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Support Experiences of Children and Youth with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Epilepsy in New Zealand Schools: A Parental Perspective

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Abstract

Medical advancements have changed the prognosis of many paediatric conditions, leading to a rise in the number of children with chronic health conditions (CHCs) who require support to gain equitable education opportunities and outcomes. Two CHCs that impact on schooling are myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and epilepsy. Previous research has detailed different supports offered by schools, but there is a gap in the literature regarding the support of children with ME/CFS and epilepsy in New Zealand schools. The current research aimed to gather parents' perceptions on the different supports available in New Zealand for their children/youth with ME/CFS or epilepsy to help with the impact their CHC has on schooling.

Participants included 20 parents of children with ME/CFS (11-20 years) and 23 parents of children with epilepsy (6-18 years). A mixed methods online survey asked for parents' perceptions of the impact that ME/CFS and epilepsy had on schooling and the support available in 'Mainstream' and 'Other' schools. Through mixed method analysis, including descriptive statistics and thematic analysis, six main themes and subthemes were identified; 1) Let-down by their own bodies, 1.1) Damaging self-concept; 2) Struggle for validation; 3) Luck of the draw: Both supportive and unsupportive experiences, 3.1) Teachers operating in a rigid system, and 3.2) Gratitude from parents; 4) Ill-suited support, 4.1) Other schools as transitional institutions; 5) Lack of understanding and discrimination; and 6) Impact of COVID-19. These themes revealed perceptions of positive support experiences with understanding teachers who formed trusting/positive relationships with parents, as well as negative experiences centred around a lack of understanding from a restrictive system not well designed to support their children with ME/CFS or epilepsy. Condition specific subthemes revealed differences between ME/CFS and epilepsy – related to condition legitimacy, symptom visibility, and funding opportunities.

Findings were also interpreted using a socio-ecological framework, which highlighted the interrelated environments surrounding the child/youth, including teachers/classrooms, schools, health/education policies, and western health conceptualisations, which likely influenced support. These findings shed light on parents' perceptions of the support of their child/youth with ME/CFS or epilepsy in New Zealand, with the hopes of informing future research or support initiatives.

Keywords: myalgic encephalomyelitis/chronic fatigue syndrome or ME/CFS, epilepsy, school support experiences, New Zealand education system, parent perspectives.

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As medicine has advanced, so too has the prognosis of most paediatric conditions, allowing children and adolescents with serious medical conditions to live long and relatively ‘healthy’ lives (Bowtell, Aroni, Green, & Sawyer, 2018; Shiu, 2001). Within school systems, this has produced a need for a shift in focus from the effects of acute illness on schooling towards the impact of ongoing medical illnesses on a student’s schooling (Bowtell et al., 2018; Shiu, 2001). Chronic health conditions (CHCs) can gravely affect a student’s education experience, impacting on such things as attendance, academic achievement, participation, and socialisation, with different medical conditions being implicated in different ways (Lum et al., 2017; Pinquart & Teubert, 2011). Subsequently, varying diseases can have different negative implications on schooling (Pinquart & Teubert, 2011), partly due to their impacts on a young person’s areas of functioning. Ro

CHCs can have a negative impact on physical functioning, academic functioning, and social functioning through a number of different health related processes (Pinquart & Teubert, 2011). CHCs can cause reduced physical functioning, through such things as pain or fatigue, and consequently may limit a student’s attendance and participation in school activities (Pinquart & Teubert, 2011). Reduced attendance may also limit learning and interfere with examinations, further impacting on academic performance (Pinquart & Teubert, 2011; Shiu, 2001). Medical conditions can also directly impact on academic functioning; for example, conditions involving the central nervous system or fatigue may cause reduced cognitive functioning. CHCs can negatively impact on school experiences through disease sequalae and treatment side-effects. For example, some medicine regimens used in the treatment of cancer and epilepsy can cause fatigue, which negatively impacts on cognitive/academic and physical functioning (Pinquart & Teubert, 2011; Shiu, 2001).

Through reduced attendance and academic functioning, along with stigmatisation, CHCs can also impact on social functioning, restricting opportunities to engage with peers and potentially causing isolation (Pinquart & Teubert, 2011; Shiu, 2001). Stigmatisation arises from the perceived social unacceptability and undesirability of a condition, often as a result of misinformed illness beliefs, which in a school setting can lead to bullying, unfair treatment, and unwarranted exclusion by both peers and teachers (Bowtell et al., 2018; Elliott, Lach, & Smith, 2005; Lewis & Parsons, 2008; Nicholas et al., 2007; Shiu, 2001).

For some semblance of normal school functioning to be achieved, students with CHCs need to be supported. Literature suggests that a range of support options are needed to help students deal with physical and emotional disease aspects. Providing support for children/youth to manage condition characteristics at school, such as medication administration, may help reduce disease burden (Renzetti et al., 2020). Supporting children/youth with the emotional toll of stigmatisation or disease burden, through school counsellors or illness education, can improve coping and reduce emotional distress (Kitto, 2010; Shiu, 2001). The construction of personalised re-integration plans to move the child from home back to schooling, with healthcare providers, teachers, and caregivers working collaboratively, have been suggested to be an adequate and sufficient support strategy (Shiu, 2001). However, these re-integration plans may not be suited to the chronicity of CHCs, which may require a plan for more long-term education strategies.

Literature further suggests that communication and collaboration are essential as a lot of teachers are misinformed about health care needs leading to stigmatisation, have inappropriate reactions to needs or limitations, and have ineffective responses to medical emergencies (Johnson, Atkinson, Muggeridge, Cross, & Reilly, 2021a; Shiu, 2001; Similä, Rø, & Nøst, 2021; Yang et al., 2021). Adequate support to help complete school work can provide students with a sense of achievement, whilst supporting attendance can increase opportunities for socialisation, reduce withdrawal, and improve overall functioning (P. C. Rowe et al., 2017). Improved attendance and academic achievement can also improve future job and education prospects, as well as help students achieve their aspirations and a sense of normality (Kitto, 2010; P. C. Rowe et al., 2017; Shiu, 2001). Time spent away from school has been implicated in social isolation and withdrawal, impacting on the child/youth’s sense of self (Parslow, Harris, et al., 2017; Similä, Nøst, Helland, & Rø, 2021). Being unable to connect with peers may lead to children/youth perceiving themselves as different, at a time when feeling the same as peers is important, particularly for adolescents. Extended absences and needing to be at home relying on the care of parents may also implicate a developing sense of independence and autonomy during such critical periods of development (Chew, Carpenter, & Haase, 2019; Elliott et al., 2005).

For the purposes of this literature review, a focussed discussion and more in-depth analysis has been undertaken, looking at the specific implications and support of two conditions. Looking at two conditions, myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS) and epilepsy, which have different symptomology and impacts on young persons but share over all implications to schooling, offers a unique opportunity to compare/contrast implications and support provision. This may allow for a broader representation of possible impacts and supports for a range of possible symptoms that may then be applied to children with diverse symptomology. Consequently, the remainder of this review will examine CFS/ME and epilepsy, reporting the specific effects ME/CFS and epilepsy have on schooling, and the different proposed and offered support options reported in the literature

Condition Characteristics and Symptomology

ME/CFS

ME/CFS is characterised by extreme fatigue, both mental and physical, that persists even after rest, with associated myalgia/muscle pain, headaches, gastrointestinal distress, neurological problems, cognitive impairment, depression, and anxiety, which are functionally disabling for children/youth (Brown & Cox, 1999; Everett & Fulton, 2002; P. C. Rowe et al., 2017; Tomoda et al., 2000). The diagnosis of ME/CFS is difficult, with the majority of literature describing ME/CFS as a diagnosis that comes after any obvious underlying causes have been ruled out. Laboratory tests yield little information, with ME/CFS remaining largely medically unexplained (Brown & Cox, 1999; P. C. Rowe et al., 2017; Tollit, Politis, & Knight, 2018). As a result, ME/CFS quite often goes undiagnosed for a lengthy period of time, with symptomology needing to be present for a period of at least three to six months (depending on the criteria used) in order to meet diagnosis criteria (Brown & Cox, 1999; Crawley & Sterne, 2009; P. C. Rowe et al., 2017; Sankey, Hill, Brown, Quinn, & Fletcher, 2006; Tillett, Glass, Reeve, & Burt, 2000). There is currently no cure and limited treatment options for ME/CFS, with patients relying on symptom management options, with previous literature detailing the use of sleep aids, pain medications, and/or activity pacing (Brown & Cox, 1999; Everett & Fulton, 2002; P. C. Rowe et al., 2017).

Epilepsy

Epilepsy is a neurological disorder characterised by a spectrum of seizure types and is one of the most common neurological and chronic medical disorders in paediatrics. Seizures are characterised by an abnormal electrical discharge within the brain, either generally or focally, which are by nature chronic and unpredictable. These electrical discharges can cause disruptions to cognitive and bodily functions, such as concentration, motor movements and bladder retention, and often result in post seizure fatigue (Chew, Carpenter, & Haase, 2017; Reilly & Ballantine, 2011). Depending on the type and severity of seizure disorder, an individual may be at increased risk of developmental delays, learning deficits/intellectual disabilities, potential psychosocial issues, behavioural and emotional implications, and experience reduced quality of life (cited in Hightower, Carmon, & Minick, 2002; Reilly & Ballantine, 2011; Snead et al., 2004). The main objective of treatment is to control these seizures as best as possible with the use of anti-epileptic drugs (AEDs) or, in more severe drug resistant cases, surgery (Danguecan & Smith, 2017). The use of AEDs can also have a negative impact on a child/youth's life as they come with associated side-effects such as light sensitivity, abdominal pain, and fatigue (Hightower et al., 2002; Lewis & Parsons, 2008).

Impact of health-related needs on schooling

ME/CFS

With the identified symptoms of ME/CFS, it is not surprising that ME/CFS has the capacity to impact on multiple areas of schooling, with some research even going as far as to identify ME/CFS as a leading cause of school absence among chronic health conditions (Brown & Cox, 1999; Crawley & Sterne, 2009; Dowsett & Colby, 1997; Everett & Fulton, 2002; Van Hoof, De Becker, & De Meirleir, 2006). ME/CFS symptoms lend themselves to having an impact on functional capacity and therefore a child/youth's capacity to attend school and/or participate in school activities. A systematic review conducted by Tollit, Politis, and Knight (2018) identified 36 papers which reported numerous areas of school functioning which were impacted on by ME/CFS. The most commonly implicated area of school functioning was attendance with 34 out of 36 research papers including this construct. Other areas of school functioning included academic functioning, provision of educational services, difficulty returning to school, achievement motivation, school level repetition, and difficulty functioning. These results were obtained using parent, family, teacher, and self-report measures as well as school attendance records (Tollit et al., 2018).

Using a large sample of 211paediatric ME/CFS patients, Crawley and Sterne (2009) demonstrated that almost 62% of children reported attending 40% or less of their expected school attendance. Those with poorer physical functioning, measured by the physical function subscale of the Short Form 36 (SF-36), were found to be less likely to attend school compared to students with better physical functioning. With this being said, 98% of children were found to have, to some extent, reduced physical functioning capacity. Crawley and Sterne found evidence to suggest an association between poorer physical functioning and increased pain and fatigue in all participants, as well as depression symptoms in older children able to complete the Hospital, Anxiety and Depression scale. What was not found was a direct association between attendance and the symptoms of pain, fatigue, depression, or anxiety. As poorer functioning was found to be associated with worsening of symptoms, it may be possible that ME/CFS is impacting on schooling via its impact on physical functioning, with symptoms that are not impeding on physical functioning not impacting on schooling (Crawley & Sterne, 2009).

An impact of ME/CFS on academic functioning was identified by Nijhof et al. (2016) when IQ scores were compared to that of healthy peers. Initial measures of IQ were identified using the standardised Dutch education test (CITO), which is a valid and reliable measure of IQ and is administered to all primary school children to determine the level of intellectual functioning and subsequent school level, thus being ‘below average’, ‘average’, ‘above average’ and ‘high. Participants with ME/CFS were diagnosed and identified post CITO. CITO measured IQ scores showed no difference between those with ME/CFS and healthy peers. However, post diagnosis IQ, measured using age-appropriate versions of Wechsler intelligence scales, was 8 points lower than healthy controls, with those with ME/CFS generally having lower IQ scores than controls in the same school level. Current IQ scores when compared to initial CITO scores in children with ME/CFS showed a diminishing of IQ and cognitive abilities across the two time points (Nijhof et al., 2016). This study is unique as it is situated within the Dutch culture where it is the norm to measure the child’s IQ before entering secondary education; this providing a rare opportunity to compare retrospectively a child’s intelligence before they were diagnosed.

Looking at broader school functioning, Knight, Politis, Garnham, Scheinberg, and Tollit (2018) demonstrated the negative impact that the fatigue and emotional symptoms associated with ME/CFS had on school functioning. Results indicated that children/youth with ME/CFS had a significantly greater number of school absences, poorer quality of life in the school setting, reduced participation, reduced school connectedness, and poorer academic performance than healthy peers. Furthermore, within the ME/CFS group specifically, condition severity (as measured by fatigue and emotional symptom severity), was significantly associated with most areas of school functioning. This was apart from no significant association being present between fatigue severity and academic performance, and between emotional symptom severity and the areas of academic performance and school absences. It is unclear if symptomology not measured, such as poor concentration and attention, cognitive difficulties, or mental fatigue, would have yielded significant associations with academic performance. Furthermore, children/youth with ME/CFS were significantly more likely to have received modified curriculum, a reduced workload, and have access to a visiting teacher service than healthy peers. Extra educational supports they were not more likely to receive included private tutoring, individual school tuition, or access to distance education. This research utilised both parent and child/adolescent reports in healthy children and those diagnosed with ME/CFS allowing for comparison with a healthy control. It appears parent report was implemented when validated measures, such as the Wechsler Individual Academic Achievement Test utilised, may not have been available for certain measures of school functioning (Knight, Politis, Garnham, Scheinberg, & Tollit, 2018).

In addition to these implications on traditional school aspects, literature demonstrated an impact from ME/CFS symptoms and resulting absences on socialisation. From qualitative interviews of 18 adolescents with ME/CFS, Winger, Ekstedt, Wyller, and Helseth (2014) identified that youth felt detached from their lives and forgotten by peers/friends and teachers due to an inability to engage in school activities. This was identified as impacting on social experiences resulting in feelings of loneliness (Winger, Ekstedt, Wyller, & Helseth, 2014). Similä, Nøst, Helland, and Rø (2021) also identified through semistructured interviews that children/youth often feared that they would enter adulthood without having developed socially among peers. Not having regular school attendance meant students missed out on a regular social life, again contributing to feelings of irritation and sadness. Not only was socialisation identified as difficult as a result of absences but also as a result of fatigue (Similä, Nøst, et al., 2021). Interviews with medical professionals shared this concern identifying social withdrawal, resulting from reduced participation in school social activities, and the subsequent impacts to emotional wellbeing and self-esteem, to be key concerns of ME/CFS in children (Parslow, Shaw, Haywood, & Crawley, 2017).

Epilepsy

Epilepsy literature has also detailed a wide range of impacts of the condition on schooling, which again, given the diverse range of symptoms, are not surprising. Given the impact of seizures on the brain and cognition, the most unsurprising implication is the impact on academic functioning, with as many as one in four epileptic children being classified as learning disabled (Reilly & Ballantine, 2011). Using the Wide Range Achievement Test (WRAT-4), Reilly et al. (2014) demonstrated that 72% of children (aged 5-15) had low achievement on at least one subtest, while 42% demonstrated under achievement on at least one subtest. These underachievement results were surprising given they were below what was expected for IQ. When investigating the impact of specific epilepsy related factors, more frequent seizures, current polytherapy, and a history of taking three or more AEDs were all significantly negatively associated with all subtests of the WRAT-4. A longer duration of epilepsy was negatively associated with word reading, spelling, and math computation WRAT-4 subtests, while a later age at first seizure was significantly positively associated with word reading, sentence comprehension, and spelling subtests. After controlling for IQ, the only significant associations that remained were for all those related to age at first seizure and for seizure frequency’s negative association with sentence comprehension. Non-epilepsy specific factors which were also significantly associated after controlling for IQ were attendance difficulties which was negatively associated with word reading and spelling, cognitive factors which were positively associated with sentence comprehension and math computation, and behavioural/psychiatric problems which were negatively associated with word reading. These results appear to indicate that IQ plays a role in low and underachievement, but that there are also other factors present affecting academic progress (Reilly et al., 2014). In utilising an achievement test with specific subtests, Reilly et al. (2014) was able to tease out the different components of academic achievement impacted by epilepsy whilst using a valid and reliable measure.

As part of a larger longitudinal study, Elliot, Lach, and Smith (2005) utilised semistructured interviews and children and youth (aged 7-18) with intractable epilepsy or refractory seizures to further understand how children/youth viewed the impact of epilepsy on their schooling. Children/youth commented on the excessive impact of physical aspects on schooling, including excessive fatigue and anergia, from both seizures and medication side effects, impacting on participation, ability to think, and their ability to remain at school. Emotional and behavioural components were also identified as impacting on schooling, including heightened emotional distress or suffering, fluctuating depression, anger and frustration, identified as resulting from the unpredictability of seizures or loss of bodily control. Epilepsy was also discussed as causing social isolation resulting from peer exclusion, discrimination, lost confidence, parental restriction, or safety concerns, with some participants reporting to rely on few close friendships and inner resilience. Cognitive implications, such as memory problems, impaired physical/mental ‘presence’, fatigue, and impaired attention or concentration were identified as impeding academic functioning and continuous learning.

All these factors were identified as being barriers to normalcy or a normal schooling experience and clearly have a drastic impact on schooling due to the nature of such symptoms. This research indicates a vast array of impacts on schooling stemming from an equally diverse range of symptoms and medication side effects. However, given the nature of epilepsy and its impact on cognitive abilities, some children may be better informants than others, with those with more severe cognitive deficits not being able to contribute qualitatively as much as others. This may explain why intellectual or learning disabilities were not reported as a cognitive implication in this study (Elliott et al., 2005).

In a study assessing the impact of epilepsy on school attendance and participation in two different cultures (Greek and Muslim), Serdari et al. (2009) demonstrated that all children (aged 6-18 years) had missed at least on school day in the last six months, with the median number of days missed being three. This was attributable to factors such as seizures during or prior to school, medical appointments, or tests, and experiencing worrying symptoms. A higher number of days off were found in children diagnosed: within the last four years; with greater disease severity; who experienced tonic-clonic seizures; who had experienced more than one seizure a month; who were on polytherapy; or who experienced medication side-effects. Non-participation in activities was found to be higher in children over twelve, when parents experienced greater seizure worry, and those who experienced tonic clonic seizures. No influence of or difference in culture was found (Serdari et al., 2009). Using semi-structured interviews of parents, Aguiar, Guerreiro, McBrian, and Montenegro (2007) also found an impact of epilepsy on attendance, identifying 88% of children (aged 6-18 years) missed at least one day of school. Reasons identified for absences included recent seizures, medical appointments or tests, and hospitalization. With regards to leaving school, out of the 60% of children who experienced a seizure at school, two thirds went home, with 46% of parents stating their child/youth should go home following a seizure at school. Furthermore, 70% of parents said that their child didn't necessarily have to experience a seizure for them to allow their child to miss school (Aguiar, Guerreiro, McBrian, & Montenegro, 2007). Epilepsy and its many facets clearly impact on a child/youth's ability to attend school, with an apparent trend being present in the types of aspects which would impede their ability to attend or participate in school.

Summary

Even though these two conditions have an apparently dissimilar nature with different symptomology, the impact that they both have on schooling appear to be synonymous with apparently no area of schooling unaffected. Those symptoms which have an apparently large impact on the child/youth (i.e., mental/physical fatigue, cognitive difficulties/deficits), also appear to impact on schooling similarly in ME/CFS and epilepsy. The main difference between the two would be the experience of seizures in children with epilepsy. Although seizures appear to have a significant impact in their unpredictable nature and loss of bodily control, amongst other things, the way these appear to impact on schooling are through the effects of seizures i.e., through post seizure mental and physical fatigue or the effect of seizures on cognitive functioning.

Impact of Stigmatisation on Schooling

Not only do the health-related needs associated with both ME/CFS and epilepsy impact on schooling but so too does the stigma associated with each condition. Stigma, influenced by condition specific attitudes, misinformation, or a lack of condition knowledge, can gravely impact on the child/youth and on schooling, ultimately resulting in discrimination through bullying and exclusionary behaviour.

ME/CFS

Winger et al. (2014) identified that youth with ME/CFS often experienced stigmatisation and discrimination relating to poor illness understandings and the invisible nature of symptoms, which often led to perceived illegitimacy of ME/CFS. Youth reported being given nicknames and labels with negative connotations, often related to assumptions or accusations of laziness from both peers and teachers. Teachers were often perceived to not believe children/youth and expressed scepticism. The link between stigmatisation and discrimination of children/youth with ME/CFS to the visibility of symptoms was represented well by the identified theme “if the illness is not visible to others, does it exist?”, with the identification that having a poorly understood illness and hard to believe invisible symptoms made explaining their illness more difficult compared to a well-known and accepted illness. This also meant that youth felt discouraged by how they were not treated as they expected someone with an illness should be treated; instead, they were being treated as if they had a mental illness or that experiences were imagined. It was unclear if this led to isolation, but participants did report that home was a refuge away from these labels and stigmatisation (Winger et al., 2014). These experiences of adolescents with ME/CFS offer a unique perception as they are directly from young people who would directly experience this discrimination and stigmatisation.

Interestingly with ME/CFS, this stigmatisation may happen within the context of a clinic or with medical professionals due to a perceived lack a medical verifiability. Hareide, Finset, and Wyller (2011) identified that most adult participants identified experiencing negative encounters with medical professionals, noting lengthy delays in the diagnosis process, scepticism and disbelief, and misdiagnoses including attributing symptoms to solely psychological causes. Positive experiences with doctors, who took complaints seriously, were the exception to the rule (Hareide, Finset, & Wyller, 2011). It is not uncommon for people with ME/CFS to experience negative connotations or stigma associated with mental illness, as described by Geraghty (2020) who identified the harmful impact of psychiatric descriptions of ME/CFS. Describing a medical condition as having no biological markers or component, instead being rooted in psychological distress, social trends, and societal distress, was described as resulting in mental illness stigma and perceptions that the person is malingering (Geraghty, 2020).

A systematic review conducted by Parslow, Harris, et al. (2017) identified multiple articles which similarly describe the struggles children with ME/CFS go through because of stigmatisation related to illness uncertainty and lack of understanding. A lack of medical explanation was identified as making explaining the diagnosis to friends or teachers difficult, with a lack of understanding further making management at and reintegration to school problematic. This sense of being disbelieved then resulted in children/youth be self-conscious of being viewed or talked about negatively and of being distrusted. The stigma associated with ME/CFS was apparently so strong that even once a diagnosis was received and children/youth were finally given a reason for their symptoms they were left with a sense of disappointment as ME/CFS was not seen or accepted as a 'proper illness' (Parslow, Harris, et al., 2017). Furthermore, research involving adults showed that being perceived by others to be lying about illness experiences resulted in incongruity between how these patients saw themselves (honest and credible) and how others saw them (dishonest and untrustworthy), adding to disease burden (Åsbring & Närvänen, 2002).

