering event or time of definite onset. A smaller subset of these patients mentioned relapsing and remitting patterns, where they remember an event or period as a child when they became ill only to remain symptom free for years, even decades, before their ME/CFS returned. While relapsing or remitting patterns are common for patients with ME/CFS [26], it is interesting that multiple participants reported experiencing remissions for many years before symptoms returned. Current literature regarding ME/CFS typically captures illness onset according to several identified patterns (i.e., acute or gradual), yet a formal labeling of ME/CFS onset patterns has yet to be accepted [27]. Unfortunately, only a few studies have examined changes in symptom presentation over the course of multiple years [28].

Subsequent themes included descriptions of functional limitations and the negative physical and psychological consequences. Namely, many participants reported feelings of being misunderstood by family members, healthcare providers, and teachers, which not only increased feelings of isolation, but delayed proper diagnosis and validation of illness experiences until much later in life. Experiences of isolation due to misunderstanding and physical limitations are frequently cited in the literature as common experiences for patients with ME/CFS [29]. For children, the ongoing and often unclear process of medical diagnosis coupled with social isolation and decreased exposure to educational and developmental opportunities further increases risk of developing anxiety and depression [30, 31], yet another theme presented in the current study. Anxiety and depression are among the most cited comorbidities of ME/CFS, primarily due to the burden imposed by illness experiences [1]. Delayed confirmation of diagnosis has also been associated with poorer treatment outcomes for children who are affected [32]. Similarly, it is not unusual that poor school functioning was a theme uncovered in the present study, as excessive school absenteeism and cognitive impairment have been cited as hallmarks of pediatric ME/CFS, both of which exacerbate social isolation and decrease overall quality of life [33]. Together, these themes align with our understanding of how the unique burdens of ME/CFS likely worsened illness outcomes and participants' ability to cope later in life. These findings highlight how understanding potential illness indicators in youth can lead to faster identification and intervention of ME/CFS in adulthood, potentially limiting further burden of the illness.

Several participants included comments that suggested positive methods of coping or ways of managing their illness. Among the most prominent of these was sharing of resources within the blog community. Because ME/CFS is stigmatized and misunderstood, it is not uncommon for patients to be drawn to the internet. Individuals with chronic health conditions often seek online communication as a way to build community, share resources, and receive validation of illness experiences [34]. Moreover, use of the internet among adolescents has only increased over the years, leading many young peo-

ple with ME/CFS to engage in online communities and forums as a way of establishing social connection and seeking information regarding their illness [35]. Other methods of coping mentioned by participants included descriptions of hobbies that they could enjoy within functional capacity, as well as therapy as a means of coping with stress, ongoing isolation, and difficulty managing symptoms. While coping mechanisms fall into several categories depending on the type of illness stressor, engaging in enjoyed activities as a means of distraction as well as learning cognitive restructuring techniques are methods children and adolescents often utilize when coping with chronic illness [35]. It is clear that social supports, understanding of illness etiology, and the ability to engage in preferred activities within functional limitations are factors that likely increase positive illness outcomes.

4.1. Limitations

There were several limitations to the current study. Our study did not have demographic information such as gender or place of residence. Factors such as these may have influenced illness experiences and outcomes, such as how location may or may not hinder one's access to treatment and resources. An additional limitation included potential sampling biases and risk of inaccurate self-report data. Because this study included anonymous disclosure of illness diagnosis and experiences, details regarding illness treatment, diagnosis, and outcomes could not be verified. Additionally, due to the anonymous and online nature of responses included in the current study, it is possible that some responses were inaccurate or portrayed as more extreme or serious. Some researchers argue that blogs promote a diary-style form of self-report which can encourage spontaneous and candid responses which could inhibit the validity of responses [36]. Similarly, the potential for recall bias due to adults reporting on experiences in childhood may be more prevalent in a diary-style of self-report, especially because commonly reported pediatric triggers of ME/CFS can be typical childhood experiences. However, reported triggers in this study reflect previous findings regarding pediatric triggers of ME/CFS, such as significant physical or emotional trauma and poor mental health, thus providing a stronger basis for validity in their responses [37]. Additionally, as this survey was not designed or administered by the authors of this study, follow up or clarifying questioning was unable to be conducted, which potentially limited depth and clarity of analysis. One big drawback of this method is the authors were unable to confirm whether reported childhood triggers were directly related to ME/CFS diagnosis or if they were common or random childhood occurrences and diagnosis occurred years later due to additional causes. Future research should include more in-depth questions on illness trajectory to better explore connections between childhood symptoms or triggers and eventual diagnosis of ME/CFS. The most serious limitation is that the blog described youth experiences with ME/CFS and probably thus recruited a sample that had more interest and possibly experiences with the content of this online blog.

4.2. Recommendations

The present study has several implications for future investigation. It is important that researchers and clinicians better understand patient-reported illness and family genetic history, patterns of symptom onset, and environmental exposure throughout the lifespan for patients with ME/CFS. Representation of these issues in the literature will bolster our understanding of possible illness triggers or predispositions to ME/CFS in childhood and adolescence, as were revealed in the present study. It will also aid in legitimizing the lived experiences of patients who do not feel believed of their illness. There continues to be a lack of representation and knowledge of this illness despite its prevalence [38]. According to Pierre Bourdieu's analysis of symbolic violence, Torrent [38] chronicles how symbolic mechanisms of violence (i.e., non-recognition, institutionalized un-care, condescension, authorized imposition of illegitimate verdicts, delegitimization, disintegration, imposition of discourse, euphemization, silencing, invisibilization, isolation, uncommunication, and self-blaming) combine with structural and societal norms to ultimately delegitimize this vulnerable population. Future researchers are encouraged to investigate the social implications of ME/CFS, and how various groups of power influence these societal norms (i.e., lack of state government funding, favoring of the medical paradigm) that may be harming patient outcomes and leading to decreased financial and occupational opportunities for adults with ME/CFS.

5. Conclusion

The current study provides an example of a collaborative approach to engaging in research on ME/CFS,

where research groups take the catalyst or inspiration of their work from patient concerns. Approaches of this nature may elevate patient voices and uncover issues that impact those who are most vulnerable [39].

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Ethical approval

The authors' Institutional Review Board was consulted via email regarding informed consent and study procedures. Due to the public nature of the blog commentary and poll, it was deemed unnecessary for review.

Informed consent

Due to the public nature of the blog commentary and poll, the author's Institutional Review Board deemed informed consent unnecessary.

Conflict of interest

The authors have no conflict of interest to report.

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