Epilepsy

The stigma associated with epilepsy has been reported to be related to firstly, enacted stigma in response to the perceived social undesirability of seizures or fear responses to confronting seizures; and secondly felt stigma resulting from feelings of embarrassment or shame of experiencing a public seizure (Lambert, Gallagher, O'toole, & Benson, 2014). Epilepsy stigma has been implicated in disclosure apprehension, with research suggesting that this apprehension is reinforced by the anxiety caused by present and potential future discriminatory behaviour (Lambert et al., 2014). Research conducted by Benson, Lambert, Gallagher, Shahwan and Austin (2015) found that due to anticipated and actual negative responses to disclosing an epilepsy diagnosis, parents and children/youth (aged 6-16 years) would intentionally not disclose the diagnosis due to fears of discrimination such as bullying and exclusion. Semistructured interviews revealed some children reported being mocked by peers who often had stereotypical knowledge of epilepsy based on misconceptions and a lack of knowledge. Children also reported feelings of embarrassment about epilepsy and their seizures. The invisible nature of some neurological aspects or a general non-seizure state also afforded children/youth the ability to sometimes conceal their diagnosis to retain normalcy and attempt to negate anticipated negative attitudes and responses to epilepsy. However, like ME/CFS the invisible nature of epilepsy was also found to be a barrier to explaining the diagnosis as children/youth did not appear to be ill in the eyes of their peers (Benson, Lambert, Gallagher, Shahwan, & Austin, 2015).

A review of qualitative literature conducted by Chew et al. (2017) revealed that some young people with epilepsy felt that their teachers showed discriminatory behaviour through over-reacting to seizures and restricting participation in schooling, leading to children/youth feeling excluded. Discriminatory restrictive behaviours were reported to likely be due to a lack of knowledge on what epilepsy was and the child/youths capabilities (Chew et al., 2017). Semistructured interviews conducted by Chew, Carpenter and Haase (2019) of youth (aged 13-16 years) found that because of institutional barriers and policies some children/youths were excluded or prevented from participating in some activities because of seizure activities. Such institutional restrictions were perceived to perpetuate epilepsy misconceptions while experiences of acceptance and inclusion from peers were seen to reinforce normalcy (Chew et al., 2019).

Common to both ME/CFS and Epilepsy

Relating to both ME/CFS and epilepsy symptoms was the stigma associated with invisible symptoms or conditions. Vickers (2000) detailed the different disease stigma resulting from invisible symptoms with some children/youth experience the stigma of malingering where the individual is perceived to be faking their symptoms and condition. The stigma of malingering is often associated with conditions or symptoms which are difficult to measure or validate, like ME/CFS or some aspects of epilepsy. A lack of knowledge around invisible conditions may also result in ignorance-based stigma and a lack of concern in circumstances when concern is appropriate, valid, and needed, such as with absent seizures (Vickers, 2000).

Regardless of the condition, the attitudes towards the child/youth and the discrimination experienced manifests in similar ways, e.g., bullying, exclusion, and emotional distress. This stigmatisation is centred around the knowledge and understanding of epilepsy and ME/CFS, which then influences attitudes. As stated previously, each condition is experienced differently, with stigmatisation against ME/CFS and epilepsy appearing to occur at opposite ends of a ‘spectrum’, depending on symptom visibility. Visible and confronting epileptic seizures and effects often produce overt fearful reactions from on lookers that can incite negative automatic reactions (Benson, Lambert, Gallagher, Shahwan, & Austin, 2017; Yang et al., 2021). The complete opposite appears to occur for ME/CFS and less-perceptible seizure types/symptoms, with such symptoms often having questionable validity, legitimacy, and impact, failing to incite concern. At one end, confronting and often scary aspects of epilepsy can incite a fear response leading to exclusion, bullying, and subsequently reduced disclosure. In contrast, ‘subjective’ indiscernible symptoms of ME/CFS and epilepsy, with questionable severity and validity, incite scepticism, reduced social tolerance, and harmful labelling.

Support for Children/Youth’s Schooling

Like any disability or condition that has the potential to negatively impact on someone’s life, children/youth with ME/CFS and epilepsy, and their families, can benefit from support. Recent research has detailed different support options and adaptations that have been both beneficial and unsupportive to children/youth with ME/CFS and epilepsy. Research has also detailed supports which may be beneficial and the potential barriers that may need to be overcome to optimise support.

ME/CFS

In the first ME/CFS research of its kind, Brigden et al. (2021) conducted qualitative interviews exploring the views held by school staff, including class teachers, heads of year, senior teachers, an intervention officer, and a specialist educational needs co-ordinator, on supporting young children (aged 5-11) with ME/CFS in the UK. It was found that the majority of teachers held positive attitudes toward their students providing them with a range of tailored support options. Findings indicated that these support options covered physical, emotional, social, and academic needs, including reducing/personalising timetables, managing workload or monitoring signs of fatigue, as well as facilitating breaks and social interactions. Support was often based on parental knowledge, the child's needs, and teacher intuition, which meant support was tailored and proactive but often not evidence-based when teachers lacked appropriate knowledge and clinician input. This support did, however, hinge on staff receiving a confirmed ME/CFS diagnosis from medical personnel. Teachers identified needing support from, and communication with, the child's medical team, with greater knowledge and information dissemination between staff and peers to further enhance their ability to support their students. A close student-teacher relationship was identified as facilitating the understanding of the child's needs and was likely fostered by the young age of children. It is unclear whether this would change with older children who often have multiple teachers and larger class numbers. Unfortunately, Brigden et al. (2021) found that not all teachers held positive attitudes, with two teachers identifying they were sceptical of the diagnosis and did not observe an impact on schooling and another teacher identifying psychological factors as a better explanation for symptoms. These experiences and attitudes may be the result of stigma, particularly mental health and invisible illness stigma (Geraghty, 2020; Vickers, 2000), and poor illness understandings or may simply be that the child experiences less severe symptoms and less of an impact on schooling (Knight et al., 2018).

The findings of Brigden, Shaw, & Crawley (2021) are interesting as they reflect mostly positive attitudes of teachers towards their students and providing support, which is not necessarily in line with the negative attitudes associated with stigma research and the perceived illegitimacy of ME/CFS. This may reflect new viewpoints and evolving understandings of supporting children with ME/CFS, as Brigden, Shaw and Crawley used a diverse range of interviews across differing school types. However, as the teachers volunteered to participate, teachers with more negative views may have chosen not to participate or self-censored negative support views to avoid responding in a socially undesirable manner. The teachers who agreed to participate and discuss their support provision experiences dealt more exclusively with diagnosed children, as an official diagnosis of ME/CFS was a recruitment criterion. The positive views identified by the researchers may not translate to children yet to obtain an official diagnosis as it was unclear if the positive support attitudes and views of ME/CFS as a medical condition were already held by teaching staff or if belief in condition legitimacy came only with a formal diagnosis (Brigden, Shaw, & Crawley, 2021).

A Norwegian study conducted by Similä, Nøst, Helland, and Rø (2021) utilised semistructured interviews to explore young persons' (aged 13-21) with ME/CFS perceptions of positive and negative factors related to adaptations in schooling and everyday life. The semistructured interview guide was developed by multiple medical professionals with experience with ME/CFS and influenced by a patient representative and previous research. It was found that young people generally perceived a lack of adaptations in school and a lack of understanding from school staff, which some identified as being the result of a lack of ME/CFS knowledge. Students often felt overlooked and disbelieved, having to struggle to get adaptations which, when offered, were overly ambitious and failed to prioritise their needs. Similarly to Brigden, Shaw & Crawley (2021), support provision, and perceived legitimacy, often hinged on a diagnosis; however, in some instances a diagnosis was perceived to make no difference. When adaptations were provided participants noted having their health concerns taken seriously and received supports such as balanced education plans, fewer lessons and tests, and socialisation opportunities, with those attending special education schools receiving all these adaptations and more. These adaptations were seen to have a positive influence on attendance and socialisation. Conducting supplementary interviews during the COVID-19 pandemic provided a unique opportunity for researchers to study students' perspectives on the pandemic online teaching plans put in place, with adaptations being deemed helpful and aiding in communication with teachers. However, few children found not being able to meet with teachers face-to-face problematic for their learning (Similä, Nøst, et al., 2021).

In utilising young people's perspectives, the authors were able to gain insight into the youths own educational experiences, negating the biases that may arise from using teacher or parental perspectives. It is unclear if this limited participation to older children/youth who had the comprehension necessary to participate in these specific interviews. Utilising a range of sources in the development of the interview guide ensured questions were well suited to ellicit the experiences of young persons with ME/CFS, especially those related to education (Similä, Nøst, et al., 2021).

These findings do not appear to be as positive as those identified by Brigden et al. (2021) but may reflect greater variation in support experiences and potentially reflect the experiences of youth more accurately, given these findings are based on child/youth perspectives. Disparities in findings may also reflect differences in support provision between Norway and England, with the potential that English schools to be more supportive.

Epilepsy

Research conducted into the support of children/youth with epilepsy also provided insight into supportive experiences. Research in the UK conducted by Roberts and Whiting (2011) using semi-structured interviews looked into the perceptions of caregivers of children with epilepsy (aged 5-12) in relation to school experiences and the supports in place to accommodate the impacts of epilepsy. The interview guide was based on previous research. Parents noted relying on teachers to monitor and communicate with home their child's symptoms and progress during medication changes, with collaborative relationships being important to positive experiences. Many caregivers reported that their child was receiving an Individualised Education Plan but noted the lengthy period taken to receive these plans, while one parent reported receiving additional funding for special education services. Parents reported that inclusion initiatives, understanding teachers, and flexibility with attendance and academic aspects, such as assignment due dates and curriculum, were essential to minimising the impacts of epilepsy and ensuring school success. One parent who opted to home school their child noted online support which allowed for easier communication with the school and kept the child in contact with peers and teachers. However, some teachers were perceived to become overprotective or restrictive of children, which parents saw to be unnecessary and as a barrier to normalcy. These supports did not come without strong parent advocacy and not all experiences were positive, with negative experiences being centred around safety issues, communication difficulties, and the lack of emergency first aid knowledge. This led parents to suggest better teacher education on the many different aspects or presentations of epilepsy, and for all teaching staff to be involved and aware of the child's epilepsy and necessary safety plans (Roberts & Whiting, 2011).

Roberts and Whiting (2011) provided unique and interesting findings on parental perspectives of positive and negative support experiences. These experiences appear to reflect a diverse range of factors and adaptations that have influenced support experiences. Researchers identified that experiences came from different schooling types, including public, private, and home-based schools. One parent commented that paying for private schooling may influence support, but it is unclear if such monetary differences produced overall differences in support. It is also unclear what other factors may influence these schooling experiences, factors such as severity of seizures or level of cognitive deficits. In utilising qualitative research, Robert and Whiting have allowed for an in-depth look at the parent's perspective, allowing for interpretation and understanding of experiences which quantitative analysis might have missed. Furthermore, by utilising caregivers as participants, experiences were likely as close as possible to the child's own experience without having to negate the issues encountered when using such young children as participants, as is seen in the next review (Roberts & Whiting, 2011).

Further research in a UK setting was conducted by Johnson, Atkinson, Muggeridge, Cross, and Reilly (2021) who recruited children (median age 10.46) with active epilepsy, along with their parents and teachers, to partake in a questionnaire to investigate education and therapeutic provision. This questionnaire was developed in partnership with the target audience and was based on clinical experience and previous research, with additional open-ended questions for parents. According to parent report 67.7% of children received Individual Healthcare Plans and 56.7% had Education and Healthcare Plans. Most parents and staff agreed that class teachers and school staff were knowledgeable and had a good understanding of the child's epilepsy and/or epilepsy in general, with 87% of teachers reporting to know how to manage their student's specific seizures. The most commonly reported support was the use of seizure management plans, which were indicated by 82% of parents and 79% of teachers. Children identified the school nurse/medical staff or any teacher close by as those who helped most with their epilepsy or seizures. Over half of the teachers reported to have had general epilepsy training while only 45% had training on specific behavioural and learning implications. Significantly more staff in special schools reported receiving training and being knowledgeable about the child's epilepsy and medications than those in mainstream schools. Findings from parents open-ended responses revealed that, unless children had extreme intellectual disabilities, parents struggled to secure an EHCP and/or therapeutic provisions and perceived a lack of recognition for behavioural and learning needs and lack of communication with home. These deficits in support lead parents to suggest desired changes including better understanding of behavioural, learning, and emotional aspects, better communication, and the inclusion of broader non-academic learning in schools (Johnson et al., 2021a).

Even though the questionnaire utilised by Johnson and colleagues (2021) was developed in a manner that took into account the perspectives of participant groups and previous research, allowing for some validity, responses were restricted to only three types of supports; seizure management plans, call a parent, or call an ambulance, relating only to emergency seizure response. It is unclear if this is a full representation of supports offered or if this imposed restrictions on findings. However, allowing for parents to provide qualitative responses to open ended questions, allowed researchers to obtain further insight into parent's perspectives of education and therapeutic supports. This research also had apparent strength in having three participant groups: children, parents, and teachers, allowing for not just one perspective and for comparison between these perspectives. However, the majority of children recruited appeared to have characteristics that precluded them from participating with only 29% of children having the capacity to complete the questionnaire, with researchers citing the young age and cognitive deficits/intellectual disabilities as the main barriers (Johnson et al., 2021a).

Common to both ME/CFS and Epilepsy

As detailed throughout these few reviews, and throughout other literature as well, children/youth, parents, and teachers have commented on different adaptations to schooling that may help or are already helping support students with the implications of their ME/CFS and epilepsy. These included supports such as reduced or flexible attendance to help with the implications of fatigue, altered curriculums or flexibility with assessments to help with the implications of reduced cognitive functioning, and inclusion initiatives to reduce isolation and improve socialisation (Brigden, Shaw, Barnes, Anderson, & Crawley, 2020; Brigden et al., 2021; Johnson et al., 2021a; Johnson, Atkinson, Muggeridge, Cross, & Reilly, 2021b; Roberts & Whiting, 2011; K. Rowe, 2020; Similä, Nøst, et al., 2021). On the other hand, an example of support that was not found to be helpful was when schools or teachers became too over protective or too restrictive as a means to try and protect children either from themselves and over exertion or for safety reasons (Brigden et al., 2020; Brigden et al., 2021; Johnson et al., 2021b; McEwan, Espie, Metcalfe, Brodie, & Wilson, 2004).

A reoccurring support that was found throughout both the ME/CFS and epilepsy literature to be helpful or potentially helpful and wanted was liaison/communication and collaboration between families/parents/children, schools or teachers, and, in ideal situations, medical professionals (Brigden et al., 2020; Johnson et al., 2021a, 2021b; Similä, Rø, et al., 2021). Communication was often found to mean that supports or adaptations were or would be suited to the child's needs and followed medical advice, while also keeping families and teachers in the loop of changes or progress (Brigden et al., 2020; Johnson et al., 2021b; K. Rowe, 2020; Similä, Rø, et al., 2021).

Another support detailed throughout the literature was actually the support of teachers, more specifically to support teachers with their knowledge and understanding of epilepsy and ME/CFS through education and training. Numerous research articles detailed the necessity of educating educators and improving their understanding, a point reiterated by children, parents, and teachers alike (Brigden et al., 2020; Johnson et al., 2021a; K. Rowe, 2020). Research by Yang et al., (2021) found that teachers lacked more than a basic understanding of epilepsy and as a result were fearful and hesitant to help during a seizure, calling for better training of teachers so that they can better help during emergency situations (Yang et al., 2021). The benefits of such training has also been reported with literature detailing better knowledge and understanding, and reduced stigmatisation (Abou Khaled, Ibrahim, & Moussa, 2020; Mecarelli et al., 2015; Renzetti et al., 2020).

Support, the environment, and the Socio-ecological model

As wider environmental and ecological factors influence health and health behaviours, it stands to reason that support would too be influenced by interrelated environments (Lyons & Chamberlain, 2006). From previous literature, it is apparent that there a multitude of factors and environments that appear to be influencing support experiences, including both immediate and wider environments and how these interact with the child’s condition, and their parents and teachers. Previous research has detailed factors close to the child with disabilities as well as wider collaborative factors which can influence and be targets for support intervention (Anaby et al., 2019). Using a socio-ecological model to further conceptualise these factors and environments as nested interrelated levels of health and support influences may help bring better understanding to support experiences and organise the extant literature.

A review conducted by Anaby et al. (2019) detailed previous research in which services and supports were provided to children with disabilities. These were identified and organised into multi-level categories as services delivered at a micro-level, including the immediate environment, and those at the macro-level, including the wider environment. Six microlevel principles or targets identified included supports for educational staff in terms of training and education aimed at increasing capacity and knowledge; services or supports within the child’s immediate environment i.e., the home or classroom; family involvement and collaboration including on-going communication and support for carers; direct group-based services for both students and teachers; pull-out therapies involving removing the child from schooling; and more traditional individual-based supports for students. The four macrolevel principles identified went beyond these direct services including collaborative interventions that included both individual and organisational levels; organised and cohesive service coordination; multilevel services; and universal design aspects. It was identified that these principles often worked best in conjunction with one another.

These micro- and macrolevel service and support interventions incorporate multi-level components, identifying support for the child with disabilities as being influenced by a system of interrelated influences with a multitude of possibilities for service intervention, highlighting the importance oof and need for a systems focus (Anaby et al., 2019).

One such systems model, which may provide for a more detailed discussion of support, is Bronfenbrenner's (1979) model of the ecology of child development or ecological systems theory. Bronfenbrenner (1979) posits child development as a complex system of relationships affected by multiple levels of the surrounding environment, from the child's immediate settings, including family and school, to the broader cultural values and customs present. These were five distinct yet interrelated systems; the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem, with the individual child at the centre. The microsystem, deemed by Bronfenbrenner as the most influential system, contains the immediate environment such as parents, teachers, and peers, where relationships are bidirectional in their influence and often very personal in nature. The mesosystem consists of the interactions between those within the microsystems, with the nature of these interactions exerting influence over the child's development, i.e., positive interactions between a parent and teacher exerting a positive impact. The exosystem incorporates other both formal and informal social structures, settings in which the developing child is not an active participant, but influence development through their indirect influence on the microsystem. The macrosystem consists of the broader established cultural and societal elements which influence belief systems and ideologies of culture. Finally, the chronosystem consists of the environmental changes occurring over a lifetime such as key historical events or life changes.

Research conducted by Brigden et al. (2020) discussed and conceptualised their findings on the integrated care of young children with ME/CFS in terms of a socio-ecological framework. Families, consisting of parents and children (5-11 years), along with teachers and clinicians were interviewed using a semistructured format with topic guides developed with previous literature and in consultation with patient and school advisory groups. Four themes were identified which were organised into interrelated levels of a socio-ecological framework. Firstly, children were placed in the individual level and identified as being too young to take responsibility of their care particularly in relation to moderating/regulating their own behaviour in a school setting. Theme 2 identified the distinct responsibilities of the carers involved with the support and care of young children with ME/CFS. Parents fell within the identified interpersonal level, or the microsystem, having a direct relationship with children, coordinating their care and being a liaison between clinicians and the school. The next level was then comprised of the interpersonal and organisational levels, or the microsystem and the exosystem, with teachers and clinicians falling within this level. Clinicians' roles were that of providing a legitimate diagnosis and advice for adaptations, while teachers were seen to implement adaptations and maintaining connections with the child and family. The next theme and aspect to the framework was the value of communication in initiating and informing support and the influence of positive relationships to integrated care. The negative influences of fractious relationships between teachers and parents were noted, with fractious relationships requiring direct intervention by clinicians. This being similar to the mesosystem described by Bronfenbrenner. The final theme and level was the optimisation of shared care which incorporated multi-disciplinary care and higher up education and health policies, deemed the policy level or another aspect to the exosystem (Brigden et al., 2020).

Brigden et al. (2020) used this framework to conceptualise their findings in terms of a system of wider environments, deeming optimal care and support as a complex system where not just one party was solely responsible. In interviewing multiple parties from different environments in which the child is involved, Brigden et al. (2020) was able to gain multiple perspectives detailing how these interrelated systems worked optimally together influencing each other and the outcomes for the child with ME/CFS. This model followed closely to Bronfenbrenner's (1979) original framework with few notable differences which were likely informed by the findings of Brigden et al. (2020). Bronfenbrenner (1979) provide distinction between the micro- and exosystem as environments which the child is an active member and those which they are not directly involved. This then calls into question why Brigden et al. (2020) combined the two. It is unclear if results suggested that social structures identified, this being teachers and clinicians, could not be separated from or exerted the same influence over care as organisational structures such as the school board or healthcare. Furthermore, this framework stops short of a macrosystem or wider cultural context, which participants may not have commented on. This research provides unique and insightful perspectives into the integrated care of young children with ME/CFS.

A socioecological approach to support provides a multi-level framework which acknowledges the complexity of the child's environment and the influence such environments have over support. The child/youth is situated in the middle with these interrelated environments surrounding them, with each level or environment exerting less immediate influence the further away from the child they get. Such models may provide a starting point for which governments can identify environments or factors which are benefiting the child or those which are potentially letting children with ME/CFS or epilepsy down but providing targets for system improvements.

The New Zealand Education System

In order to support children with disabilities, the New Zealand government or The Ministry of Education has a number of systems in place to try and support children/youth with chronic illness. Firstly, special education services offer a number of options to support students with special education needs and their caregivers. This may include providing onsite help through support workers, occupational therapists etc, or special education units, or providing funding for resources such as a teacher aide (Ministry of Education, 2021, May 07). Te Kura or correspondence school is another schooling option in New Zealand, which offers distance learning from early childhood through to the end of secondary schooling or NCEA level 3 education (Ministry of Education, 2022, April 28). New Zealand also has three Regional Health Schools, located in Auckland, Wellington, and Christchurch, with a teacher being made available to a child/youth anywhere in the country while the child remains enrolled at their regular school. Regional health schools aim to support students, who have numerous absences due to illness or numerous hospital stays, in their learning and eventual return to mainstream schooling. This includes children with chronic physical and psychiatric illness, and those recuperating and in need of support for their return to school (Ministry of Education, 2022, May 12). However, not every child/youth with a chronic medical condition may satisfy the eligibility criteria for such support. Alternatively, a school may also choose to handle the situation at their discretion, accommodating the child/youth when and where they can. Special assessment conditions may be offered when physical, medical, sensory, learning disabilities, or psychological challenges are present and would impact on national level assessments. Guidance is also available from the Ministry of Education for early learning services and schools to support students with health conditions; however, these are only to inform educators and are not compulsory (Ministry of Education, 2022, May 28; Ministry of Education, 2021, October 21).

The Current Research

Given the evidence discussed on the negative impacts of the health-related needs associated with ME/CFS and epilepsy on schooling, along with the evidence discussed on supports or lack thereof available to such children across different countries, providing a perspective on the support experiences of children/youth with ME/CFS and epilepsy in a New Zealand context would provide novel and pertinent information to further current literature. As there is yet to be such research, the current research aims to look at the parental perspectives of the supports available to children/youth with ME/CFS and epilepsy within the New Zealand education system. This aim will be met by answering the research question What are parents' perceptions of the support/s available to their school aged child/youth to help with the impact of ME/CFS or epilepsy in a New Zealand schooling context? As this is research yet to be undertaken within a New Zealand setting, this exploratory research will provide novel findings, which will hopefully inform future research and targeted interventions for improving the schooling experiences of children/youth with ME/CFS and epilepsy within New Zealand schools.

Method

Participants

Parents/caregivers of school aged children (aged between 5 and 20) with ME/CFS or epilepsy and experience of the New Zealand education system were recruited through an ME/CFS or epilepsy organisation. As it was anticipated that some children may have to repeat a school year, as well as parents being allowed to answer retrospectively, the age bracket was increased to include older youth. Parents/caregivers of children/youth with ME/CFS or epilepsy without experience of the New Zealand education system were excluded based on not meeting the inclusion criteria for this study. Non-identifiable general demographic information (gender, age, and ethnicity) was collected about the parent/guardian and their child/youth. Those with incomplete quantitative data were excluded from quantitative analysis. This demographic information is presented in Table 1.

Procedure

An extensive search of the literature was conducted investigating chronic health conditions in schools and the impact chronic illness has on schooling. This search produced literature responses with regards to chronic disabilities, chronic learning disabilities, and chronic health conditions such as cancer, asthma, and cystic fibrosis. This initial search was conducted to get a general understanding of how chronic health conditions may impact on schooling. This search was then refined to specifically ME/CFS and epilepsy and how these impact on schooling, specifically.

The literature search then continued specifically into the support for children/youth with chronic health conditions in schools. This included actual support, proposed support, and wanted support from the perspective of students, parents, teachers and the institutions. Once a general understanding was reached, the literature search was refined to include only the support relating to children/youth with ME/CFS and epilepsy. A thorough literature review was then conducted pertaining to children/youth with ME/CFS and epilepsy, the specific impact these conditions have on schooling, and the support relating to a schooling context. Research ethics were then sought and due to the nature of the project, it was judged by peer review to be low risk, so was not reviewed by the university's Human Ethics Committees.

Once the aim to look at the parental perspectives of the supports available to children/youth with ME/CFS and epilepsy within the New Zealand schooling system was formulated, a literature search was conducted to specifically look for a questionnaire designed to answer the research question 'what are parent's perceptions of the support/s available to their school aged child/youth to help with the impact of ME/CFS or epilepsy in a New Zealand schooling context?'. The perspectives of children/youth's themselves were not sought due to the vulnerable status of young persons and the potentially unreliable or insufficient responses they may produce due to their age and understanding. It was clear from the literature that this was a relatively novel research question and that there was no existing useable questionnaire that would adequately answer our research aims. Subsequently a new questionnaire was designed to answer this specific research question, calling on both quantitative and qualitative data. It was perceived by researchers that a mixed methods design would provide richer findings with regards to these experiences, with the positive attributes of both quantitative and qualitative methods (Bishop, 2015). This included creating a new set of questions, along with open ended responses, to measure parental perspectives of the support provided by school systems to children and youth with ME/CFS and epilepsy. Within the questionnaire, measures of condition impact, health and school outcomes, and efficacy of support were all created using previous research and influenced by pre-existing valid and reliable measures, which are all cited within the relevant sections under materials. Again, when designing this new questionnaire, the perspectives of children and youth were not included. Designing a questionnaire that was at a primary school reading level and comprehension would not have allowed for the depth of responses we were hoping to obtain. The questionnaire is detailed in the materials section and the ME/CFS version is attached in Appendix A. The two questionnaires were created identical, except for the list of epilepsy symptoms which is detailed in 'Materials'.

This questionnaire was then sent to a Massey University School of Psychology Programmer/Analyst for it to be put into Qualtrics, university software designed to host online questionnaires. Once the online survey was created, it was reviewed by the lead author multiple times and any mistakes or bugs were identified and corrected. When the online version of the survey was up and running to a satisfactory level, friends and family of the lead author were recruited to complete the online survey using fake biographies composed by the lead author. These ten fake profiles were created, incorporating different possible participant traits i.e., demographic information, condition type, degree of impact, institution supportiveness etc. This was done so that as many response options as possible could be selected, before genuine participants completed the survey, to ensure questions and responses made sense to lay persons, as well as to ensure that all response options worked, were recorded, and any appropriate follow-up questions associated with specific questions were asked. No issues or difficulties were reported.

Relevant organisations were then identified and contacted to request that the invitation to participate in the research, along with a link to the online questionnaire, be disseminated to parents or guardians of children with ME/CFS or epilepsy. The link given led potential participants to an information page introducing the researchers and detailing the research project. This included a project description and invitation to participate, participant identification and recruitment information, selection criteria, data management and storage information, participant's rights, and researcher contact information. Consent to partake in the research was implied through the completion and return of the questionnaire. Participants were informed that they could withdraw at any time or refuse to answer any question. Participants were also asked to acknowledge that they had read and understood the information sheet for this study and consented to the collection of responses, by indicating a 'Yes' or 'No' response.

All data, both complete and incomplete, was stored securely on a Massey University database. If participants were interested in receiving a summary of the research and results an email address was provided once the questionnaire was complete. The email address provided was kept separate and was not linked to the completed survey.

Materials

All information pertaining to educational experiences was collected via an online survey, created by the author. This online survey collected both quantitative information, via closed questions, and qualitative information, via open ended questions asked at the end of each section, simultaneously. These questions asked participants to add to or elaborate on any of the topics raised by the survey questions. This meant parents responded to the given closed questions but were also able to provide additional information they perceived to be pertinent to their child/youth's schooling experience. A mixed methods approach was chosen so the benefits of both quantitative and qualitative data could be used simultaneously, gathering quantitative data on perceptions of specific support experiences, and qualitative data on parents' subjective perceptions and experiences of support. Specifically, the authors wanted the generalisability of quantitative methods whilst still considering the participant and their individual experiences through qualitative methods, with the potential for more data and richer findings to be obtained with the hopes that they would go on to inform future research and support initiatives (Bishop, 2015). This was also identified through the consumer review process as an important aspect to include, asking for a mixed methods approach with more options for participants to respond in an open format.

The quantitative aspect of the survey asked parents or guardians of children/youth with epilepsy or ME/CFS about; non-identifiable general demographic information (gender, age, and ethnicity) for both the parent or guardian and the child/youth; the specific health-related aspects which impact on schooling; the attendance, academic and quality of life outcomes of their child/youth; which specific areas of schooling were impacted on and the degree of impact; the degree of disclosure of diagnosis; and what support was offered by the education institution in order to broaden understanding of the support provided by New Zealand educational institutions to children/youth with ME/CFS and epilepsy. Questions asked about the disclosure of diagnosis and support appeared twice in the survey, once with regards to ‘Mainstream’ schools and then again for ‘Other’ schools i.e., regional health schools and Te Kura (New Zealand correspondence schools) if applicable. All responses were pre-defined and closed, except for ‘other’ options, where applicable, to allow for participants to enter in a response not available for selection.

The open-ended questions followed each topic section, asking participants to add to or elaborate on any of the topics touched on. This qualitative aspect was added in addition to allow for the collection of subjective perceptions of experiences and following consumer review and in acknowledgement of the desire to share experiences in an open format.

Once research ethics approval was obtained, both surveys were sent to heads of respective organisations, i.e., Epilepsy New Zealand and Support for Carers of Youth with ME/CFS group, as well as to several consumers, identified by the academic supervisors from previous research contacts, who then reviewed the surveys. All suggestions were reviewed by the lead author and academic supervisors to determine the validity of each and how best to incorporate necessary edits or contributions.

The current aim of the research was influenced by existing literature, which was also used to develop the sections and questions asked in the online survey. All questions were asked in current and past tense to enable parents to answer with regards to a current or previous education institution.

Initially, participants’ eligibility was determined by asking if their child/youth had experience with the New Zealand education system. The first section then asked for the parent and child/youth’s demographic information including gender (male, female, non-binary, other), age, and ethnicity (New Zealand European/Pakeha, New Zealand Māori, Pacific islander, Asian, Middle Eastern/ Latin American, African, other). Age was recorded using a simple drop-down selection. These response options were derived from the most recent New Zealand consensus data.

The second section asked for the child/youth's health related information, specifically if the child/youth experienced symptoms and/or healthcare needs that impact/impacted on schooling and if so, what the main impacting symptoms and/or health care needs were. This was done using two lists, one of symptoms and the other health care needs, which allowed participants to record as many as applied. The list of epilepsy symptoms were; tonic-clonic seizures, absence seizures, other seizure type, intellectual disabilities, physical fatigue, mental fatigue, incontinence, cognitive impairment/deficits, reduced concentration, emotional concentration, reduced concentration, emotional dysregulation, and other. The list of ME/CFS symptoms are included in Appendix A page 101. Each list was compiled using a large variety of previous research studies, incorporating every symptom or healthcare need. A 'set' list obtained from one online source was not utilised as, when compared and cross referenced across multiple sources, no list appeared complete (Brown & Cox, 1999; Chew et al., 2017; Everett & Fulton, 2002; Lewis & Parsons, 2008; Reilly & Ballantine, 2011; P. C. Rowe et al., 2017; Snead et al., 2004; Tollit et al., 2018; Tomoda et al., 2000). Consumer review was also used, and missing responses were added to the list, the wording of some options was also changed to more accurately reflect the child/youths' experiences, and examples were added to improve understanding. The term 'healthcare needs' was an amalgamation of treatment options e.g., treatments, management options such as medications and lifestyle changes, and medical appointments such as GP and specialist visits. Health related information was not obtained with regards to specific educational institutions to reduce the length of the questionnaire and load on parents completing the questionnaire. This was also done so a broader understanding of the symptoms and health care needs experienced in a general educational context could be obtained.

In addition to symptoms and health care needs, the frequency with which a child/youth experienced negative attitudes in the form of discrimination or prejudice in response to their health condition (in relation to the school environment) was asked using a 5-point Likert scale. Responses included: 'Always', 'Often', 'Sometimes', 'Rarely', and 'Never'. Stigmatisation measures were initially investigated but were deemed too lengthy to be included in this research, plus had the additional barrier of being patented. Discrimination and disease stigma was nonetheless included, as they were determined to be an important aspect of health that could have an impact on schooling. This decision was made following a review of the literature which demonstrated both ME/CFS and epilepsy have associated stigma that impacts on schooling through how the institution and teachers view and treat child/youth, as well as how peers treat them and how teachers/institutions deal with negative peer relationships (Benson et al., 2015; Chew et al., 2017, 2019; Lambert et al., 2014; Parslow, Harris, et al., 2017; Winger et al., 2014). A single question, refined from the main stigmatisation and discrimination issues faced, on the experience of negative attitudes was deemed sufficient. This second section was included to gain an idea of the child/youth's health condition to utilise in analysis to gain an understanding of the efficacy of support.

The third section was comprised of health outcome questions in order to gain an understanding of how (and to what extent) ME/CFS and epilepsy affect schooling. In line with previous research, parents/guardians were asked about their child/youth's attendance, academic performance and quality of life. Attendance was measured by asking parents to indicate the average number of hours their child/youth attended in an average week, using 3 hourly increments. This was different from previous research as consumer review indicated that a half day measurement was too restrictive and inappropriate. The parents' perceptions of academic performance and quality of life was measured using a Likert scale, with the responses; 'Excellent', 'Above average', 'Average', 'Below average', and 'Very poor'. Using Te Whare Tapa Wha – a Māori model of health developed by Mason Durie (1998, as cited in Stephens, 2008) comprised of four pillars, taha tinana (physical health), taha hinenagro (mental health), taha whanau (family health) and taha wairua (spiritual health) – and a pre-existing quality of life measure (Knight et al., 2018; Varni, Seid, & Kurtin, 2001). Quality of life was determined to be comprised of their physical health, mental health, social relationships, and sense of meaning and purpose.

This was to enable exploration of the potential efficacy of support, specifically if support aligned with specific needs to gain an understanding of their schooling experiences attendance, academic performance, physical health, mental health, and quality of life. These were asked for both ME/CFS and epilepsy, as evidence suggested all aspects may be affected in both ME/CFS and epilepsy, to some extent. Previous research, which measured attendance and absences, often used self-report days and half days as their unit of measure (Aguiar et al., 2007; Knight et al., 2018; Serdari et al., 2009). In line with this, attendance was original set to be measured in 'half days' via self-report. However, following consumer review, 'half days' was determined to be too large of a unit, with one consumer stating that their child, on average, would not even attend one half day in a week. Subsequently, attendance was measured in hours using ten 3 hourly time frames from 0-3 to 30+, with 30 hours or more being classed as full-time attendance. The set-up of this question for both surveys can be seen in Appendix A page 106. As far as we are aware, no other research has used ‘hours’ as a unit to measure attendance, but it was important to listen to consumers and be inclusive of all students’ schooling experiences.

Academic performance, unlike previous research, was not measured using an intelligence score (Knight et al., 2018; Nijhof et al., 2016; Reilly et al., 2014), but simply by the parent’s perception of the child/youth’s academic performance on a 5-point Likert scale. Responses included ‘Excellent’, ‘Above average’, ‘Average’, ‘Below average’, and ‘Very poor’. As this project utilised the parents’ perspective and did not include any direct measurement of the child/youth, such intelligence and achievement tests were deemed inappropriate. Furthermore, as this research topic is focused on support (and not the impact in terms of academic performance and achievement) such measures would have unnecessarily complicated the survey.

To determine the child/youth’s quality of life a set of four questions were constructed using the Māori model of health Te Whare Tapa Wha and a pre-existing quality of life measure. These questions asked about the parent’s perspective of their child/youth’s physical health, mental health, social relationships, and their sense of meaning and purpose. Like academic performance, answers were given on a 5-point Likert scale, with the response options ‘Excellent’, ‘Above average’, ‘Average’, ‘Below average’, and ‘Poor’. The main scales of the PedsQL 4.0, which asked about physical health, psychosocial health, emotional functioning, social functioning, and school functioning aspects (Varni et al., 2001), were adapted using Te Whare Tapa Wha, as a measure of quality of life. Pre-existing measures were adapted to avoid using an additional lengthy questionnaire, which would have unnecessarily increased the length of the survey and burden on participants, while also considering Māori experiences of health. ‘Social relationships’ was included, as opposed to taha whanau, in order to fit the schooling context. The child/youth’s ‘sense of meaning and purpose’ was adapted from te taha wairua to remain culturally sensitive without alienating non-religious/spiritual families.

The fourth section was used to determine the specific areas of schooling affected by the impact of these conditions. This was done so that a comparison could be made with the support offered, to further determine the efficacy of support and whether support aligned with the impact of each condition. In order to reduce the length of the questionnaire and potential burden to participants, a table was created, with four columns and 12 rows, where parents could indicate the areas of schooling affected by the impact of symptoms, health-care needs, and prejudice/discrimination. These health-related aspects were listed in the second, third, and fourth columns. The areas of school, developed using pre-existing literature (Aguiar et al., 2007; Crawley

& Sterne, 2009; Elliott et al., 2005; Everett & Fulton, 2002; Knight et al., 2018; Nijhof et al., 2016; Reilly et al., 2014; Serdari et al., 2009; Similä, Nøst, et al., 2021; Similä, Rø, et al., 2021; Tollit et al., 2018; Winger et al., 2014) and consumer review, was listed in the first column. Participants were instructed to indicate if a particular area of school was affected by any of the three health-aspects by going across the rows and clicking on the appropriate boxes. The table created for both questionnaires can be found in Appendix A page 110. Similar to the symptoms and healthcare needs lists, no set list was utilised and any possible area of schooling that could be impacted on (that was mentioned within the literature) was added. Through the literature review and consumer review process, it was, again, determined that no pre-existing list contained every potential area of schooling, so a collated list of options was comprised. Furthermore, an 'other' option was added so that any area that had not been mentioned could be recorded by the participants.

In addition, a 'no impact/none' option was added to the table in the event that any of the three aspects of the child/youth's health did not impact on any area of schooling. If a parent indicated a 'No impact/None' response, a follow-up question was asked to determine if this was because symptoms, healthcare needs, and/or prejudice/discrimination had no impact on schooling or if the child/youth was sufficiently supported by the institution resulting in no impact. Parents were then asked to what extent they thought their child/youth's health condition impacted on schooling. The response options were 'Not at all', 'Very little', 'Somewhat', and 'To a great extent'.

Starting from the fifth section, questions and answers were separated based on the education institution, and the questions asked once for 'Mainstream' school and then again for 'Other' schools, beginning with 'Mainstream' schools. The reason for this being that it was considered that 'Mainstream' schools and 'Other' schools, such as regional health schools and Te Kura, are quite different, so experiences of these institutions needed to be separated out. This was so that comparisons could be made between the support offered by the different education institutions. Parents were initially asked if their child/youth had been involved with 'Mainstream' schools while they have been unwell, with a 'Yes' or 'No' response. If a 'No' response was recorded, a follow up question asked what the reason was for the child/youth not having been involved with a 'Mainstream' school. Two possible responses were offered, the first option being 'child/youth was diagnosed before school age so went straight into another education institution, such as regional health schools and/or Te Kura'. The second was an 'other' option allowing the parent to record the specific reason behind this. The questionnaire then automatically directed them to the section of questions related to 'Other' schools. If a 'Yes' was reported then the questionnaire continued. As this research specifically focused on the support offered for the health-related aspects that impact on schooling, parents/guardians were asked to complete the next section in relation to the 'Mainstream' school, past or present, that their child/youth spent the most time involved with whilst having a ME/CFS or epilepsy diagnosis.

The sixth section asked about whether the child/youth was still involved with this institution. If a no response was given, parents were asked why the child/youth had been moved from this institution. This was done with the aim of gaining an understanding of why a child/youth may have been removed from a school, more specifically if this shift was related to their health condition and/or the support provided by the institution in question. The list of potential options was again comprised using literature, mainly qualitative research, where these reasons were teased from parent, teacher, and student reports. The consumer review process also enabled the list to be filled out until consumers were happy that the list of options was complete. The list of options from both questionnaires is recorded in Appendix A page 114.

The seventh section asked about the disclosure of the child/youth's health condition to the school. First, participants were asked if the institution had been informed of the child/youth's ME/CFS or epilepsy. If a 'Yes' response was given then they were asked if the institution was made aware of the impact the condition had on schooling, with three possible responses 'Not at all aware'; 'Partially aware'; and 'Fully aware'. If either of the last two responses were selected - meaning that the institution was/is, to some degree, aware of the impact of their child/youth's health condition - a follow-up question was asked regarding who had informed the institution of the impact of their child/youth's health on schooling. Six possible responses were presented, and parents were able to select as many responses as applied to their child/youth including 'You or other parent/guardian'; 'General practitioner'; 'Specialist'; 'Other medical professional'; 'Previous educational professional'; and an 'other' option for parents to specify another party if applicable. If a 'No' response was given to the initial disclosure question or an initial 'Yes' response followed by 'Not at all aware' for the second question, then another follow-up disclosure question was asked asking why the institution had not been made fully aware of the impact of their health on schooling. The list of potential responses, where they could select as many as applied, were; 'Not necessary'; 'Private information'; 'Fear of discrimination (unfair treatment, exclusion, bullying etc)'; 'Have not gotten around to it'; 'Lack of specific medical expertise'; 'No reason'; and 'other'.

This was done as previous research indicated that non-disclosure and lack of communication can be a barrier to receiving adequate support. Furthermore, research suggested that the level of knowledge teachers had about a child/youth's functional capacity influenced how understanding and supportive they were towards the student (Chew et al., 2017). This was further backed by Brigden et al. (2020) who demonstrated that the degree to which the school was informed of the health status and the party, i.e., medical professionals vs. parents, who informed the institution may influence the efficacy of support provided (Brigden et al., 2020). Although potential barriers to receiving support was a minor component of this research and not directly related to the main research question, it was perceived to be a key component to receiving effective support, which may unnecessarily show institutions to be unsupportive when they are not aware of the condition and its implications.

The eighth section was concerned with the support and supportiveness of an institution. More specifically we asked about the kinds of support provided by the 'Mainstream' school, the kinds of support their child/youth used, and the kinds of support they believed their child/youth needed. Asking about the three facets of support was done in response to consumer review. Initially participants were asked about the support supplied by the institution, but it was identified that the school may have provided plenty of support that simply does not fit the child/youth's specific needs, so is therefore unsupportive. Through the consumer review it was decided that asking about both the support provided and the support used would provide a better understanding of this relationship. The support needed was also added to see if the parents could identify additional necessary support that was not offered.

To reduce the length of the questionnaire, a second table was created with 4 columns and 23 rows. The first column listed potential support types relevant to the schooling environment. Again, as this specific area was not well researched, a list of potential support types that might be offered was comprised using multiple research articles (Brigden et al., 2020; Brigden et al., 2021; Johnson et al., 2021a, 2021b; McEwan et al., 2004; Roberts & Whiting, 2011; K. Rowe, 2020; Similä, Nøst, et al., 2021; Similä, Rø, et al., 2021; Yang et al., 2021). This included support types from research specifying support options provided by schools, parent and student requests for specific support, and teacher support recommendations, found in both qualitative and quantitative research. The remaining three columns asked for the types of support provided by the school, the types of support used by your child/youth, and the types of support needed. Participants were instructed to answer in relation to their child/youth's health condition and to indicate the kinds of support that applied by clicking on as many of the appropriate boxes as required. A copy of this table can be found in Appendix A pages 120 and 121. This question was asked in order to answer the main research question of what support was offered by the different New Zealand education institutions and the efficacy of such support, i.e., does this support align with the impact of the child/youth's health and adequately support the child to a satisfactory level

Participants were then asked to indicate the extent to which they thought this institution supported their child/youth with the impact their ME/CFS or epilepsy had on schooling. Responses were given on 4-point Likert scale including 'Not at all'; 'Very little'; 'Somewhat'; and 'To a great extent', with an additional option to indicate if their child/youth's health condition 'Does not impact on schooling'. If a 'Not at all' or 'Very little' response was given. The participants were then asked a follow up question 'What do you think stopped the institution from supporting your child/youth?'; the list of potential responses can be found in Appendix A page 123. Parents were then asked if they were satisfied with the level of help/support provided by the school, with a 5-point Likert scale for response options including, 'Very dissatisfied', 'Dissatisfied', 'Neither', 'Satisfied', and 'Very satisfied. Finally, participants were asked whether they agreed that the school/educational professionals could benefit from training and education on their child/youth's health condition, again with a 5-point Likert scale including 'Strongly agree', 'Agree', 'Neither agree nor disagree', 'Strongly disagree'.

These three questions were asked to gain an understanding of the efficacy of support from the parents' perspective; more specifically if the support received adequately supported the child/youth to a satisfactory level. One of the more frequently asked questions when investigating schooling, with regard to epilepsy and other specific health concerns as well as disabilities in general (Kampra et al., 2017; Porter, Georgeson, Daniels, Martin, & Feiler, 2013), was the parental satisfaction of support and school services. This was often used as a gauge of the school's level of support. Participants were then asked what they believed stopped the institution from being supportive in order to identify potential barriers to support, including things such as disclosure, stigmatisation, funding limitations etc. This was again comprised using a range of literature articles which mentioned different challenges and barriers encountered, as well as consumer review to design a specific list suited to students with ME/CFS and epilepsy (Aguiar et al., 2007; Benson et al., 2017; Brigden et al., 2020; Chew et al., 2017, 2019; Johnson et al., 2021a; Kampra et al., 2017; Roberts & Whiting, 2011; Similä, Nøst, et al., 2021). These questions marked the end of the questions pertaining to 'Mainstream' schools

The ninth section was where the first questions relating to 'Other' schools i.e., RHS or Te Kura began and where repetition of previously asked questions, relating to 'Mainstream' schools, occurred. This section began by asking participants if their child/youth had been involved with another education institution that was not a ‘Mainstream’ school i.e., RHS or Te Kura, with ‘Yes’ and ‘No’ response options. If a ‘No’ response was recorded a follow-up question was asked about why the child/youth had not been involved with ‘Other’ schools. The response options to choose from included: ‘Did not know about these education institutions’, ‘Child/youth does not meet the criteria’, ‘Enrolment process too difficult’, ‘Do not see this as necessary’, ‘Do not believe that such education institutions could meet your child/youth’s needs’, and ‘Other’. The participants were then informed that this concluded the survey. If a ‘yes’ response was recorded then a follow-up question was asked asking if they wished to answer questions about their child/youth’s involvement with ‘Other’ schools, again with ‘Yes’ and ‘No’ response options. If a ‘No’ response was indicated, then the participants were informed that this concluded the questionnaire.

If a participant had had experience with ‘Other’ schools and wished to answer questions about their child/youth’s involvement, then the online questionnaire continued on to the next set of questions. Participants were then presented with a message that informed them that the institutional experiences we were interested in were related to the institution that their child/youth had spent the most time enrolled with, which could be either a current or past enrolment. From here questions previously asked about ‘Mainstream’ school experiences were repeated but in the context of ‘Other’ schools.

Firstly, participants were asked if their child/youth was still involved with this institution. If a ‘no’ response was indicated parents were asked why they had moved their child/youth from this institution. The list of possible responses was compiled using previous qualitative research and consumer review which had described reasons why they were no longer involved with a school. This question was asked as it had become apparent, through the consumer review process, that such ‘supportive’ institutions, designed to aid child/youth with health conditions or disabilities, may not be setup for students with ME/CFS or epilepsy. In line with the Mainstream’ school questions this was specifically looking to explore if this shift in schools was related to their health condition and/or the support provided by the institution in question. The list of possible responses can be found in Appendix A page 128; they are different to the list used for ‘Mainstream’ schools, as additional response options were added at the request of consumers to better suit ‘Other’ schools.

The eleventh section was a repeat of the disclosure questions previously asked in section seven. However, the question about why the institution was/has not been made fully aware is worded differently in this section. In this section the question asks, ‘why was/has this institution not been made fully aware of your child/youth’s health condition/health needs?’

The twelfth section asking about the support and supportiveness in ‘Other’ schools was a repeat of section eight asking about the support and supportiveness of ‘Mainstream’ schools. The instructions used and table presented for the support provided, used, and needed were the same in both sections. A copy of this table can be found in Appendix A pages 134 and 135. Participants were then again asked to identify what they thought stopped the institution from supporting their child/youth. The list of options to answer this question was also identical to the one presented in section eight. All other questions in this section were repeated identically to that of section eight. These two sections, section eight and twelve, were kept as close to each other as possible to allow for the best comparison between the different education institutions. At the end of section 12 the questionnaire was terminated, with the message “This concludes the questionnaire. Thank you for taking the time to participate in this research. We at Massey University greatly appreciate your contribution”.

Data Analysis

A mixed method approach to analysis was utilised so that the research question could be sufficiently answered, as it was apparent that neither qualitative nor quantitative data alone could answer this. In doing so the research draws on the strengths of both types of methods, allowing for more breadth and depth. Thematic analysis was employed for the qualitative data while descriptive statistics were run on the quantitative data. Due to limitations imposed by the survey response rate and smaller sample size, quantitative statistics were restricted to simple descriptive statistics

Thematic analysis (Braun & Clarke, 2006) was performed on the qualitative data, initially by the lead researcher. As this is a relatively under-researched area, analysis sort a rich thematic description of all of the parents’ comments in order to identify predominant themes related to perceptions of support experiences. Themes were identified using bottom-up inductive analysis, with the idea that analyses would be data lead and themes would be strongly linked to and representative of the data sets themselves. However, it must be acknowledged that research is not carried out in a vacuum and may be influenced by previous theory and research along with the researcher’s theoretical interests and life experiences. Themes were identified at the semantic level with the surface or explicit meaning of the words or data being captured in the codes, with a progression to interpretation bringing in previous research/theory and broader cultural understandings and implications (Braun & Clarke, 2006; Terry, Hayfield, Clarke, & Braun, 2017).

Thematic analysis followed the six-step process proposed by Braun and Clarke (2006), which began with the reading and familiarisation of each of the data sets. This included engaging with the data and noting down initial ideas which reoccurred within the data sets. Immersion with each data set was initially done separately, with the lead researcher becoming familiar with the ME/CFS qualitative data first, then with the epilepsy qualitative data second. Interesting aspects and features of both data sets were identified in a methodical systematic manner and were used to generate initial condition specific codes. Initial codes were then analysed and compared across the two conditions for similarities and differences. When it became apparent that there was a great deal of similarity in these initial codes they were compiled into draft versions of overarching themes and condition specific subthemes. When initial codes were the same, these were compiled into subthemes which were not condition specific. These themes were then reviewed by the original researcher and the supervising researchers to make sure that they were synonymous with original codes and with the data set as a whole. Any themes that required re-coding, were. These themes were then rigorously refined, defined, and given names that encapsulated the meaning of each theme in relation to parents' subjective perceptions about their child's support experience. To provide supporting evidence for the themes, direct quotes were taken from each of the raw data sets, with these condition specific quotes providing evidence for the overarching themes, collectively. These quotes were reported in the findings within each relevant theme. Each quote is given an identifying code – ME for ME/CFS and Ep for epilepsy to identify the condition group, and a number identify participants while keeping anonymity – for example, a quote from the first parent participant with a child with ME/CFS would be represented by (ME1). Qualitative data was examined and re-examined, moving from the original data set to the coded data set and to the themes and back, employing a recursive process to ensure the validity of the themes identified. Thematic analysis was overseen by the supervising researchers, with themes, and accompanying quotes, being reviewed and discussed to ensure these were valid and reliable representations of the data (Braun & Clarke, 2006; Terry et al., 2017).

Quantitative data was analysed using IBM SPSS statistics software, where descriptive statistics were run. This included simple frequency and descriptive statistics of participant characteristics and simple frequency statistics of data obtained from each of the survey questions, with percentages being calculated where appropriate. For participant characteristics of both parents and their children, frequency statistics were run on gender and ethnicity data, while descriptive statistics were used to identify the mean and range of parent and child/youth ages. Simple frequency statistics were run for all questions expect for the questions relating to supports 'needed', 'provided', and 'used', which required additional analysis. Further analysis was run, for both 'Mainstream' and 'Other' schools to create the inverse variable of 'not provided'. Data was then examined to determine instances when a support type was 'needed' and simultaneously 'not provided', creating the variable 'needed and not provided' which was used as a measure of unmet need. Missing data points were removed on a question-by-question bases rather than removing a participants entire data set. As survey response was low, and participants were able to skip survey questions, it was decided between the researchers that removing whole data sets would exclude valuable and pertinent quantitative and qualitative data from analysis. Once qualitative themes were identified, the lead researcher went through each quantitative question and analysis to determine which analyses complimented and supported the qualitative themes. Relevant statistics were then presented in tables within the relevant themes.

Findings

Participant characteristics

As shown in Table 1, a total of 20 parents of children with ME/CFS and 23 parents of children with epilepsy completed the online survey. Of the ME/CFS participants, 90% of parents and 50% of children/youth were female, whilst of the epilepsy participants, 100% of parents and 48% children/youth were female. With regards to the children/youth for which parents were answering the questionnaire about, the mean age for children/youth with ME/CFS was 15 years of age, with an age range of 11 – 20, and for children/youth with epilepsy was 12 years of age, with an age range of 6 – 18. Of the parents of children with ME/CFS, two participants were excluded from analysis on age due two outliers indicating parents were 15 years of age, which when cross referenced with the age of their child were deemed as likely mistakes. Other characteristics of parent participants and their children/youth can be found in Table 1.

Themes

As it was identified that there was insufficient quantitative data (due to a lack of response to the survey), both quantitative and qualitative data were analysed. Qualitative themes were identified from the comments left by participants and descriptive statistics were obtained from survey responses. Findings will be reported using the identified themes and subthemes as headings with relevant descriptive statistics being reported within each theme. The six main themes and subthemes identified were: 1) Let down by their own bodies, 1.1) Damaging self-concept; 2) Struggle for validation; 3) Luck of the draw: Both supportive and unsupportive experiences, 3.1) Teachers operating in a rigid system, and 3.2) Gratitude from parents; 4) Ill-suited support, 4.1) Other schools as transitional institutions; 5) Lack of understanding and discrimination; and 6) Impact of COVID-19. Main themes were then also divided into condition specific subthemes. Descriptive statistics,

Table 1

Parent participant and child/youth characteristics

Participant Characteristic	ME/CFS (%) N=20		Epilepsy (%) N=23	
	Parent	Child	Parent	Child
Gender				
Male	2 (10)	8 (40)	0	12 (52)
Female	18 (90)	10 (50)	23 (100)	11 (48)
Non-binary	0	2 (10)	0	0
Other	0	0	0	0
Age				
Mean	48	15	44	12
Range	39 – 58	11 – 20	32 – 55	6 – 18
Ethnicity				
New Zealand European/Pākehā	18	20	19	17
Māori	2		2	2
Pacific Islander	1	1	0	0
Asian	0	0	0	0
Middle Eastern/Latin American/African	1	1	1	1
Other	2	1	1	3

from the quantitative data, relevant to and in support of these themes are reported within each theme and presented in Tables.

Theme 1: Let down by their own bodies

Both the quantitative and qualitative data show parents perceived an impact on and disruption to their child/youth's schooling as a result of their ME/CFS or epilepsy. Qualitative results revealed the condition specific subthemes; inability to socialise and participate for ME/CFS and implications for academic ability, attendance, and behaviour for epilepsy, reflecting perceived impacts that appeared to be specific to the condition. Quantitative analysis revealed that all parents, from both condition groups, indicated that their child experienced symptoms that impacted on schooling, whilst almost all indicated that there were healthcare needs that impacted on schooling (17/20 ME/CFS parents; 21/23 epilepsy parents). All parents of children with ME/CFS indicated that their child/youths' health condition impacted on schooling 'to a great extent'. When parents of children with epilepsy were asked to what extent they believed their child/youths epilepsy impacted on epilepsy 1 parent indicated 'very little', 6/23 parents indicated 'somewhat', and 16/23 parents indicated 'to a great extent'.

Table 2

Number of parents indicating that symptoms and healthcare needs impact on specific areas of schooling

Area of school impacted	ME/CFS (%) N=20		Epilepsy (%) N=23	
	Symptoms	Healthcare	Symptoms	Healthcare
No Impact	0(0)	1(5)	2(9)	1(4)
Enrolment	10(50)	5(25)	6(26)	7(30)
Attendance	16(80)	13(65)	17(74)	15(65)
Participation	17(85)	12(60)	16(70)	14(61)
Concentration	17(85)	9(45)	18(78)	12(52)
Work Completion	18(90)	11(55)	17(74)	11(48)
Academic Performance	16(80)	11(55)	17(74)	13(57)
Socialisation	18(90)	12(60)	13(57)	8(35)
Student Teacher Relationships	18(90)	10(50)	10(44)	8(35)
Emotional Wellbeing	15(75)	12(60)	13(57)	9(39)
Other	2(10)	0(0)	0(0)	0(0)

ME/CFS Theme 1: Inability to Socialise and Participate. The ME/CFS quantitative results show that parents of children/youth with ME/CFS perceive an impact on traditional school aspects, i.e., participation, work completion and concentration, and on social aspects of schooling. As shown in Table 2, symptoms were the most commonly indicated condition characteristic to impact on schooling. This is likely due to the debilitating nature of ME/CFS symptoms, in particular fatigue. These findings are similar to what has been detailed in previous research, which clearly shows an impact on attendance and participation (Crawley & Sterne, 2009; Tollit et al., 2018) , academic performance (Knight et al., 2018; Nijhof et al., 2016), and socialisation (Similä, Nøst, et al., 2021; Winger et al., 2014). Implication for student teacher relationships was also identified, which is similar to findings of Similä, Rø, et al. (2021) who found this relationship to be impacted on by constant absences. Alternatively, a negative student-teacher relationship may be fostered through the scepticism surrounding ME/CFS as identified by previous research (Parslow, Shaw, et al., 2017; Van Hoof et al., 2006).

Further findings from the quantitative data revealed healthcare needs were not indicated as often and may be perceived to have less of an impact due to a fewer number of treatment/management options being offered to people with ME/CFS (Everett & Fulton, 2002; Parslow, Shaw, et al., 2017; P. C. Rowe et al., 2017). Those which were indicated appeared to be responses to main symptoms such as fatigue which would require monitoring of activity levels which may impact participation or socialisation (Brigden et al., 2020; Brigden et al., 2021).

Findings pertaining to the impact of symptoms on school were backed up further by the qualitative comments made by the parents. Parents perceived disruption to traditional school aspects, including participation, “we and she expected that she could participate but her fatigue was too burdensome” (ME6), and attendance, “her illness is too severe for her to attend school” (ME20). Implications to academic performance were also identified with one parent identifying an “inability to engage in formal learning because of cognitive fatigue” (ME12). Both quotes identified mental and physical fatigue as barriers to schooling, which was also identified by parents as making school inaccessible to children, stating “[the child] was unable to access education” (ME16). Furthermore, it appeared that parents perceived an impact on socialisation and the inability to maintain friendships was reflected in this parent’s quote: “but being unwell has made it challenging to maintain [peer relationships]” (ME8).

The time spent at school appeared to be reduced due to fatigue and other symptoms which subsequently impacted on the young person’s ability to engage in school and with peers. These findings are similar to Winger et al. 2014 who identified that youth felt locked in their bodies by fatigue, where periods of being bed ridden, due to fatigue, were seen as a barrier to participation and prohibited school attendance, participation in leisure activities, and social experiences (Winger et al., 2014). Parents appeared to also be concerned with the consequences of reduced attendance and isolation commenting, “Not being able to consistently manage to attend school, or extra-curricular activities leads to an isolation that is harmful mentally as well as physically” (PME5), a concern echoed by Parslow, Harris, et al. (2017) who noted that the isolating effects of constant bed rest and absences denied the child/youth of a normal social experience (Parslow, Harris, et al., 2017).

Epilepsy Theme 1: Implications for academic ability, attendance, and behaviour. As with previous research, that centres implications around academic performance and reduced cognitive functioning/learning disabilities (Austin, Huberty, Huster, & Dunn, 1999; Reilly et al., 2014; Reilly & Ballantine, 2011), the current quantitative results show that parents perceived epilepsy symptoms and healthcare needs to impact on traditional school aspects such as concentration, academic performance, and attendance. Previous research also describes an impact on attendance due to seizures, before, during, or after school hours, post seizure fatigue, and medical appointments (Aguiar et al., 2007; Serdari et al., 2009). Parents indicated both symptoms and healthcare needs impact on the same areas of schooling. Epilepsy symptoms impact on the functioning of the child/youths’ brain, causing such affects as mental fatigue, reduced concentration, and cognitive impairments/deficits, as well as intellectual disabilities. Seizures may also cause impaired functioning through mental and physical fatigue, impacting on the child’s ability to participate or even attend school activities (Austin et al., 1999; Reilly et al., 2014; Reilly & Ballantine, 2011). Previous research shows anti-epileptic medications to have numerous side-effects that impact on all areas of school functioning, like concentration and participation. Healthcare needs such as medical appointments, tests, and hospitalisations also impact on attendance and ultimately academic performance if too many absences were accumulated, a point backed by the findings of Serdari et al. (2009)

These quantitative findings were reiterated in the qualitative data. Parents perceived their child's intellectual disability, if present, along with medications and absences to be a huge disruption to learning, commenting "his intellectual disability has had a severe impact on his academic ability" (Ep17), and "…was academically above. This has steadily declined due to medications and the effect the seizures have on his brain. Absences don't help" (Ep1). It would not be surprising for parents to perceive an impact to academic performance if their child had an intellectual disability; this may even be the parents main concern if their child/youth had a prominent impairment. Previous research has attested to the commonality of intellectual disabilities and cognitive deficits impacting on academic achievement (Johnson et al., 2021a; Reilly et al., 2014; Reilly & Ballantine, 2011). Absences were also noted by parents, likely as a result of seizure effects or medical appointments, with one parent noting "she has missed years of school and there is no system to help make that up" (Ep22). This was similar to the findings of Aguiar et al. (2007) and Serdari et al. (2009) who detailed an impact on attendance with days being missed resulting from recent seizures or symptoms and medical appointments. Within the parents' comments was also a note of a behavioural implication, "behaviour escalates when tired, further impacting on participation at school, standdowns etc" (Ep14), which were perceived by parents to impose on participation or result in removal from school when a child was stood down. These findings were similar to Elliott et al. (2005) who found a multitude of epilepsy aspects which impacted on several different areas of schooling, including the effects of fatigue, cognitive, memory, and attention impairments, and emotional and behavioural implications on attendance, participation, and academic performance (Elliott et al., 2005).

Subtheme 1.1: Damaging Self-Concept. It was apparent that parents saw these impacts from ME/CFS and epilepsy as failing their children and youth. Their bodies and the consequences of their child/youth's health conditions were perceived to interfere with a critical period of these young people's lives as well as resulting in feelings of frustration over not being able to do things peers their own age could do. One ME/CFS parent commented that it was a "terrible time to be unwell as you are developing your identity and sadly he has lost faith in his body" (ME1), and a parent of a child with ME/CFS commented “At times he becomes frustrated as he can’t do the same things other 16-year-old boys do” (Ep1). Particularly with older children and youth, this is a time to develop identity and a sense of self, as well as increased independence and autonomy, with the restrictions imposed by their own bodies not only interfering with social and educational activities but also result in frustration and lowered confidence (Elliott et al., 2005; Parslow, Shaw, et al., 2017). These findings are similar to Elliott et al. (2005) who identified that the restrictions imposed by seizures resulted in frustration and children/youth seeing themselves as different at a time when being and feeling the same as peers is the desired and valued norm (Elliott et al., 2005).

Theme 2: Struggle for Validation

Throughout the comments made by parents for both conditions, there was the ongoing theme of a constant struggle, that seemed to be faced by both the parents and the children/youth themselves. This struggle appeared to be the struggle for validation of their child/youth’s health condition and their symptoms, which seemed to stem from the visibility of such disease characteristics. For ME/CFS this was for the validation of the condition itself, for the legitimisation of ME as a medical condition which impacts on functioning. For epilepsy this was for the validation of symptoms which were not as immediately visible as more commonly known epilepsy symptoms.

ME/CFS Theme 2: Struggle for condition validation. It was apparent that parents struggled with getting both medical and education professionals to take their child/youth’s condition seriously. Sceptical interactions with medical professionals had implications for gaining the diagnosis crucial to receiving support with one parent commenting “it’s been hard getting a diagnosis so hard getting support” (ME3). These comments gave a sense that their child/youth’s needs and concerns were not taken seriously very early on in their illness journey, which is similar to previous research noting adult ME/CFS patients experienced diagnosis delays, misdiagnosis, and scepticism or disbelief from medical professionals (Hareide et al., 2011). This may be a result of the somewhat untestable nature of ME/CFS with Horton et al. (2010) identifying that without the development of a definitive ‘test’ some medical professionals would remain doubtful of the existence of ME/CFS.

Obtaining a diagnosis recognised by schools was also identified as being a struggle with schools apparently being particular about which medical professionals would suffice with one parent commenting that “We had a great knowledgeable GP but they didn’t think that was enough” (ME18). This was identified by one parent as a potential issue, with policy level determinants to which certificates may or may not be accepted, commenting that there was a “problem in the policy in the [Other] schools regarding medical certificates and ‘specialist’ reports” (ME6). This struggle was likely amplified by the integral nature of medical certificates in legitimising an ME/CFS diagnosis and validating impacts, as one parent stated, “As my son wasn’t diagnosed, it was assumed it was truancy” (ME16), with their struggles apparently trivialised and stigmatised. These findings are supported within the literature, identifying a formal ‘legitimate’ diagnosis as pivotal in having schools view the impacts of ME/CFS as legitimate (Similä, Nøst, et al., 2021; Similä, Rø, et al., 2021), with Brigden et al. (2021) finding that teachers emphasised the need for a formal diagnosis to satisfy the policy/organisation level for the implementation of certain supports. This struggle did not appear to be isolated to legitimising symptoms through a diagnosis but appeared to also apply to the necessary health-care needs implemented by parents to manage their child/youth’s symptoms, stating “School has kind of been accusing, that we seem to just be leaving him with no schooling, but I’ve been trying to pace him” (ME3). This was similar to what was identified by Winger et al. (2014) who found that youth often perceived teachers to not believe them and expressed scepticism around diagnosis and impacts accusing children of being lazy. The parents’ accounts reflected their experience of ME/CFS as a stigmatised condition with connotations of malingering, that may be disbelieved by both medical and educational professionals.

Epilepsy Theme 2: Struggle for symptom validation. Unlike ME/CFS, epilepsy is a well-established legitimate condition with testable characteristics that lead to a diagnosis. However, it was apparent that there were symptoms and medication side-effects that their child experienced which were not taken seriously by the education community and required parents to fight for such symptoms to be recognised as impactful, as reflected in the quote “there is minimal support for these children [with absent seizures] without intense advocacy from parents and medical teams” (Ep2). This not only related to the invisible symptoms or side-effects occurring in the classroom but also to seizures and side effects that occurred at home. One parent noted that “because her seizures have never occurred at school there is a misconception by some educators that they aren’t that big of a deal” (Ep18), highlighting the role that visibility has in determining teacher’s disease perceptions.

It appeared that there was a pre-conceived idea of what epilepsy looked like and anything outside of those symptoms and disease characteristics were deemed as not impactful. This is reflected in one parent’s comment “Currently you need to have seizures at school or significant global delay to receive any funding” (Ep2), and the comment there’s “support provided around health needs but very limited support around learning needs available.” (Ep7). Not falling within the realm of stereotypical epilepsy was described to be distressing to some as this meant their child missed out on funding while clearly experiencing impactful symptoms, stating it was "distressing as child is not intellectually disabled but has learning disability combined with med and seizure side effects" (Ep14). These findings are similar to Johnson et al. (2021) who identified that children with obvious and severe intellectual disabilities had easier access to supports than those with less 'severe' behavioural or learning implications, further identifying parents had to struggle to get their mainstream schools to recognise and support these 'less emphasized' symptoms (Johnson et al., 2021a). Narrowed ideas of what epilepsy experiences looked like for children/youth may stem from stereotypical representations of epilepsy in the media or previous experiences with seizures that were confrontational and frightening, (Benson et al., 2017; Yang et al., 2021). This may lead to 'overreaction' or a potential over-cautious response to providing support (Chew et al., 2017), while less frightening symptoms may, comparatively, be considered less important (Reilly & Ballantine, 2011).

Theme 3: Luck of the draw: Both supportive and unsupportive experiences.

When it comes to receiving support, it was clear that parents perceived a wide range of support, some completely unsupported through to amazing support from all system levels, making these educational experiences highly varied. This was made apparent within and between the quantitative data and qualitative comments and was clear in both ME/CFS and epilepsy cohorts, as well as in 'Mainstream' and 'Other' schools. It also appeared that the provision of support occurred at differing levels of the education system, which provided some explanation for the variation in both quantitative and qualitative data.

In response to being asked to what extent the institution supported their child with the impact of their health condition on schooling, the two most commonly selected answers were 'somewhat' and 'to a great extent' for both ME/CFS and epilepsy in both 'Mainstream' schools and 'Other' schools. As shown in Table 3, the percentage of parents answering 'somewhat' or 'to a great extent' made up 73% or more of the total answers. This depicted a picture of parents feeling supported by these schools.

Given that it is possible support may be present but that it might not be to a satisfactory level, parents were asked if they felt satisfied with the level of help/support provided by the school in question. Answers given - pertaining to children with ME/CFS for 'Other' schools and children with epilepsy for both 'Mainstream' and 'Other' schools - were generally positive. The most commonly indicated answers were 'satisfied' and 'very satisfied', as shown in Table 4. However, as shown, there were still some parents who indicated 'dissatisfaction' and 'neither'. For children with

Table 3

Extent to which parents perceived their child/youth to be supported with the impact of their health condition on schooling

Support Extent	ME/CFS		Epilepsy	
	Mainstream (%) N=18	Other (%) N=15	Mainstream (%) N=20	Other (%) N=4
Not at all	1 (6)	2 (13)	1 (5)	0 (0)
Very Little	3 (17)	2 (13)	4 (20)	0 (0)
Somewhat	8 (44)	3 (20)	8 (40)	0 (0)
To a Great Extent	6 (33)	8 (53)	7 (35)	4 (100)

ME/CFS in ‘Mainstream’ schooling these were the two most commonly indicated answers. Similarly, the second most commonly indicated answer for children with epilepsy attending ‘Mainstream’ school was ‘dissatisfied’. This indicates a varied level of satisfaction with the level of support provided, more so with ‘Mainstream’ schooling, and that some parents may perceive a high level of support but may not be fully satisfied with the support provided.

Table 4

Parent satisfaction level with the level of help/support provided by the school

Satisfaction Level	ME/CFS		Epilepsy	
	Mainstream (%) N=18	Other (%) N=15	Mainstream (%) N=20	Other (%) N=4
Very Dissatisfied	3 (17)	3 (20)	1 (5)	0 (0)
Dissatisfied	5 (28)	1 (7)	5 (25)	0 (0)
Neither	4 (22)	3 (20)	3 (15)	0 (0)
Satisfied	3 (17)	3 (20)	9 (45)	3 (75)
Very Satisfied	3 (17)	5 (33)	2 (10)	1 (25)

When the qualitative data was examined, it appeared that there was a variation between conditions in the provision of support. More specifically, for ME/CFS it appeared support was based on the school they attended, namely the level of understanding of school staff around ME/CFS and the types of relationships formed between parents/families and education professionals. The presence of these factors being at any given school appeared to be up ‘to the luck of draw’. For epilepsy, support appeared to also be based on which school and teachers’ children/youth had but also on if their child was ‘lucky enough’ to meet the criteria for funding and had the support of the school to obtain funding for support. There were also non-condition specific subthemes present. The first subtheme being around teachers supporting children as best they could within the rigidity of the school system and the second theme being the apparent gratitude that parents had for the support their child did receive when their child was lucky enough to receive support.

ME/CFS Theme 3: Luck of which school is attended. As an almost entirely invisible illness shrouded in scepticism, finding a school and subsequently teachers which believe the child/youth's experiences may simply be up to the luck of which school the child is able to attend. This was reiterated in the parents' comments, noting both supportive and unsupportive experiences, which appeared to be based on the understanding of and condition knowledge possessed by the specific educational professionals at a school. One parent commented "my child has experienced support and compassion, and also misunderstanding and prejudice, but mostly has experienced inadequate support" (ME20) identifying misunderstanding and prejudice as contributing factors to unsupportive education experiences. Another parent commented on the prejudice that comes with the stigma of malingering stating that "the main troubling thing for me was the attitude of many staff members that kids who behave like this are 'school refusalists' because this is simply not true" (ME6). Misunderstanding may result from insufficient 'proof' or 'clinical' input from delayed diagnosis, while prejudice may stem from ill-informed illness beliefs, stigma, and perceived lack of believability, or just a general lack of condition knowledge within the specific school (Similä, Nøst, et al., 2021; Winger et al., 2014).

When it was identified that children/youth were lucky enough to attend schools with educational professionals who were understanding of a child/youth's specific needs, parents described positive educational experiences, which was apparent in the comment "they in large part show great understanding of the limitations my daughter needs to work around and help her prioritise her assessments" (ME5). In support of these findings, Brigden et al. 2021 found that teachers viewed important adaptations which successfully supported students to respond flexibly and proactively to the individual physical, emotional, and cognitive needs of their specific student (Brigden et al., 2021). When negative experiences were described, this was down to the teacher's reluctance to catering to the specific needs of the child, reflected in the comment "Some teachers extremely resistant to adapting to child's needs" (ME19), likely as a result of symptoms not being taken seriously and being dismissed. These findings are supported by Parslow, Shaw, et al. (2017) with medical professionals identifying understanding and positive attitudes from schools and teachers to contribute to supportive experiences, with negative attitudes and a lack of understanding acting as barriers to support. Similä, Nøst, et al. (2021) also noted that the main barriers, identified by youth, to accessing helpful educational adaptations were not being listened to, taken seriously, or believed by teachers, demonstrating the integral role individual teachers have in a positive schooling experience (Similä, Nøst, et al., 2021).

Taking this idea further, supportive experiences also appeared to be a product of the type of relationships and communication between the specific educational professionals and the child/youth's parents/families, with trust playing a consequential role in these relationships. This was highlighted by one parent's comment on their child/youth's education experiences stating, "She is enrolled at an unusually flexible and supportive school that trusts parents and places a child's individual needs first" (ME12). This quote suggests that this experience was not the norm and hinged on a positive trusting relationship between school staff and parents, where accounts of their child/youth's health and education needs were believed and put first. This idea was further illustrated by one parent's comment that "my son's college have always been open to learning about my son's condition from me" (ME18), again identifying that trusting parents accounts of disability positively influenced support. When negative interactions were detailed as impacting on support parents noted a lack of liaison or communication commenting that "Schools generally and teachers are terrible at keeping in touch and sending any form of work home or contacting the child" (ME8).

These findings are similar to what was discussed in Brigden et al. 2020 who identified the importance of the relationship between parents and school professionals, specifically the importance of communication between the two parties and the implications this had for individualised care and support, with factious relationships impacting negatively on children. This then meant that some parents apparently felt the need to shop around or find new schooling areas commenting, "we had to move schools to get a better and more sympathetic outcome for [the] child" (ME19). The fact that this parent spoke of having to swap schools in order to gain a more supportive experience for their child, further highlighted just how school-dependent support may be, making the supportive and understanding nature of the school and its teachers, in particular for those parents unable to 'shop around', up to the luck of the draw. This was ultimately identified in the comment "luckily the primary, intermediate, and secondary schools have all been accommodating" (ME1).

A lack of knowledge or understanding and a lack of condition visibility and legitimacy impeding support also appeared in the quantitative findings. The qualitative findings (suggesting support was school and staff dependent) were backed by the quantitative data. When parents indicated that they felt their child was unsupported, the most commonly indicated reason given for why they perceived a lack of support in 'Mainstream' schooling was that their disease was not taken seriously by educational professionals. The next most common reasons were that education professionals were too busy to keep attending to the chronic nature of the condition, institutional rules did not allow for flexibility, and funding limitations. The same reasons were given most commonly for 'Other' schools as well as including the reasons educational professionals did not understand needs and excluding funding limitations. These quantitative findings further support the idea of support being tied to the institution, its individual staff, and their ME/CFS understandings

Epilepsy Theme 3: Luck of which school attended and lucky to have funding. Like ME/CFS, it appeared that support was also dependent on the teachers at a given school and their level of understanding or personal experiences with epilepsy. A teacher's approach to epilepsy and the fear surrounding some seizures was identified as a barrier to support, as identified in the comment "I think a lot of teachers worry about having to deal with a seizure, which is understandable. When they become aware of how to deal with one, or have dealt with one, some of that is alleviated" (Ep1). This quote further highlighted the influence of the teacher's individual past experiences of seizures, which in this case had an apparent positive effect on support. The influence of the individual teacher was also highlighted by another parent who commented that "the battle refreshes every year with every new teacher" (Ep14). This quote was interesting as it might speak to the teacher's knowledge and how much a teacher needs to be educated by the parent on individual needs but may also represent that each year with each new teacher the lottery begins again bringing new unknown challenges to obtaining support.

Not only was individual understanding apparently important but the value of adequate and effective communication was also highlighted, with one parent stating "even when I update the school it seems the teachers aren't made aware of these new facts. Some teachers didn't even realise she was epileptic" (Ep18). This quote highlights how poor communication between schools and home, and even within schools themselves, can result in health needs being undervalued or missed resulting in inadequate support. The importance of having knowledgeable teachers and effective communication was identified in previous research by Roberts and Whiting (2011) who found that negative support experiences were related to communication difficulties and a teacher's lack of seizure first aid knowledge, and by Johnson et al. (2021) who found that teacher understandings of seizure management and perceived competency, or lack thereof, played a role in parents' reluctance for their child to attend school.

In a bid to improve their odds in this so-called 'postcode lottery', parents also spoke of this same 'shopping around' behaviour, identified by ME/CFS parents, to try and identify a school that was more supportive and accommodating to their child's needs, with one parent stating that their “child has been to 3 primary schools, very difficult to find a supportive school” (Ep14). Reilly and Ballantine (2011) noted that the provision of support would likely depend on the provision policies within a given schooling area. Where supportive institutions were found, they worked around the individual child and their specific needs. One parent commented “we live rural, so we are lucky to have good support from her school they work around her needs and wellness” (Ep5), speaking of being lucky to live within such a rural community. It may be possible that rural schools have smaller class numbers allowing more one-on-one time with teachers to work around needs, or a more tightknit community may lead to a better relationship between parents and teachers and better support. A similar and interesting finding identified by Roberts and Whiting was the potential impact of private versus public schools on support, postulating that private schools may be influencing positive support experiences.

Within the epilepsy data were the additional findings of the perceived stringency to funding and support criteria and the subsequent perceived influence of luck when a child met these criteria and received support. One parent commented that “funding is so difficult to get, and children have to be really struggling to get learning support” (Ep7), meaning that a lot of children who did not meet this level but still struggled with schooling were going unsupported. One parent took this further commenting “I have been advocating… to consider altering criteria for learning support and funding streams for children with epilepsy” (Ep1) attesting to the rigid nature of criteria meaning advocacy for change was necessary. This resulted in a sense of luck when children did qualify for funding, represented in this parent’s comment, “my son is lucky to have funding due to his severe learning needs, so he has had a lot of support” (Ep17). This is not to say that their child/youth is necessarily lucky to experience severe disease attributes but lucky that they have the necessary symptoms and severity to meet the criteria when other struggling children/youth do not, and so go unsupported. These findings are similar to Johnson et al. (2021) who found that obtaining support for children with more severe intellectual disabilities and those attending special schools was smoother than those in mainstream schools, whose parents identified the process as ‘onerous and bureaucratic’ with lengthy waitlists and inconsistent waitlists (Johnson et al., 2021a)

Again, the ideas within this theme were supported by the quantitative data and the reasons given for why parents indicated the extent to which their child was supported to be ‘very little’ or ‘not at all’. Only those in ‘Mainstream’ schooling indicated that they felt this way and the most commonly indicated reasons were that educational professionals did not understand needs, educational professionals forgot about the needs of my child/youth, funding limitations, disease not taken seriously by educational professionals, and educational professionals were not flexible, highlighting the role of individual teachers and schools in determining supportive experiences

Subtheme 3.1: Teachers operating in a rigid system. Where children were lucky enough to be at a supportive institution with supportive teachers there was the apparent perception that educational professionals were operating within a rigid system, making the allowances they could up until a point where the system itself was a barrier to support. Parents noted support which came despite funding limitations commenting that teachers/school were "very supportive where they can be given that there is no funding to assist with this" (Ep1), highlighting the imposition funding limitations pose to receiving full support. Furthermore, parents saw teachers doing what they could within the constraints of rigid education requirements, commenting "our college has always been supportive of my son but some aspects that have arisen have been a direct result of the limitations of the educational system and their hands being tied" (ME18), with another parent noting "The school were helpful where they could be within the constraints of NCEA rules" (Ep1). This was also seen to apply to the apparently different operational guidelines of 'Other' schools as one parent saw that "Our daughter's assigned teacher was great but the narrow guidelines around the role of the ['Other'] school teacher was really counterintuitive" (ME14), with a narrowed focus hindering the full support of all their child/youth's needs. Parents seemed aware of and understanding of the fact that in these instances schools/teachers were doing what they could where they could, for their child, in a system where restrictions were unavoidable. This is similar to what was described in Brigden et al. (2021) where teachers identified being constrained by organisation and policy level structures which required an official ME/CFS diagnosis for the provision of certain supports.

Subtheme 3.2: Gratitude from parents. It was apparent that some parents were grateful for the support, particularly when the school and teachers took into account the child's needs with one parent commenting that "['Other' school] was amazing and I will always be thankful to the teacher we had and also that the ['Other' school] did not try and force him back to school before he was ready" (ME1). Another noted that additional care from nurses, likely with medical needs, was also supportive stating "the nurses at school are lovely and supportive also" (Ep1). Even in instances when the support was not sufficient, parents of children with ME/CFS were still grateful that the intention to support their child was there, represented by a parent noting that there was "good profession and good intentions but not the level of support needed" (ME19). It may be that families have had the child/youth's struggles disregarded before or have encountered funding and organisational barriers, so to just have a school acknowledge that the child needs support and attempt to provide it gives parents a sense of gratitude.

Theme 4: Ill-suited support

From both the quantitative and qualitative data it was clear that there were unmet needs for both ME/CFS and epilepsy, with supplied support not meeting the needs of children and children being left needing different forms of support. This was apparent in the comments made by parents with two condition specific sub themes arising. For ME/CFS it appeared parents viewed education as a one size fits all system not suited to their child. For epilepsy, parents seemed to perceive support as too narrowed, calling for a broader range of support. A third non-condition specific theme of 'Other' schools being seen as transitional institutions was also identified.

Firstly, as shown in Table 5 it was apparent that there were supports needed in 'Mainstream' schools that were not being provided to children in both ME/CFS and epilepsy groups. The most commonly indicated needed support type, for children with ME in Mainstream schooling, was 'adequate communication with home'. For children with epilepsy in Mainstream schooling, the most commonly indicated needed support type was 'opportunities to rest'. As demonstrated in Table 5, these supports were not always provided with the percentage of unmet need, or times support was needed and not provided, being 78% for 'adequate communication with home' for ME/CFS and 36% for 'opportunities to rest' for epilepsy in Mainstream schools.

As shown in Table 5, there are a great number of support types for which need is going unmet, for children with ME/CFS in 'Mainstream' schools. This may represent unmet needs and a poor number of supports being provided to address the needs of children/youth with ME/CFS. However, given that there would appear to be few parents indicating needed supports, shown by the small percentages, across an apparently large range of support types it may simply not be feasible for schools to provide all of the possible needed supports indicated. As shown in Table 5 there are some needed support types which are, to some degree, being met. These supports appear to be those which the school or a teacher may be able to provide on their own to children without the need for outside system support or funding, such as 'inclusion initiatives'. This ties into the previously discussed subtheme 3.1 'Teachers operating within a rigid system'

It was alarming that the most indicated needed support type of 'adequate communication', was also one of the most unmet support types, for children with ME/CFS in mainstream schooling, as shown in Table 5. There is a wealth of literature detailing the integral role of communication in making sure that all parties are on the same page and that teachers are aware of how the child's ME/CFS impacts on their schooling and which adaptations are best suit these needs (Brigden et al., 2020; Brigden et al., 2021; K. Rowe, 2020; Similä, Nøst, et al., 2021; Similä, Rø, et al., 2021).

Teachers may be too busy and stretched across a whole mainstream class to keep the child at the forefront of their mind to then adequately communicate with home how the child is doing. The invisible nature of ME/CFS symptoms may perpetuate this as the teacher may not see the student's struggle (Vickers, 2000).

What was interesting about the 'Mainstream' epilepsy data was that the support types which were needed and provided mirrored the symptoms and impacts that might be more readily associated with stereotypical aspects of epilepsy. For example, being 'responsive to emergencies' would support tonic clonic seizures and a 'teacher aid' may support severe learning disabilities. It is possible that stereotypical symptoms, and the need to support them, are those which occur more frequently and more obviously in the classroom. As shown in Table 5, such support types had the lowest percentage of unmet need. These findings are similar to that of previous research detailing that the most commonly reported supports provided by schools and teachers, including individual healthcare plans, appeared to be emergency responses to and the management of seizures (Johnson et al., 2021a; Yang et al., 2021).

However, what was surprising in the 'Mainstream' epilepsy data was the amount of unmet need for other learning support types, as shown in Table 5. A 'teacher aid', which may be the more extreme academic or learning support type, seemed to have a lower unmet need percentage, while other learning support types, such as 'additional learning resources' and 'tutoring support', which may not be sufficiently support severe disabilities, were 100% unmet. It may be that a lack of funding or resources means that few types of learning support can be offered and the type that may be most effective for all degrees of disability was what is being made available. Alternatively, the criteria in place for children with epilepsy to gain funding may be so stringent and require such a high degree of impairment that those children who do qualify for funded support have an impact that warrants the level of support a teacher aid provides. Children with less severe or other symptoms not included in criteria, who need and may benefit from supports like tutoring are precluded and may not receive funding for support. This is similar to what was described by Johnson et al. (2021) with parents wanting more but experiencing difficulty in obtaining support for less severe learning and behavioural difficulties (Johnson et al., 2021a).

For both ME/CFS and epilepsy, within the 'Mainstream' school data it appeared that there was greater unmet need when it came to support types that may require system level intervention such as additional funding or decision making from higher schooling authorities. This can be seen in Table 5 by the higher percentage of unmet need for the support types 'additional learning resources', 'tutoring support', and 'exam flexibility'. It would appear that this would not be the fault of the individual school or teaching staff but may be more representative of a system level gap falling within the macrosystem level of a socio-ecological model. This trend was also more apparent within the ME/CFS data than the epilepsy data, as shown in Table 5, and may be the result of the stigma surrounding ME/CFS. Overall, there was also an apparent difference in unmet need for 'Mainstream' schools between ME/CFS and epilepsy which may also reflect differences in perceived condition legitimacy and ability to receive funding/resources.

As shown in Table 6, there are again a number of needed supports which are going unmet for children with ME/CFS in 'Other' schools, similarly to 'Mainstream' schools. However, there are apparently fewer parents indicating supports as being needed, which may be indicative of less need in 'Other' schools, or less expectation of 'Other' schools given the different learning environments. An interesting finding from this data was that one of the most commonly indicated needed support types was 'flexible attendance', which 'Other' schools did not appear to fully provide as shown by the unmet need, indicating that 'Other' schools were not working around the needs of the child. Given that children with ME/CFS have been shown to struggle with attendance (Tollit et al., 2018), it seems counterintuitive to not respond flexibly to this need. Responding flexible to attendance needs or reducing attendance/timetables to help with the implications of symptoms, such as fatigue, was a main support suggested and provided throughout the support literature (Brigden et al., 2020; Brigden et al., 2021; K. Rowe, 2020; Similä, Nøst, et al., 2021). In conjunction with the commonly indicated 'needed' support of 'opportunities to rest' these findings may reflect 'Other' schools forcing attendance and their transitional nature, supporting the findings discussed in Theme 4.1 'Other schools: Transitional institutions.

Another interesting finding within this data was another most commonly indicated needed support type going unmet, this being 'positive attitudes and understanding'. Given the stigma surrounding ME/CFS and the resulting stigmatisation it is unsurprising that parents are wanting/needing positive attitudes and understanding for their child, but that this is not happening as it is not uncommon for children to be met with scepticism and discrimination (Winger et al., 2014). What is surprising was that this is happening within 'Other' schools where one might expect a higher tolerance for stigmatised chronic health conditions. In contrast with this, Similä, Nøst, et al. (2021) found that children in special schools identified and valued the good atmosphere within such schools, likely resulting from the close and positive contact established with teachers.

Table 5

Mainstream School Support Types Needed by the student, Not Provided by the School, and When a Support Type was Needed and Not Provided

Support type	ME/CFS			Epilepsy		
	Needed (%) N=16	Not provided (%) N=16	Needed and not provided (%)	Needed (%) N=20	Not Provided (%) N=20	Needed and not provided (%)
None	1 (6)	12 (75)	-	2 (10)	17 (85)	-
Help with treatments e.g, medication	1 (6)	15 (94)	1 (100)	7 (35)	12 (60)	3 (33)
Opportunities to rest	4 (25)	9 (56)	3 (75)	11 (55)	8 (40)	4 (36)
Opportunities to study from home	6 (38)	9 (56)	5 (83)	8 (40)	16 (80)	7 (87)
Flexible attendance	5 (31)	5 (31)	3 (60)	9 (45)	11 (55)	4 (44)
Space to rest	3 (19)	12 (75)	3 (100)	10 (50)	11 (55)	6 (60)
Additional learning resources	6 (38)	14 (88)	6 (100)	10 (50)	15 (75)	10 (100)
Flexible toilet breaks	3 (19)	14 (88)	3 (100)	3 (15)	13 (65)	1 (33)
Help with accidents	2 (13)	16 (100)	2 (100)	4 (20)	14 (70)	2 (50)
Teacher aid	3 (19)	16 (100)	3 (100)	8 (40)	12 (60)	5 (38)
Tutoring support	5 (31)	14 (88)	5 (100)	8 (40)	20 (100)	8 (100)
Catch up lessons	5 (31)	14 (88)	5 (100)	9 (45)	20 (100)	9 (100)
Online learning	4 (25)	14 (88)	4 (100)	8 (40)	18 (90)	7 (87)
Extensions	5 (31)	16 (100)	5 (100)	7 (35)	16 (80)	6 (86)
Exam flexibility	6 (38)	16 (100)	6 (100)	7 (35)	17 (85)	6 (86)
Curriculum flexibility	5 (31)	10 (63)	3 (60)	8 (40)	13 (65)	6 (75)
Adequate communication with home	9 (56)	10 (63)	7 (78)	8 (40)	10 (50)	4 (50)
Responsive to emergencies	2 (13)	14 (88)	2 (100)	4 (20)	8 (40)	1 (25)
Responsive to bullying	2 (13)	16 (100)	2 (100)	6 (30)	14 (70)	3 (50)
Counselling support	3 (19)	12 (75)	2 (67)	5 (25)	16 (80)	5 (100)
Positive attitudes and understanding	6 (38)	10 (63)	5 (83)	8 (40)	10 (50)	4 (50)
Inclusion initiatives	5 (31)	12 (75)	3 (60)	9 (45)	12 (60)	5 (56)
Other	1 (6)	0	-	0	0	-
Overall			87%			67%

Note: Needed and Not Provided = Number of times participants indicated a support type was needed and it was not provided by the school representing an unmet need; Overall = Overall support needed but not provided expressed as a percentage; - = No initial 'Needed' support so no unmet need.

Table 6

Other Schools Support Types Needed by the student, Not Provided by the School, and When a Support Type was Needed and Not Provided

Support type	ME/CFS			Epilepsy		
	Needed (%) N=13	Not provided (%) N=13	Needed and not provided (%)	Needed (%) N=4	Not Provided (%) N=4	Needed and not provided (%)
None	1 (8)	10(77)	-	0	3 (75)	-
Help with treatments e.g, medication	0	11(85)	-	0	3 (75)	-
Opportunities to rest	1 (8)	8 (61)	0 (0)	2 (50)	0 (0)	0 (0)
Opportunities to study from home	2 (15)	3 (23)	1 (50)	1 (25)	1 (25)	0 (0)
Flexible attendance	3 (23)	4 (31)	2 (67)	1 (25)	1 (25)	0 (0)
Space to rest	1 (8)	10 (77)	1 (100)	1 (25)	1 (25)	0 (0)
Additional learning resources	1 (8)	9 (69)	1 (100)	1 (25)	1 (25)	0 (0)
Flexible toilet breaks	0	11 (85)	-	0	2 (50)	-
Help with accidents	0	12 (92)	-	0	3 (75)	-
Teacher aid	2 (15)	11 (85)	2 (100)	0	3 (75)	-
Tutoring support	2 (15)	10 (77)	1 (50)	0	2 (50)	-
Catch up lessons	1 (8)	11 (85)	1 (100)	1 (25)	3 (75)	1 (100)
Online learning	2 (15)	7 (54)	1 (50)	0	1 (25)	-
Extensions	2 (15)	10 (77)	1 (50)	0	2 (50)	-
Exam flexibility	2 (15)	12 (92)	2 (100)	0	2 (50)	-
Curriculum flexibility	2 (15)	9 (69)	1 (50)	1 (25)	1 (25)	0 (0)
Adequate communication with home	1 (8)	6 (46)	1 (100)	1 (25)	1 (25)	0 (0)
Responsive to emergencies	0	12 (92)	-	0	2 (50)	-
Responsive to bullying	0	13 (100)	-	0	2 (50)	-
Counselling support	0	13 (100)	-	1 (25)	3 (75)	1 (100)
Positive attitudes and understanding	3 (23)	7 (54)	3 (100)	1 (25)	1 (25)	0 (0)
Inclusion initiatives	2 (15)	10 (77)	2 (100)	1 (25)	1 (25)	0 (0)
Other	1 (8)	0	-	0	0	-
Overall			75%			17%

Note: Needed and Not Provided = Number of times participants indicated a support type was needed and it was not provided by the school representing an unmet need; Overall = Overall support needed but not provided expressed as a percentage; - = No initial 'Needed' support so no unmet need.

For children with epilepsy in ‘Other’ schools, as represented in Table 6, we can see that there are very few children/youths attending ‘Other’ schools, as well as very few supports being indicated, by parents as being needed. For those supports that are being indicated as being needed only two of these supports are going unmet - ‘catch up lessons’ and ‘counselling’. Both visible and invisible symptoms associated with epilepsy open a child to stigmatisation and bullying from both teachers and peers (Chew et al., 2019; Vickers, 2000), whilst behavioural and emotional symptoms have been demonstrated to impact on schooling (Elliott et al., 2005). This would make supporting children through counselling important. However, it may be likely that not all schools have the capacity to provide counselling services. The unmet need of ‘catch up lessons’ is also indicative of a child/youth needing further assistance with the impact of epilepsy on both participation and academics. It may be that the ‘Other’ schools are pushing the child/youth and not providing enough time for the child/youth to complete tasks and not working around their specific needs. This may be catching up on lessons impacted on by symptoms such as absent seizures or memory impairments port seizure (Elliott et al., 2005). Research reported flexibility with aspects of attendance, curriculum, and due dates to be helpful for children with epilepsy (Roberts & Whiting, 2011). Similar to the ME/CFS data, having parents indicate ‘opportunities to rest’ as the most commonly indicated needed support speaks to ‘Other’ schools emphasising attendance when children can otherwise not, resulting in needing opportunities to rest when engaged with ‘Other’ schools. However, given there are only four epilepsy data sets for ‘Other’ schools these findings need to be interpreted with caution.

It is unclear exactly why such few numbers of children with epilepsy attended ‘Other’ schools, but when asked why their child had not been involved with ‘Other’ schools; 44% of parents indicated they did not know about these institutions; 28% indicated they did not see ‘Other’ schools as necessary; 17% indicated that their child/youth did not meet the criteria; and 11% indicated that they did not believe that such an institution could meet their child/youth’s needs. It may be that children with epilepsy receive funding or support that allows them to be sufficiently supported and remain in ‘Mainstream’ schools, more often than children with ME/CFS. This may produce a situation where there is minimal need for ‘Other schools to be suggested to or considered by parents as a ‘better’ schooling option. The fact that there appears to be less unmet need in ‘Mainstream’ schooling for children with epilepsy may indicate more support opportunities, supporting this idea. Alternatively, as indicated by some parents, the stringent criteria or not being made aware of such institutions may reflect a systems level issue as a barrier to attendance.

For both ME/CFS and epilepsy it appeared that there was greater unmet need in ‘Mainstream’ schools than there was in ‘Other’ schools. These quantitative results show a smaller number of both needed and not provided supports for ‘Other’ schools, resulting in a subsequent smaller unmet need. This may be that ‘Other’ schools are better placed to support children/youth with disabilities. This has been detailed in previous research by Similä, Nøst et al. (2021) who identified that children with ME/CFS attendings special schools received all the supports offered in ‘Mainstream’ schools, as well as additional alternative supports not offered by ‘Mainstream’ schools.

ME/CFS Theme 4: A one size fits all system is not enough. It was apparent from the parents’ comments that some parents did not perceive the school system to be well-suited to children with ME/CFS, resulting in their child either receiving ill-suited support or no support at all. When support was provided, and allowances were made parents often perceived this to fall short of their child’s support requirements, with their child remaining insufficiently supported, as noted by one parent’s comment that “we have found compassion, understanding and adaptation but it seems not enough support” (ME20). This was often in relation to attendance and participation in school with one parent commenting that the school was “accommodating in accepting a reduced timetable but he couldn’t even make it for that” (ME15). This was also found in relation to ‘Other’ schools with one parent commenting that they were “my son is enrolled with [‘Other’ school] but is not currently engaging” (ME8).

This may be that the impact that debilitating fatigue, in particular if a child is bed bound, is having on attendance and participation requires adjustments and accommodations beyond which the school is capable of providing (Crawley & Sterne, 2009; Tollit et al., 2018). Alternatively a lack of clinical input or diagnosis may lead to presumptions of a child’s capacity leading to over-active plans, beyond which the child can cope (Similä, Rø, et al., 2021). These findings are similar to what was described by Similä, Nøst et al. (2021) who detailed the provision of overambitious attendance plans to be implicated in negative educational experiences (Similä, Nøst, et al., 2021). In contrast to these findings, Brigden et al., (2021) identified that teachers perceived reduced timetables as a feasible and acceptable form of support; however, these were reportedly based on individual academic, social, and energy needs as well as subject preferences so may represent more ‘tailored’ activity management than the current findings.

Supports were also perceived to fall short in relation to academics and educational adaptations, which appeared to centre around reducing the curriculum as indicated by the parent’s comment “she has received support from [‘Other’] schools but her curriculum has had to be highly reduced” (ME20). Due to the inability to participate in school it would appear that the only adaptation schools were able to make was to reduce the workload on the child to fit in with their limited attendance. This may be an effective tool in helping the child in the short term but may also mean that the child’s education is unnecessarily restricted resulting in a loss of education when adaptations are not clinically informed, a point reiterated by Similä, Rø, et al. (2021). Such an impact may be evident in the current findings with one parent commenting “has meant he was unable to access education [and] has left school with no qualifications” (ME16).

This inability to gain a useable qualification may be a result of ill-informed or ill-suited support options resulting in education being inaccessible for this child/youth, or alternatively this child/youth may be experiencing symptoms severe enough that their ME/CFS, unfortunately, was incompatible with education. Furthermore, one parent commented on needing academic support for the number of absences experienced, wanting the school to simply keep the child/youth up to date on missed lessons stating, “it would be good if teachers could keep my child up to date on what to do if they are not at school, my child really has no idea what she’s doing at school” (ME11). This finding is similar to what was described by Similä, Nøst, et al. (2021) who identified that some children often studied from home without input from or communication with a teacher, instead having to rely on notes from peers. Not only is academic performance impacted on by cognitive symptoms and fatigue but is also impacted by the sheer number of absences these children experience. This comment speaks to not only missed support opportunities but also highlights again the need for better communication in improving support.

Parents also commented on wanting schools to help their child with social interactions, as well as education or health needs, but schools still appeared to fall short of this desire. One parent questioned the design of ‘Other’ schools with the child/youth not being given the opportunity to socialise or reduce the isolating effects of ME/CFS, stating “if the aim is to help children keep social connection… why are [‘Other’] school teachers not allowed to work with a group of children… have to just work 1:1 with the [‘Other’] school teacher which does not aid social interactions” (ME14). After being unable to attend ‘Mainstream’ schooling and suffering the consequences of isolation through disease processes this approach to ‘Other’ schooling was perceived as “counterintuitive” to reducing isolation - even potentially reinforcing notions of loneliness and being detrimental to mental health if schooling is likely to be the child’s only form of peer contact for the foreseeable future. One parent commented “I do get the fact that their policy and procedures are not written for long term ill people” (ME6), speaking to the parent’s perception that some aspects of ‘Other’ schools were not designed to support children needing long term adaptations, and that they are almost resigned to receiving support better suited to other children. Previous research details that instances where socialisation was prioritised by the school and incorporated within education/timetable plans children had positive support experiences, while schools which did not prioritise social interactions, contributing to minimal contact with peers, resulted in negative experiences (Similä, Nøst, et al., 2021).

In some cases, this perception of ill-suited support extended to the entire schooling system in general with one parent finding that “the mainstream system was unworkable”, resulting in the withdrawal of their child stating that “we had to home school as my daughter was unable to attend” (ME2) opting for a schooling environment where their healthcare and educational needs could be sufficiently managed. This was not uncommon with another parent noting a similar experience, commenting “we pulled this child out of school at age 6 to home-school because it offered the most flexibility” (ME12). Having the option to choose home-schooling is of course not an option for every family but reflects an almost extreme reaction to being confronted with a schooling system not suited to supporting their child/youth’s needs. Even ‘Other’ schools, with some aspects being designed to aid children/youth with an illness to maintain a reasonable education, appeared to not be suitable for children with chronic conditions, as indicated by the comments “The system is not set up well for long term chronically unwell children” (ME8), and “I felt [‘Other’] schools had no tolerance of the long-term sick students” (ME6). From comments it was clear schools were seen by some parents as schooling systems designed with either healthy children in mind or designed for those children with acute health conditions who would eventually recover.

In contrast to the current findings, Brigden et al. (2021) provided quite positive findings on support for children with ME/CFS with most teachers reporting to provide tailored education plans supporting attendance, academic, social, and emotional needs. However, where this research differs is that it is solely the perspective of school staff, which may result in participants potentially self-censoring negative views, whilst parents may not, providing a broader range of support experiences inclusive of negative experiences. Brigden et al. (2021) also utilised a younger child base, exclusively within primary school, whilst the age of children/youth included in the current study ranged from 11 to 20 with a mean of 15 years. It is unclear if such positive support experiences identified by Brigden et al. (2021) may be isolated to younger children. Furthermore, this was a study conducted in a UK context, and may simply represent a geographic difference in support provision and funding opportunities. Finally, children in the current study were not precluded from participation on the basis of a formal diagnosis, as they were in Brigden et al. (2021), meaning some children within the current study were yet to obtain an official diagnosis, which may account for differences in support experiences as a formal diagnosis has been shown to improve support (Brigden et al., 2020; Similä, Nøst, et al., 2021; Similä, Rø, et al., 2021).

Epilepsy Theme 4: Need for broader support. Like parents of children with ME/CFS, these parents also perceived that schools were not well placed to look after their children with epilepsy, identifying a system level gap that their child was falling through. This was made apparent by one parent's comment that the "Ministry of Education and subsequently schools are not well placed to support children with epilepsy symptoms and health needs therefore there is minimal support for these children" (Ep2), identifying government agencies as not catering to the chronically ill and being a potentially source ill-suited support. It was apparent from comments that parents perceived children to be being let down when it came to learning needs and invisible/less well-known symptoms with support being centred more around emergency seizure response. Broadening support options to include learning needs was commented on with one parent stating that they, "would like more supports put in place that combine learning and health needs" (Ep7). Parents still acknowledge the need to support their child with health needs, and perceived this to be present, but saw that support in general was narrowed and exclusive of learning needs. This was represented by this parent's further comment that there was "support provided around health needs but very limited support around learning needs available" (Ep7).

Given the impacts of epilepsy on academic performance and attendance, it is unsurprising that children were falling behind on their education, with parents seeing this and in response wanted better adaptations which supported learning needs. This was reflected in one parent's comment that their "Child is very behind in learning but does not qualify for any additional assistance" (Ep14). This comment linked back into the difficulties in meeting criteria for funding and additional assistance, with children unable to meet the threshold going unsupported. These findings are further supported by the quantitative findings mentioned previously which too spoke to a dearth of learning supports. These findings are similar to Johnson et al., (2021) with parents identifying, that without severe intellectual disabilities, they struggled to secure EHCP/supports and perceived a lack of recognition of the behavioural and learning needs of their child.

Parents also saw ill-suited support when it came to the invisible symptoms, which were perceived to be less well recognized by teachers and the system as having an impact on schooling. Thus, parents saw schools to be only concerned with emergency response, as reflected in a parent's comment stating that the "school only concerned about what to do in case of a seizure, not about medication effect on concentration and speed of brain processing" (Ep19). It was clear that this parent perceived the school to fail to cater to less emergency-based care with the school's support clearly being oriented towards stereotypical seizure symptoms. This focus was not perceived to be limited to the school with other parents perceiving this focus to extend to support provided in the form of training provided by a charitable non-government organisation to teaching staff, as indicated by a parent's comment that,

> "School also got a [charitable non-government organisation] to come to talk to all staff, but this was based on seizure symptoms, not about the ongoing chronic effects of epilepsy and epilepsy medication side effects, or the cognitive effects of undetected seizures or seizure recovery" (Ep14).

As one of the reoccurring perceived barriers identified in obtaining support was the difficulty in meeting stringent criteria to receive funding it is not surprising that parents repeatedly perceived higher up school and health agencies, as being implicated in poor support. It was apparent that these structures were working off stereotypical potentially outdated ideas of what epilepsy looked like and how it impacted on schooling. These findings are similar to what were described by previous research which details support from teachers to consist mostly of emergency responses and the handling of seizures in the school specifically through seizure management plans (Johnson et al., 2021a; Yang et al., 2021). However, such a focus may be important as seizures may be life threatening and require emergency response to ensure the child's safety. This may mean that there is a shift in focus, intentional or not, with other epilepsy aspects being comparatively less important resulting in the potentially limited resources going towards life-saving support implementation. Previous research has actually noted that negative support experiences were centred around safety issues and a lack of emergency first aid knowledge among school staff (Roberts & Whiting, 2011). Research has also indicated that some teachers are fearful of witnessing seizures and show concern over being held responsible or liable if something were to go wrong (Yang et al., 2021), thus making sure teachers and schools know what to do in an emergency may negate this.

Subtheme 4.1: Other Schools as transitional institutions. When it came to non-Mainstream schooling, parents of children with ME/CFS commonly commented on the structure of these schooling systems and the aim of these institutions being very ill suited to long term chronic conditions. 'Other' schools were often viewed as transitional institutions, as identified in one parent's comment, "the fact the ['Other'] school movement had a motive and agenda to get the number of kids on their role reduced and get them back to school quickly" (ME6), with another noting that “they were all about transitioning back to school” (ME18). It may be that ‘Other’ schools were simply trying to help children to return to ‘Mainstream’ schooling, but parents commented on the pressure that this placed on children with parents noting that this led to the child pushing themselves past their capabilities, commenting “the transitional role of [‘Other’] school, always pushing her to attend more when she had reached her limit” (ME9).

There was also the perception that the chronicity of ME/CFS clashed with the nature of ‘Other’ schools, with this same parent commenting that the school “believed as she wasn’t going to get better then she didn’t meet the ‘transitional role’ of [‘Other’] schools” (ME9). However, the transitional nature of ‘Other’ schools was not always seen as a bad thing with one parent perceiving it as a natural step on their child/youth’s road to recovery, stating “if she becomes well enough she could go to their premises to meet the teacher as a transition to school” (ME20). This is somewhat similar to the findings of Similä, Nøst et al. (2021) and reported negative adaptations relating to overambitious attendance plans and a failure to prioritise the child/youth’s needs. It appeared that these institutions are not designed as permanent education solutions with teachers likely not being trained as nurses with the capabilities to permanently handle health needs, resulting in potentially incongruence between ‘Other’ schools and long-term illness. As there were only four children with epilepsy who attended ‘Other’ schools this was not a theme identified in this cohort.

Theme 5: Lack of understanding and discrimination

A general lack of knowledge and understanding was an apparently common theme identified by parents as not only the most apparent reason for a lack of appropriate support but also contributing to stigmatisation and discrimination. This was particularly apparent when the disease characteristics were less visible or harder for teachers to believe or accept resulting in discrimination which made schooling experiences traumatic for children with ME/CFS and restrictive and exhaustive for children with epilepsy. In both instances this resulted in a perception by parents of a need for better education for teaching staff on ME/CFS and epilepsy.

When the quantitative survey asked parents about how often they themselves or their child experienced prejudice or discrimination, parents of children with ME/CFS most commonly indicated ‘often’ and ‘sometimes’, and parents of children with epilepsy most commonly indicated ‘sometimes’ and ‘rarely’. It is possible that ME/CFS parents perceived more discrimination due to the illegitimacy that shrouds ME/CFS as a health condition, whilst epilepsy has only some symptoms with questioned validity. Quantitative data also showed parents to indicate that they believed teachers could benefit from training and education around their child/youth’s health condition. As shown in Table 7, when asked the degree to which parents agreed with the need for education the majority of parents, of both ME/CFS and epilepsy children in ‘Mainstream’ and ‘Other’ schools, indicated that they ‘agreed’ or ‘strongly agreed’. The percentage of parents who agreed to some degree was highest for ‘Mainstream’ schools. ‘Mainstream’ teachers may have less understanding or training on medical conditions, whereas those in ‘Other’ institutions may have to have some understanding to work at an institution such as a Health school.

Table 7

Degree to which parents agree whether or not schools/educational professionals could benefit from training and education

Agreement Level	ME/CFS		Epilepsy	
	Mainstream (%) N=18	Other (%) N=15	Mainstream (%) N=20	Other (%) N=4
Strongly Disagree	0(0)	1 (7)	0 (0)	0 (0)
Disagree	0(0)	0 (0)	1 (5)	0 (0)
Neither	2 (11)	4 (27)	3 (15)	1 (25)
Agree	7 (39)	6 (40)	8 (40)	3 (75)
Strongly Agree	9 (50)	4 (27)	8 (40)	0 (0)

This is supported by epilepsy research which found that school personnel in special schools were significantly more likely to have epilepsy knowledge and have received training on aspects of epilepsy than staff in mainstream schools (Johnson et al., 2021a). Previous research clearly indicates a benefit of epilepsy training programmes for teachers with knowledge and understanding on management of these conditions improving with reduced stigmatisation post training (Abou Khaled et al., 2020; Mecarelli et al., 2015; Renzetti et al., 2020). In saying this, as shown in Table 7, some parents perceive that further education is neither warranted nor unwarranted, so it may be reasonable to conclude that some teachers do take an interest in the conditions that children in their specific classrooms may have.

ME/CFS Theme 5: Left traumatised. There was the perception from some parents that the entire system lacked the knowledge and understanding to deal with children with ME/CFS leading to a perceived incongruence between a school’s understandings of support needed, or not needed, and the support actually needed, as one parented commented the “[‘Other’] school had a disappointingly outdated approach to her condition” (ME15). This may be related to old understandings of ME/CFS as a mental health condition or as the fabricated illness of a malingerer, for example in Munchausen’s or Munchausen’s by proxy (Brigden et al., 2021; Geraghty, 2020; Van Hoof et al., 2006; Vickers, 2000). This is similar to what was identified in Brigden et al 2021 who noted that one teacher questioned the cause of the symptoms experienced and subsequent impact on schooling, identify mental health, specifically stress and anxiety, as the more likely cause.

The constant struggle against such perceptions of ME/CFS and the accompanying stigmatisation appeared to leave parents exasperated by the way their child was treated, taken aback and shocked by the lack of sensitivity and the sense that gaining an education was a cruel joke, with one parent commenting that they had "decided education was a joke for people with this illness with this kind of cruelty" (ME6). The idea of being denied an education and the discrimination and bullying experienced was perceived by one parent to be the reason behind their child's hesitance to return to school stating,

> "We have been asked by the MOE to get him signed back up with ['Other'] school, but he is refusing because of his perception around how he was treated by them. He is refusing to have anything to do with them. It has been an extremely traumatic experience for us all." (ME8)

The fact that this parent went as far as to call their child's schooling experience as traumatic speaks to the damage scepticism has in the school setting, in particular the negative impact on the student-teacher relationship and how the child views themselves and the education system. Evidence suggests that having people question the truthfulness of illness accounts may create dichotomy between one's own sense of morality and others' perceptions of their morality, contributing to a heavier disease burden (Åsbring & Närvänen, 2002). In this case, potentially having teachers view a child's illness experiences as false, while a child knows these experiences to be true, may be harmful to how the child perceives themselves and teachers.

This finding is similar to what was described by Winger et al. (2014) with youth reporting that home had become a shelter where they could avoid facing discrimination and being labelled lazy by teachers. It was clear that this discrimination was having knock on effects to the family likely impacting on home life, with intense advocacy likely reducing the time or energy dedicated to family life and other children. A similar finding was noted in Parslow, Shaw, et al. (2017) with clinicians detailing a profound impact on families, impacting on family activities and burdening sibling and parent relationships. Parents themselves were not exempt from being the targets of stigmatisation, for if people perceived the parent to be going easy on the child and not forcing the attendance of an 'apparently' healthy child, as indicated by the quote "everyone at school and in the family and our friends, thought we were being soft on her by letting her wag school" (ME6), parents may be labelled ‘bad parents’. This in a way meant parents were fighting against two types of discrimination, from the stigmatisation of their child/youths ME/CFS and from the stigmatisation of perceived negative parenting.

Epilepsy Theme 5: Fear based restriction. Likely as a result from a lack of knowledge and understanding, parents of children with epilepsy found that their child was often excluded by schools or teachers because of fear around seizures. This discrimination was viewed by parents who saw that some situations or activities provoked a sense of unease with staff around what might happen in the event of a seizure, with one parent commenting that “despite having protocols in place there is a huge fear of her epilepsy and her schooling is restricted because of this” (Ep11). Teachers may have ill-informed preconceptions of what every child’s epilepsy looks like and are subsequently ill-equipped to deal with seizures, assuming the worst-case scenario of stereotypical seizures and restricting participation to avoid such instances. This may be both in an attempt to protect the child and other students, but also potentially to protect schools from liability in the case of an emergency (Yang et al., 2021). One parent commented “our daughter was excluded from many activities because of health and safety. The fear of the law is stronger than people’s desire to be helpful” (Ep22) identifying structures beyond the individual teacher or school which resulted in the, potentially unnecessary, exclusion of their child.

Previous research supports this finding identifying that youth perceive institutional barriers to prevent them from fully participating and engaging in school activities, only being allowed to attend school camps when teachers claimed responsibility for monitoring and supervising the child (Chew et al., 2019). This is not only harmful to the child/youth’s education but may result in hesitancy in disclosing an epilepsy diagnosis to future schools for fear of discriminatory exclusion, a point backed by previous research (Benson et al., 2017; Lambert et al., 2014).

This discrimination is likely in response to potentially overt and confronting symptoms but may also be applicable to less visible symptoms. One research study conducted found that most parents and school staff perceived inclusion in school based activities, but parents that did perceive school-initiated exclusion felt that this was related to behavioural and learning issues, an inability of staff to manage seizures, and/or lack of training (Johnson et al., 2021b). Discriminatory experiences parents perceived in response to obtaining support for invisible symptoms were also noted with parents, like parents of children with ME/CFS, feeling exasperated by this daily struggle of obtaining recognition and support for their child’s symptoms. This is reflected in the comment from one parent that the "entire experience is exhaustive and discriminatory due to the invisible nature of neurological illness" (Ep2).

Theme 6: Impact of COVID-19

Although COVID-19 was not something that was directly asked about in the survey, two parents – one with a child with ME/CFS and one with a child with epilepsy – commented on the impact of the COVID-19 pandemic on their child/youth's schooling. Both parents spoke of the negative implications this had on their child's schooling, especially the impact of fear and isolation. For one parent, COVID-19 seemed to compound the negative effects of reduced attendance on their mental health, commenting "this was very hard for us and over COVID as well" (ME11), with the lack of contact with peers during this period likely further contributing to their sense of isolation.

For the other parent, the inherent fear surrounding COVID-19 was enough to set the child's attendance progress back, commenting "before COVID-19 they were attending school for longer hours but now it's quite scary to send her into the environment" (Ep5). This regression may be a result of the uncertainty around what these new conditions meant for the child's schooling and health, and the inherent risk associated with sending their child into an environment where the risk of contracting COVID-19 was high, especially seeing as though the child already had compromised health,.

However, the parent of the child with ME/CFS also commented on the positive impact of the adaptations put in place during the pandemic, with the availability of one-on-one tutoring via video chat at home enabling the child to learn from home with the parent commenting, "this was good over COVID and on video chat" (ME11). These adaptations likely made at home learning more accessible and likely made keeping in touch with teachers about educational content easier. These results are similar to the findings of Similä, Nøst, et al. (2021) who identified online learning adaptations, in response to COVID-19, made completing work and communicating with teachers easier, putting them on 'equal footing' to peers.

Discussion

Main Findings

The aim of this research was to answer the research question 'What are parents' perceptions of the supports available to their school aged child/youth to help with the impact of ME/CFS or epilepsy in a New Zealand schooling context?' The quantitative and qualitative findings of this research offered a wide range of different parental perspectives into the schooling experiences of children with ME/CFS and epilepsy. As identified in the findings, the qualitative data revealed six main themes, which were separated into condition specific sub themes, with quantitative data providing support for these themes. Where applicable some themes contained subthemes, which are outlined below. The six main themes and non-condition specific subthemes identified were: 1) Let down by their own bodies, 1.1) Damaging self-concept; 2) Struggle for validation; 3) Luck of the draw, 3.1) Teachers operating in a rigid system, and 3.2) Gratitude from parents; 4) Ill-suited support and 4.1) Other schools as transitional institutions; 5) Lack of understanding and discrimination; and 6) Impact of COVID-19.

The first theme *'let down by their own bodies'* highlighted the impact that ME/CFS and epilepsy has on children/youth and their schooling experiences. Parents comments on the impacts on socialisation, academic achievement, and attendance gave a sense of helplessness for these children to be in control of their bodies, hindering a 'normal' school experience. For children with ME/CFS there was a perceived impact on participation, attendance, socialisation, and the schooling experience on the whole. The debilitating fatigue, and sometimes bed/house bound state, experienced by young persons with ME/CFS may reduce curriculum engagement and participation in full school days, cutting children off from their education and socially from peers, trapping them in bodies which bar a normal school experience (Crawley & Sterne, 2009; Knight et al., 2018; Parslow, Shaw, et al., 2017; Similä, Nøst, et al., 2021; Winger et al., 2014). The impact of stigmatisation and discrimination to school experiences may also explain the perceived impacts to socialisation and attendance (Parslow, Shaw, et al., 2017; Similä, Nøst, et al., 2021; Similä, Rø, et al., 2021; Van Hoof et al., 2006; Winger et al., 2014).

For children/youth with epilepsy the main implications perceived by parents were to academic performance, attendance, and ramifications from behavioural implications. Given the impact of epilepsy on the brain, and subsequent intellectual/cognitive deficits and behavioural/emotional symptoms, along with post-seizure fatigue, healthcare needs, and side-effects of anti-epileptic medication, such implications are unsurprising (Aguiar et al., 2007; Dal Canto et al., 2018; Elliott et al., 2005; Reilly et al., 2014; Reilly & Ballantine, 2011; Serdari et al., 2009). The possibility for restricted attendance/participation by parents and teachers/schools, stemming from protectiveness and fear of discrimination, or actual discrimination and fear based restriction, may also explain a perceived impact to attendance (Aguiar et al., 2007; Benson et al., 2017; Chew et al., 2019; Elliott et al., 2005; Lambert et al., 2014; Yang et al., 2021).

In addition to this idea of children with ME/CFS and epilepsy being let down by their bodies was the development of the subtheme ‘damaging self-concept’. The consequences of having these ‘bodies’ at such a crucial period of development meant that parents often commented on the frustration and sense of missing out their child experienced, likely originating from feelings of differentness from peers, a sense of being left behind, and lack of faith in their body’s abilities (Winger et al., 2014). When children/youth needed to see themselves as ‘same’ to their peers, a lack of autonomy through a reliance on adults for medical care would have broadened any gap between self and peers created by their health, particularly for older children (Elliott et al., 2005; Parslow, Shaw, et al., 2017). A clear impact on mental health was also identified as young people grappled with these implications to their identity and what this meant for where they ‘belonged’ in life, bringing about a perceived sense of hopelessness and uncertainty for their futures while their lives were on hold (Similä, Nøst, et al., 2021).

The second theme *‘struggle for validation’* reflected the struggle that parents, and their child/youth, had to go through for their condition and/or symptoms to be legitimised and deemed to have an impact on schooling warranting support. This appeared to be centred around a lack of condition or symptom visibility, in particular the invisible nature of ME/CFS driving a lack of condition believability from school staff before, and even sometimes after, receiving that elusive official diagnosis. A diagnosis was often described as being difficult to get, likely caused by the scepticism within the medical community surrounding ME/CFS and its almost untestable nature going against the physical illness model evolved using pathology and evidence-based western medicine. Some medical professionals were reported to go as far as to say that as long as there was no definitive ‘test’ they would remain doubtful about the existence of ME/CFS (Horton et al., 2010). This often resulted in an ME/CFS diagnosis being delayed, missed, or even disregarded, with symptoms being no longer believed once a diagnosis of ME/CFS was on the table. Such scepticism means that some parents must visit multiple different clinicians, often of different background or specialty, in order to obtain documentation of a diagnosis, which was sometimes not enough to satisfy schools. Again, living in a westernised community where evidence-based western medicine is the norm, proof from alternative practitioners, other than general practitioners or paediatricians/specialists, may not pass as a legitimate diagnosis nor satisfy the policy/organisation level for the implementation of certain supports.

An official ME/CFS diagnosis has been identified throughout previous literature as being pivotal in having schools believe in a student’s ME/CFS diagnosis and to gaining support (Åsbring & Närvänen, 2002; Brigden et al., 2021; Similä, Nøst, et al., 2021). Given the invisible nature of

ME/CFS symptomology, without a diagnosis it may be hard for some teachers to believe that there is a genuine impact on schooling. This would appear to be the same scepticism behind the struggles with medical professionals with lack of visibility driving perceived illegitimacy and stigmatisation. Those struggling through the difficult diagnosis journey yet to be diagnosed by an 'appropriate' clinician would also likely be struggling with the educational professionals for their child/youths' invisible symptoms to be perceived as impactful and warranting support.

Furthermore, the reported reluctance of schools to provide support without a formal diagnosis or to accept a diagnosis from an 'alternative' practitioner may stem from western medicine ideologies but may also result from a necessity to not harm students. A formal diagnosis would likely provide schools/teachers with confirmation of impact, an idea of the type of impacts a child/youth is likely to experience, or a point of contact or reference within the medical community to be a source of information on helpful adaptations. Research shows that without such formal diagnosis teachers may implement support adaptations that go against best practice and may be harmful to the child/youth (Brigden et al., 2021; Similä, Nøst, et al., 2021).

The case was similar for children/youth with less visible, less well-known epilepsy symptoms, the impact of which was doubted or would fail to satisfy specific funding criteria for support. It appeared that there were misconceptions surrounding epilepsy and what 'impactful' epilepsy would look like, with the more confronting and potentially scary aspects of the diagnosis being given more weight with the less visible or well-known symptoms going by the wayside. Those seizures which are more overt in nature requiring immediate emergency response may be confronting and potentially scary to witness, sticking in the mind and influencing perceptions of what epilepsy looks like (Benson et al., 2017; Yang et al., 2021). The previous experiences a teacher may have with students with epilepsy and tonic clonic seizures and/or intellectual disabilities may influence perceptions of how epilepsy impacts on schooling.

Furthermore, as previous research has indicated, teachers may gain illness understandings from mainstream media (Yang et al., 2021). It is possible that there may be an over representation of more dramatic seizures or severe intellectual disabilities and an under-representation of invisible symptoms or medication side effects, resulting in misconceptions of how epilepsy might impact on schooling (Reilly & Ballantine, 2011). This may then also influence funding criteria through this same under-representation of invisible symptoms but also through a potential 'weighing' of symptoms determining those more overt symptoms to require the limited funding resources. Subsequently parents must struggle against teachers and schools to have them recognise the impact of less visible or confronting symptoms whilst also fighting the system for these same symptoms to be included in the criteria for support funding.

However, in contrast to the battle and struggle described by parents in the current study some previous research indicates a reluctance to disclose an epilepsy diagnosis when symptoms are less visible. In these instances, parents and/or children refrained from disclosing their child's medical condition unless absolutely necessary or a child is 'outed' in the school context. This is likely an attempt to protect their child from the discrimination associated with the stigma of those more dramatic overt epilepsy symptoms and maintain some sort of normal schooling experience (Benson et al., 2017; Chew et al., 2019; Yang et al., 2021). The symptoms experienced in these cases may be less severe and less impactful on schooling allowing the child/youth to progress normally through school without the need for support. It is clear that the parents in the current research, making these comments, are in a space between these two types of epilepsy, those with obvious implications and those who 'pass as normal' and do not require support, a space that clearly requires strong advocacy to have their schooling concerns taken seriously.

The third theme *'luck of the draw: Both supportive and unsupportive experiences'* arose from parents varied responses and satisfaction, which appeared to be based on individual teachers/schools or on the symptoms experienced. The school attended seemed to determine support for both ME/CFS and epilepsy with teacher understanding, adequate communication, and a positive trusting parent-teacher relationship denoting a supportive experience, with less supportive institutions being sceptical of disease experiences and denying support without funding or clinical input. The level of knowledge and understanding of disability, and its impact on schooling, is a factor that seems obvious when considered. Given the stigma and ill-informed illness beliefs surrounding both ME/CFS and epilepsy, in particular perceived illegitimacy or seizure fear, it is not surprising that a teacher's knowledge and understanding of disability would influence belief in an impact and support provision. Knowledge may not only negate stigma but also ensure support is individualised and reactive to a child's needs. Having such understandings may hinge not only on prior knowledge but on effective communication and positive trusting relationships between parents and teachers. A trusting relationship may mean invisible or contested disease attributes are believed at face value, with teachers trusting a parents account of disability, which may be particularly important when children are undiagnosed, as was the case in some children with ME/CFS.

These positive relationships have also been implicated in previous research to fostering open lines of communication, which were also essential for effective transmission of health and education information. Effective and open communication, was found to result in teachers requiring less input from clinicians, with illness information being communicated to the school via parents instead (Brigden et al., 2020). Instances of effective communication may also be related to the parents' own knowledge and ability to relay this information in a manner that instils confidence with the school and satisfaction that the parent prioritises their child's needs and is a sufficient point of medical contact (Brigden et al., 2020). A parent's advocacy or communication style may also influence this relationship with research showing parents who took a grateful, engendered, and appreciative approach had generally better more trusting relationships with teachers when compared to parents who took a more strategic/compromising advocacy approach or a forceful/demanding approach (Rehm, Fisher, Fuentes-Afflick, & Chesla, 2013)

Furthermore, within the findings of the current research, across both ME/CFS and epilepsy, was the idea of shopping around for different more supportive schools. This was likely in order to find understanding knowledgeable teachers with whom parents could form positive and communicative relationships with, obtaining the best most sympathetic outcomes for their child. This is comparable to the idea of a 'postcode lottery' and the inequitable distribution of resources across different geographic areas or postcodes, often in relation to healthcare. In this instance we see that finding a supportive institution may be dependent on support polices and resources in the school area the child/youth has access to (Reilly & Ballantine, 2011) .

Some parents of children/youth with epilepsy also perceived luck to be involved when their child met the strict criteria to receive funding for support. This was clearly not that parents felt lucky that their child had more severe epilepsy, but may be more representative of relief that their child has met such stringent criteria, an event to them that may have felt like winning the lottery. Every set of criteria has a cut-off line, meaning that there were unlucky children experiencing an impact for which support is needed and justified but instead fall short of this cut-off and go unsupported, a point also illustrated in previous research (Johnson et al., 2021a). Furthermore, the process of gaining support may be lengthy (Roberts & Whiting, 2011), so when their child finally meets criteria parents may feel lucky that their child is finally gaining the necessary support needed to gain an education. This may be especially true for these less visible symptoms or medication side effects which apparently required extra advocacy. Furthermore, luck may arguably have played a role in which specific symptoms were determined, at the time of the development of criteria, as impactful.

The perceived ‘luck’ of attending a school with supportive staff was highlighted by the sub-theme ‘teachers operating in a rigid system’ where parents perceived supportive teachers who were restricted by the rigidity of the school system. Teachers or schools may have some control over their individual classrooms or day to day running of the schools, allowing them some influence in the support of chronically ill children, i.e., minor adjustments such as some flexibility in attendance and work completion. However, as schools and teachers are responsible for the education of numerous children/youths using a national curriculum with yearly standards and requirements, providing adaptations without the support of the education system itself may be difficult.

Attending a school where staff go to the absolute limit of what the system allows, providing support despite constraints, such as funding or medical certificates, parents may view their child as exceptionally lucky. This theme introduces the notion of a system level gap, where it is not the teachers or even the schools halting support provision but the requirements of the schooling system itself. This ties into the ideas of who gets funding or special resources, and which supports are made available to which conditions/children. Lastly for Theme 3 was sub theme 3.2 *‘gratitude from parents’*. Unsurprisingly, parents conveyed a sense of gratitude for the positive educational experiences their child received typically as a result of being supported. When educational staff were doing all they could within the confines of this rigid system, regardless of support outcome, it was clear parents were grateful for the school’s intentions.

The fourth theme ‘*ill-suited support*’ represented the number of unmet needs indicated and the perceived insufficiency of the support that was provided in both ‘Mainstream’ and ‘Other’ schools. Parents of children with ME/CFS perceived support to be a one size fits all system designed for healthy or acutely unwell students failing to cater to chronic illnesses, particularly chronic fatigue, with the supports provided falling short of the child/youth’s needs. This was perceived with regards to most areas of schooling including, attendance and participation, academic supports, and socialisation resulting in the perception of education being inaccessible. Quantitative findings pointed to a similar lack of support. These findings may be related to the number and range of needs conflicting with restrictions imposed by system requirements and funding, as well as stigmatisation diminishing perceived impact and need for supports. The supports made available in schools may also be better suited to more common conditions, catering to those children closer to the mean of a ‘childhood conditions’ bell curve. Previous research noted the availability of information resources for teachers for conditions such as asthma, diabetes, epilepsy, allergies… but a complete dearth of resources for ME/CFS (Brigden et al., 2020). The same concept of a ‘childhood conditions’ bell curve may be similarly responsible for these findings. It is also possible that some children may simply be too unwell to engage with any schooling even with adaptations, reflecting severe illness rather than poor support, as condition severity has been associated with a greater impact on schooling (Knight et al., 2018).

A potentially alarming finding in the ME/CFS ‘Mainstream’ quantitative results was the unmet need of ‘adequate communication’ which has been established as being integral to adequate support provision (Brigden et al., 2020; K. Rowe, 2020). It may be that invisible symptoms are being missed/unseen or stigmatised resulting in the minimisation of the need for support or communication with home (Vickers, 2000). Alternatively, fractious relationships between carers and schools or certain parental advocacy/communication styles may lead to breakdowns in communication (Brigden et al., 2020).

Epilepsy parents viewed support as too narrowed focusing on what schools viewed as necessary seizure support rather than on specific health and education requirements of their child with epilepsy. Quantitative results from ‘Mainstream’ schools echoed this with supports provided being synonymous with the stereotypical symptoms associated with epilepsy. This may be as these symptoms are what are most commonly experienced or what are represented as being the most common and impactful. The focus on such symptoms, particularly emergency responses, are of course necessary, as something that is deemed life threatening is important and will obviously be given top priority. Less visible symptoms, like with ME/CFS, may go unnoticed or underrated/minimised due to the invisible nature (Vickers, 2000). This perceived narrowed focus was also reflected in the surprising number of unmet needs for a range of learning supports, except for ‘teacher aid’, a finding reiterated in the qualitative comments with parents wanting more learning supports. With the huge range of supports needed and limited resources, a line unfortunately has to be drawn on which supports can be provided and which cannot. Like with ME/CFS, the range of supports needed may simply be too much for system restrictions. As a result, support may be better suited and more available to those whose epilepsy fit a certain niche, with a dearth of resources meaning only those ‘severely’ impeded are able to receive support.

The restriction imposed by funding on resource availability and support was also apparent in the quantitative findings for both conditions. It appeared that parents perceived greater unmet needs for those types of supports requiring resources beyond what the teacher or school could offer without additional funding. This is quite an intuitive finding as support is likely restricted to what can be functionally and realistically provided with the monetary resources available. This finding links in well with Theme 3.1 ‘Teachers operating in a rigid system’. This may also be the reason behind why there was apparently fewer unmet needs in ‘Other’ schools than ‘Mainstream’ schools as some of these schools may have better funding specifically for providing these kinds of supports.

When it came to ‘Other’ schools, parents of children with ME/CFS felt let down further by the transitional nature of these institutions, which were seen to aim towards returning children/youth to ‘Mainstream’ schooling rather than aiming to be a permanent source of support for children. This again may be due to limits in funding or resources and these schools’ ability to support children long term. Alternatively, returning an unwell child to regular schooling with their regular teachers and peers, and achieving a sense of normalcy for the child may be a goal that a lot of families and teachers work towards. This may be a model that works for other health conditions but was apparently an ill-suited modus operandi for those with chronic health conditions particularly chronic fatigue. This points to a system level problem with these children falling through the cracks.

The second to last theme, Theme 5 ‘*lack of understanding and discrimination’* outlined perceptions of outdated approaches to support driven by misinformation or stigmatisation resulting in perceived discrimination and a need to better educate teachers. Views of the system being ill-equipped to support their child with ME/CFS, resulted in a sense of exasperation with parents identifying the trauma of such discrimination on their child with ME/CFS and their families. Such experiences lead to the implicit acceptance of children not returning to schooling because of and in avoidance of discrimination and further trauma. Discriminatory experiences and outdated approaches likely stem from the stigma surrounding ME/CFS perpetuated by its invisible and contested nature. Perceptions of faking or malingering are common amongst conditions which are difficult to measure or validate (Vickers, 2000), whilst psychiatric descriptions of ME/CFS as a mental health condition may also result in the stigmatisation of ME/CFS and the diminishing of physical symptoms (Geraghty, 2020). Being potentially unaccepting of ME/CFS as a medical diagnosis, teachers may search for explanations perceived to be ‘more likely’, these being psychiatric explanations or perceptions that the child is faking resulting in harmful discrimination.

Furthermore, teachers’ understandings may rely heavily on the knowledge of doctors and a diagnosis, so in instances when a child’s doctor is sceptical and a diagnosis is delayed, negative sceptical views held by teachers may be reinforced. With children being identified as malingering, parents were not exempt from discrimination themselves, potentially being labelled bad parents for indulging absenteeism. It is then not surprising that experiences were perceived as traumatic on a family level, with the trustworthiness of accounts, and essentially of self, being scrutinised. Parents perceptions of the system being ill-equipped with out-dated understandings and approaches brings in the idea of a potentially discriminatory education system providing inequitable support. This idea may be supported further by the current findings and the fact that epilepsy, a legitimate health condition, appeared to garner more perceived support and sympathy than ME/CFS.

Parents of children with epilepsy also perceived a lack of understanding and knowledge leading to discriminatory experiences with parents calling for further training of education professionals. The stereotypes around what epilepsy looked like were an apparent influence on teachers' understandings of epilepsy, with the confronting nature of overt symptoms shaping subsequent fear of seizures amongst teachers. This fear was witnessed by parents and perceived to culminate in the fear-based exclusion of their child. Previous research details this exclusion as being the result of both positive discrimination and an attempt to protect children, or the perception that they would not know how to handle a pupil's seizure and did not want to be responsible or liable (Johnson et al., 2021b; Yang et al., 2021). Linked into previous themes and following on from these stereotypical representations, parents also perceived discrimination around the potential prioritisation of overt symptoms and lack of support for less obvious symptoms, which, similarly to ME/CFS, gave a sense of exhaustion to this daily struggle for recognition (Reilly & Ballantine, 2011).

This perceived lack of understanding in teachers and schools resulted in a consensus in both participant groups of a need for training and education of school staff in both 'Mainstream' and 'Other' schools and was a pervasive theme throughout the quantitative and qualitative data. Neither teaching groups are trained medical professionals so may lack the knowledge and understanding to deal with the complexity of both conditions. Training and educating educators is a well-supported idea in the literature and is implicated in positively impacting on knowledge, understanding and stigmatisation post training (Renzetti et al., 2020). Improving knowledge and understanding is an essential aspect to reducing negative illness beliefs and stigmatisation leading to discrimination.

The final theme was a very interesting theme as it reflected parents' perceptions of the influence of COVID-19 on the schooling experiences of children with ME/CFS and epilepsy. Even though such experiences were not asked about directly – as the survey was created before the pandemic – these parents still felt that the experiences of the impact of COVID-19 and subsequent nationwide adaptations were worthwhile commenting on. Negative perceptions were noted by parents of both ME/CFS and epilepsy, who commented on the negative impact of isolation on already poor mental health and the impact of COVID-19 related fear on the child's attendance.

Given that a global pandemic is uncharted territory for parents, it is unsurprising that parents perceived negative impacts to their child's mental health and experienced fearful responses. With such isolation from peers, as well as the likely additional stress and disruptions to family life, it is not unlikely that COVID-19 would impact on mental health. Resulting fears around potential infection, and the implications this would have to both the child and the family (i.e., poor health or impact of time off work on income), are also not unbelievable. It is unclear if the perceived fear was that of the parent and their reluctance and hesitance to send their unwell child to school during a global pandemic and the inherent risks associated with this; the child's fear of being in a classroom environment during a pandemic; or a combination of the two. Recent research on the impact of COVID-19 on children with chronic physical illness, found psychological distress of children during the pandemic to be associated with COVID-19 worry, effects of social isolation or restriction, and their psychological distress pre-COVID. Elevated COVID-19 related worry in parents was associated with poorer family functioning, parental stress, financial concerns, and pandemic psychological distress (Ferro et al., 2021).

There was also a positive impact of COVID-19 perceived with the introduction of online learning and video conferencing with teachers making learning for their child with ME/CFS more accessible. These adaptations were supports which parents commented on as being needed by their child with ME/CFS, so it is not surprising that COVID-19 adaptations had the potential to benefit this child. Similä, Nøst, et al. (2021) found similar results on the influence of learning adaptations in response to COVID-19, with children with ME/CFS finding an online learning environment to support their learning and facilitate communication with teachers and peers. However, as the survey used in the current research did not directly ask about perceptions of the impact of COVID-19 and, unlike Similä, Nøst, et al. (2021), follow-up interviews were not conducted to enquire about this impact specifically, it is highly likely that these findings do not reflect the extent of parents' perceptions, not dissimilar to an iceberg.

These perceptions paint an interesting picture of parents' experiences of the support of their child with ME/CFS or epilepsy. The impact that these conditions are having on their children are resulting in schooling experiences which are leaving children to lose faith in the bodies which are hindering a normal schooling experience. It was apparent that such implications were worrisome to parents and resulted in a need for advocacy, for parents to stand behind their child and make sure that their child's needs and impacts on education were recognised as being impactful and warranting support. Unfortunately, due to invisible symptoms, misinformation, and disease stigma this was often a struggle that did not always result in the positive outcomes parents hoped for.

Institutions were perceived by parents to be both supportive and un-supportive with the supportive nature of a school often being up to the luck of the draw on which school their child was able to attend, with a school's individual teachers playing a significant role. For children with epilepsy, parents also perceived luck to be involved with whether or not their child meet the stringent criteria in place for funding for support. It was apparent from these perceptions that instances of their child going unsupported happened enough that when their child was supported, they were lucky to be so. It was apparent that there was the perception that the design of the system and system requirements, rather than the individual teachers or schools, was the biggest barrier to support, with system level gaps and a design not suited to these particular children. At play was also the influence of a lack of understanding resulting in discriminatory support experiences that left some children traumatised and excluded. On top of all these support experiences was the added hurdle of a global pandemic, which negatively impacted on mental health and attendance, but also resulted in the benefit of nationwide at home adaptations which unsurprisingly suited the needs of children with ME/CFS.

Condition specific differences in support

There are clear differences and similarities within these themes between children/youth with ME/CFS and those with epilepsy, which appear to be based around the symptoms experienced, the visibility of these symptoms, and the subsequent perceived legitimacy of said symptoms or condition as a whole. Firstly, the way the two conditions impacted on schooling is determined by the symptoms experienced by each child. The most impactful symptom experienced by children/youth with ME/CS appeared to be debilitating fatigue which had a large impact on their attendance or participation in scholastic and social activities. For epilepsy, the most impactful symptoms were those seizures that impacted on the functioning of the brain resulting in learning deficits or intellectual disabilities and behavioural implications. Where the two conditions shared an overlap was with the symptom of fatigue, which both children with ME/CFS and epilepsy experienced. This caused similar impacts to attendance, participation, and socialisation, albeit to differing degrees given the apparent difference in symptom severity. The two conditions also shared an apparent impact on sense of self as symptoms impeded development and participation in key developmental milestones.

An interesting similarity between the two conditions was the struggle that parents went through to have their child/youth's symptoms taken seriously, as both legitimate and impactful on schooling. As previously discussed this boiled down to the visibility of such symptoms and this invisibility leading to doubt and the perception that there was no impact on schooling requiring support. Both epilepsy and ME/CFS have symptoms which are less visible and may either go unnoticed by school staff or have the impact disregarded or misattributed to other causes such as poor behaviour or psychology. This resulted in a shared strong advocacy role of parents of children/youth with ME/CFS and epilepsy to gain the support their child desperately needed. Where this struggle diverged was in determining the validity of each as a legitimate medical condition, with this being centred around pathology and testable criterion, and their presence in epilepsy and absence in ME/CFS, making the struggle with ME/CFS being one for condition validation not just for symptom validation.

With regards to support, both parents of children with ME/CFS and epilepsy noted supportive and unsupportive experiences, which ultimately hinged on very similar conditions. Supportive experiences for both conditions were perceived to be contingent on specific schools and teachers, especially when teachers were understanding and formed trusting positive parent-teacher relationships with open lines of communication. The contestable nature of ME/CFS meant that the influence of trust in parent-teacher relationships was highlighted more by parents of children with ME/CFS than with epilepsy, particularly when awaiting diagnosis. Teachers willing to provide support to children within the rigidity of the schooling system was an experience perceived by parents of both children with ME/CFS and epilepsy. With regards to both supportive and unsupportive experiences, gratitude was expressed by parents of both condition types, but was more apparent in parents of children with ME/CFS. This was likely the result of the questionable validity of ME/CFS making interactions where their child’s needs are acknowledged and taken seriously the exception to the rule.

It was apparent that the established validity of epilepsy as a medical condition provided some advantages to support provision with an apparently greater number of support types being provided to children with epilepsy. Firstly, there were fewer ‘unmet’ needs in children with epilepsy, with those support types which required funding appearing to be provided more readily to children with epilepsy than to children with ME/CFS. From qualitative comments, parents of children with ME/CFS also noted an unworkable system with a greater number of schooling areas for which there was not enough or ill-suited support, including attendance, participation, academic performance, and socialisation. Parents of children with epilepsy perceived a need for broader support options encompassing learning and behavioural supports, as well as incorporating the health needs of both visible and invisible symptoms. These findings gave the impression of overall ill-suited support for children with ME/CFS, whereas for children with epilepsy there was the perception of a need to build on and broaden the support that was already there.

Findings also showed apparent condition specific differences in obtaining funding for support, as these opportunities to receive funding seemed almost exclusive to children with epilepsy. Subsequently, the apparent struggle against the system for symptoms to meet criteria for funding was experienced more in children with epilepsy. An apparent lack of funding opportunities for children with ME/CFS may have meant not meeting such criteria was not discussed to the same extent by parents of children with ME/CFS. Children with ME/CFS also seemed overwhelmingly more likely to attend and have support experiences with ‘Other’ schools. The funding opportunities granted to children with epilepsy may allow them to remain enrolled with ‘Mainstream’ schools more often the children with ME/CFS. The types of support more readily provided in a ‘Mainstream’ setting may also be better suited to the needs of children with epilepsy making ‘Mainstream’ schools a better fit for children with epilepsy. Both parents described similarities in discrimination in the access and inequitable distribution of support leaving parents feeling exasperated and traumatised. Condition specific differences and similarities may be attributed to condition and/or symptom visibility, the perceived legitimacy of said condition as an impactful medical condition, and the resulting stigmatisation impacting on understanding and subsequent willingness to provide support.

Findings in the context of a socio-ecological model

What was apparent from the findings was how parents’ perceptions of supports available to their child/youth with ME/CFS or epilepsy could be interpreted using a socio-ecological model. Of particular relevance were Bronfenbrenner’s (1979) ecological model and the framework from Brigden et al. (2020) for the integrated care of children with ME/CFS. Similarly to both models, the current findings can be conceptualised into levels of nested systems with the individual at the centre, with each level becoming more distant from the individual person. Each of these two models had their pros and cons that were relevant or not to the current findings, with the socio-ecological framework proposed by Brigden et al. (2020) having the most apparent relevance. The current findings will be discussed in terms of the framework proposed by Brigden et al. (2020) with similarities and differences being highlighted, and where applicable elements of Bronfenbrenner’s (1979) ecological model being used to enhance the current framework. A visual representation of the current findings within a socio-ecological is included in Appendix B.

At the centre of a socio-ecological framework is the individual level, which in this instance is the child/youth and their ME/CFS or epilepsy healthcare needs which impact on schooling. As previously discussed in theme 1 *'Let down by their own bodies'*, parents perceived their child/youth to experience symptoms which impacted on schooling in different and significant ways. These individual symptoms, particularly the different symptoms of ME/CFS and epilepsy, and their subsequent impact, may likely determine what supports would be reactively provided. This is reflected in the differences in theme 1 in the main areas of schooling indicated as being impacted on by parents of children with ME/CFS vs. children of epilepsy. Furthermore, the influence of the individual level was also apparent in theme 2 *'struggle for validation'*, with both parent group perceiving condition invisibility and condition specific stigma, to hinder support provision. Parents of children with epilepsy also saw perceived symptom severity to play a role in determining whether funding for support was granted or not. The framework proposed by Brigden (2020) used their individual level as a means to describe how the child is positioned to care for themselves and manage their own health, which clearly, given the young age of participants, was limited in capacity. This differs from the current research as parents did not detail a roll of their child/youth, beyond their individual health condition, in support provision. This is important to note as it avoids any potential victim blame that may arise if supports are ineffective, placing the duty of effective support provision with the school staff and system.

Following Brigden's (2020) framework, the next level of influence is the interpersonal level, representing the environment and people most immediate to the child. In the context of the current findings this is the parents of these children, the teachers, and the clinicians involved with the child's care. It is clear from the current findings that this immediate environment influences support, more specifically an individual teacher's understanding of ME/CFS or epilepsy and impact. An example from the current findings would be within theme 3 *'luck of the draw: both supportive and unsupportive experiences'* and a teachers fear of seizures being perceived to influence a teachers approach to children and as a potential barrier to support. Similarly, from the ME/CFS findings, parents perceived the attitude of teachers towards ME/CFS as a condition, whether they saw the child as ill or as a malingerer, to highly influence support. The clinician's roll was also highlighted in theme 2 *'struggle for validation'* and the struggle that parents of children with ME/CFS would go to in order to find an understanding doctor willing to believe in the conditions legitimacy and provide a diagnosis.

Where the current findings diverge from Brigden et al. (2020), is with the need for a separation between the interpersonal and organisational level, as a combined interpersonal/organisational level is limited in its applicability to the current findings. Having a separation between the interpersonal and organisational level is needed to aptly describe the influence of these environments on support. A distinction between the actions and influence of the teacher and that of schools or school boards was apparent throughout theme 3 *'luck of the draw: both supportive and unsupportive experiences'*, but more so in subtheme 3.1 *'teachers operating within a rigid system'.* Subtheme 3.1 fully encapsulated this distinction with parents noting teachers to often be as supportive as the could be within the constraints of a rigid school system, providing those supports available without additional funding and in keeping with national education standards. There is also some, but limited, evidence within the ME/CFS data that the same could be said for a distinction between clinicians and medical institutions, as different doctors would be sort when a diagnosis was not obtained, indicating a distinction between individual clinician understandings and medical institutions. Teachers or classrooms and the schools and school systems, as well as clinicians and medical institutions would appear to influence support provision in their own uniquely distinct ways, as represented in the framework devised for the current research, with teachers and clinicians remaining in the child's immediate environment, the interpersonal level.

The next aspect to the socio-ecological model, before the organisational level, is the communication, interactions, and relationships within the child/youth's interpersonal level. This is often represented as a distinct level called the mesosystem, with Bronfenbrenner's (1979) theorising positive relationships to exert a positive impact on child development. Brigden et al. (2020) highlighted the importance of good communication and relationships with the nature of the relationship between schools and parents often determining the level of direct communication/input needed from clinicians. Similarly, the influence of the interrelations and communication between aspects of the interpersonal level is apparent in the current findings, firstly with parents of children with ME/CFS indicating wanting more support in the form of 'adequate communication with home' within theme 4 *'ill-suited support'.* This was both the most commonly indicated needed support and had a high unmet need, indicating this was valued by parents as important to schooling and was not always provided likely hindering support. Moreover, in theme 3 *"luck of the draw: both supportive and unsupportive experiences"*, findings highlighted the influence of both communication and trusting and positive relationships on support. For example, positive trusting relationships between parents and teachers were seen to aid support in children with ME/CFS, while parents of children with epilepsy saw poor communication/dissemination of diagnosis between parent and teacher, and amongst teachers, to impede support. Such interrelations likely aid in the transfer of medically pertinent information, ensuring that supports are individualised and reactive to the child's needs.

Utilising both Bronfenbrenner's (1979) model and the framework proposed by Brigden et al. (2020), the next level of the socio-ecological model used to conceptualise the current findings is the organisational/community level. This is the first of two exosystem levels, the second being the policy level, with the exosystem representing the formal and informal social structures and settings the child is not an active participant in. As previously argued, a distinction is warranted for the current research between the interpersonal and organisational levels, which were combined in Brigden et al. (2020).

The organisational level, which according to the current findings, is made up of multiple influencing structures, such as mass media, school type, and medical institutions. From the epilepsy findings in theme 4 *'ill-suited support'*, the supports most commonly perceived by parents to be offered, along with the perceived focus on seizure response by teachers, appeared to be influenced by stereotypical epilepsy and seizure understandings. Such stereotypical understandings may be influenced by representations in media, as previous research indicates that the understandings of epilepsy held by teachers were shaped by mass media and the internet (Johnson et al., 2021a). Furthermore, theme 4 findings indicate that the type of school had an apparent influence over support, with parents perceiving greater unmet need in 'Mainstream' schools than in 'Other' schools, apparently more so for ME/CFS. This was also reflected in the satisfaction level with 'Mainstream' schools receiving generally lower satisfaction ratings for both ME/CFS and epilepsy. These differences may be down to larger class numbers in 'Mainstream' schooling reducing the teachers available time for children/youth with disabilities. 'Other' schools in general may also be better equipped to support a student's disabilities. However, findings from subtheme 4.1 *'Other schools as transitional institutions'* indicate that parents perceived attendance pressure within 'Other' schools to be unsupportive and detrimental to the child's health and schooling. All these findings speak to an influence of organisational structures on the perceived supports provided to children/youth with ME/CFS and epilepsy.

Similar to Brigden et al. (2020), the current findings reflect an influence on support from further exosystem structures, this being the policy level. This policy level relates to health and education policies influencing support, particularly funding for supports. Brigden et al. (2020) found the policy level integral to the optimisation of integrated care as it was the health and education policies that would enable shared care. Brigden et al 2020 also identified that at an organisation/policy level a formal ME/CFS diagnosis was essential for adaptations and supports to be implemented at school. This is very similar to what was identified in theme 2 *'struggle for validation'* with parents of children with ME/CFS perceiving delays in and struggles with obtaining a diagnosis as a barrier to receiving support. A formal diagnosis is likely required by different education policies for the implementation of supports, with the implementation of health plans requiring a health professional. In subtheme 3.1 *'teachers operating in a rigid system'* parents also commented on the system restrictions, such as NCEA requirements, which placed strain on a teacher's ability to implement adaptations and supports. Furthermore, the epilepsy criteria for funding which parents perceived to be a barrier to support, mentioned across multiple themes, is also determined within this policy level. Such education and health policies are likely important to the overall functioning of school systems, dictating best practice and determining the equitable distribution of resources, and for the most part likely benefit the child.

The final layer of the current framework is the cultural level, a level not included in the Brigden et al (2020) framework but is present in Bronfenbrenner's (1979) model called the macrosystem. This incorporates the cultural structures dictating social norms and ideologies already established in society that influence support. Given the findings in Theme 2 *"Struggle for validation"* and Theme 5 *"Lack of understanding and discrimination"* it is apparent that the well-established macrosystem views regarding invisible illnesses and conditions are influencing support. This seems particularly relevant to ME/CFS and the perceived illegitimacy and scepticism surrounding ME/CFS and its validity as a medical condition. As previously discussed it is possible that the cultural influences that shaped medicine within a New Zealand may have resulted in the perceived illegitimacy of conditions that do not have clear pathology or fit a certain mould. These influences include western conceptualizations of health, in particular the biomedical model of health, which has a mechanistic and empirical approach to health rooted in biology (Lyons & Chamberlain, 2006).

Even though understandings of health have evolved, a preoccupation with biomedical determinants of health may bias clinicians' perceptions of conditions that currently lack verifiability, such as ME/CFS. Without such evidence some clinicians may readily dismiss biology and jump to non-medical conclusions, as with the psychiatric model of ME/CFS. This model was shown to have a negative influence on understanding, meaning clinicians were hyper-vigilant to psychiatric determinants and patients were labelled with the stigma of mental health or the stigma of malingering (Geraghty, 2006). This influence of western conceptualizations of health may also play a role in the emphasis seen to be placed on obvious life-threatening seizures when compared to less visible, potentially less verifiable symptoms of epilepsy, such as fatigue. These ideologies and beliefs of where illness or disease comes from and what constitutes a medical illness likely trickle down influencing which conditions and symptoms are seen as medically impactful and warranting support. Such views and subsequent difficulty in obtaining a diagnosis or in meeting medical criteria may further influence teachers views of the child and their condition resulting in stigmatisation

Similarly, to both the example socio-ecological models used, interpreting the current results in terms of such models has revealed a great number of structures influencing support. In terms of Bronfenbrenner's (1979) ecological model, however, it may be argued that the greatest influences on the supports available to children/youth are not in the interpersonal level but lie in the broader structures. From parents' accounts, it appeared that for the most part teachers within the immediate environment were doing what they could within a rigid system ill-suited to supporting children with ME/CFS and epilepsy. It was this schooling system, comprised of exosystem social structures and wider cultural components, with its rigidity and poor adaptability to invisible illnesses and symptoms that was apparently failing these children and their education. Brigden et al (2020) also found that it was all components within their framework which aided integrated care of children with ME/CFS.

What is important to note, and is reflected in the current findings, is the influence of outside forces, in this case COVID-19, on the functioning of the proposed socio-ecological framework. From the current findings, and those of Similä, Nøst, et al. (2021), it is apparent that the COVID-19 pandemic likely caused disruption to all levels of the socio-ecological framework, likely causing changes to policy, and the running of organisations, particularly with the closure of schools. This led to the need for nation-wide adaptations, put in place to cater to lockdowns and the students' inability to physically attend school. The introduction of at home online learning initiatives were, as previously mentioned, perceived to have both a positive and negative impact on schooling, affecting mental health and attendance but also improving communication and flexibility partake in schooling remotely. Essentially, over the course of 2020 (and likely beyond) COVID-19 completely changed schooling and how children/youth were taught, impacting on the education of every New Zealand child/youth.

Novelty

Considering this discussion, the current findings provide a novel perspective into the supports available to children/youth with ME/CFS and epilepsy in a New Zealand context. As far as the authors are aware, previous research is yet to look at the support available within New Zealand schools for these specific CHC's by utilising parent's perspectives. Recruiting parents of both children with ME/CFS and parents of children with epilepsy, allowed comparison between the two conditions, offering a novel look at the support of different yet similar conditions, with symptoms of varying nature, severity, and visibility. As far as the authors are aware, comparison between ME/CFS and epilepsy, specifically, has not been reported. The current research provides novel findings especially with regards to support and discrimination experiences of a well-established medical condition (epilepsy) and those experiences of children with a condition with questioned legitimacy (ME/CFS). This also provided comparison of the supports provided to symptoms which appeared to occur on a spectrum of visibility, from highly invisible ME/CFS symptoms to less visible learning and behavioural epilepsy symptoms to confronting and overt epileptic seizures.

Furthermore, conceptualising these findings in terms of a socio-ecological framework provided a novel perspective on the differing levels of influences of support, allowing a better look at the complex system of environmental influences, as a whole. This research also contains perspectives of the influence of COVID-19 on support experiences, uniquely collected during New Zealand's first lockdowns in 2020. Even though these were the perceptions of only two parents, they provided a novel insight into the impact of New Zealand's pandemic led adaptations for children with ME/CFS and epilepsy, when they were first implemented.

Strengths and Limitations

The current research has several strengths related to the utilisation of parents instead of teacher or child participants, the utilisation of the consumer review process, and having a mixed method design. Utilising parents' perspectives allows for a unique look into support in schools, with parents positioned to speak on behalf of their child/youth and not likely biased towards self-censoring for socially desirable responses, as can be the risk with teacher perspectives of support.

The consumer review process utilised within the methods and survey development process meant that the views of parents of children with ME/CFS and epilepsy were considered from very early on. This meant that the survey could be as sensitive as possible with potentially insensitive or incorrect information being removed and unable to influence results. This process further improved quantitative and qualitative data collection, for example; having limitless comment box sizes and changing attendance from half days to three hour chunks, better reflecting the minimal and scattered attendance often experienced by children with ME/CFS. Utilising a mixed methods design was also a strength as this allowed for the collection of quantitative data, as specific support experiences with potential generalisability, and the qualitative subjective perceptions of parents which rounded out and completed the insufficient quantitative data.

The current research also has a number of limitations related to the participant group utilised, the type and design of the survey, and the impact of COVID-19. Firstly, parents were utilised as a means to circumvent using a highly vulnerable unwell children/youth. However, this did mean that support experiences were that of the parent not the child and may potentially be an inaccurate representation. Participants were also self-selected resulting in potential bias with those choosing too participant potentially having particularly positive or negative experiences. These are also the perspectives without any verification or cross referencing with the schools, so this does need to be taken into account when interpreting results.

Secondly, the survey was not a pre-validated measure but was designed by the researchers with consumer consultation. In hindsight, the survey itself was quite lengthy, potentially putting respondents off, with some questions also being identified by some participants as slightly ambiguous or difficult to understand. These aspects may have resulted in skipped or missed questions, incomplete surveys, and fewer responses, which may explain the low response rate. The qualitative aspects of the survey also had limitations around data collection, with these just being open-ended comment boxes. These did not allow for follow-up by the researcher to clarify responses or to ensure there was saturation of the qualitative data. Being a computer survey, this may have also limited qualitative responses or lead to ambiguity, as opposed to face-to-face interviews where tone and body language could have been factored in to responses.

Finally, although the survey itself was created before COVID-19, data was obtained mid to late 2020 during New Zealand's first encounters with COVID-19 The first nationwide lockdowns occurred in March 2020 with a move to at home and online learning. New Zealand's COVID-19 response strategy meant that throughout 2020 there were changes and differing restrictions around learning and whether this was at-home online learning or in the school setting. These restrictions were also geographically varied with some parts of the country returning to school whilst others continued with at-home online learning. This likely provided significant disruption to not only schooling but home life and general stress levels, but also gave chronically ill students more opportunities to have at-home online learning supports.

The impact of COVID-19 on perceptions of support was not something that was a reoccurring theme but was touched on by two parents and realistically could have impacted on the support of many more children but was not discussed. Furthermore, this likely impacted on survey completion, with COVID-19 disruptions potentially making parents ‘time-poor’. The impact of COVID-19 really needs to be taken into consideration when interpreting these results as there may be hidden impacts not seen or accounted for by the researchers. Findings related to COVID-19 are very interesting as these adaptations were shown to be helpful but were made in response to a global pandemic affecting millions of people who all needed educational adaptations at the same time. It is unclear if the identified benefits will be taken into consideration and implemented on a more permanent bases for those with ME/CFS or similar health conditions.

Another unforeseen limitation of the current research was the very few responses provided for children with epilepsy attending ‘Other’ schools, with only 4 out of the 23 parent respondents having children with experience with ‘Other’ schools. It is not fully clear why this is but may be the result of children with epilepsy being supported more effectively with their education at ‘Mainstream’ schools that there was little need for them to attend ‘Other’ schools. Alternatively, difficulties in meeting criteria or simply parents not being made aware of the existence of such institutions may have caused few children with epilepsy being involved in such institutions.

Future Research

The current research provides multiple avenues for future research into the supports provided in New Zealand schools. Building on from the current findings and conducting qualitative interviews with parents may provide a richer look into parents’ perspectives of supports, without the restrictions of an online survey. Furthermore, Like Brigden et al. 2020, it would be interesting to obtain the perspectives of all the parties involved in the child’s immediate interpersonal environment, thus being parents/children, teachers, and clinicians. This may provide a more in-depth look into school supports from multiple differing perspectives reducing the possibility for bias and potentially providing a better representation of the state of school supports. In particular, the perspectives of educational staff and comparing these to the themes identified in the current research to identify points of consensus and contention. Using the devised socio-ecological model, research investigating the proposed influencing environments and the relationships within may provide us with a better look at just how influential these supports are on the child and the support that is provided to them. All of these could eventually lead to the identification of the factors and barriers that need to be removed or altered for better support of children with CHC, in particular for ME/CFS and epilepsy.

Future research could also benefit from further investigation into the impact of COVID-19 on the support provided to children/youth in New Zealand with ME/CFS and epilepsy. This would be very interesting to see if more parents share similar perceptions with those two parents in the current study who commented on adaptations. In particular, the influence of mass provision of online learning resources and the implementation of at home learning on the schooling of children who needed such supports pre-COVID-19. These mandatory restrictions during the out-break are the same supports that many parents in the current study indicated as being needed for their child with ME/CFS and epilepsy. Previous research conducted with children with ME/CFS in a Norwegian context found that the online teaching implemented during the Norway COVID-19 response was described as having a positive effect on social life and education (Similä, Nøst, et al., 2021).This would provide a unique retrospective look at the perceptions on how the New Zealand response impacted on learning.

Conclusion

In conclusion, this research provides novel insight into the way parents perceive the support available to their children with ME/CFS and epilepsy in a New Zealand schooling context. These results shine a light on the perceptions of positive support experiences with teachers working with parents through trusting positive relationships to support the child/youth as best they can within the constraints of the school system. Findings also show negative support experiences perceived to result from a restrictive school system that was not really designed to support these children to the extent that is needed for their unique impacts. Interpreting these findings using a socio-ecological framework also highlighted the interrelated environments surrounding the child which had influence over support experiences. All of these findings shed light on the parents' perceptions of the support of their child/youth with ME/CFS or epilepsy in New Zealand, with the hopes of informing future research or support initiatives.

References

Abou Khaled, K. J., Ibrahim, M. I., & Moussa, R. F. (2020). Impact of epilepsy training on school teachers and counselors: An intervention study in Lebanon. *Epilepsy & behavior reports, 14*, 100365.

Aguiar, B. V. K., Guerreiro, M. M., McBrian, D., & Montenegro, M. A. (2007). Seizure impact on the school attendance in children with epilepsy. *Seizure, 16*(8), 698-702.

Anaby, D. R., Campbell, W. N., Missiuna, C., Shaw, S. R., Bennett, S., Khan, S., . . . GOLDs. (2019). Recommended practices to organize and deliver school-based services for children with disabilities: A scoping review. *Child: care, health and development, 45*(1), 15-27.

Åsbring, P., & Närvänen, A.-L. (2002). Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative health research, 12*(2), 148-160.

Austin, J. K., Huberty, T. J., Huster, G. A., & Dunn, D. W. (1999). Does academic achievement in children with epilepsy change over time? *Developmental medicine and child neurology, 41*(7), 473-479.

Benson, A., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2015). "I don't want them to look at me and think of my illness, I just want them to look at me and see me": child perspectives on the challenges associated with disclosing an epilepsy diagnosis to others. *Epilepsy & Behavior, 53*, 83-91.

Benson, A., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2017). Parent perspectives of the challenging aspects of disclosing a child's epilepsy diagnosis to others: Why don't they tell? *Chronic illness, 13*(1), 28-48.

Bishop, F. L. (2015). Using mixed methods research designs in health psychology: An illustrated discussion from a pragmatist perspective. *British journal of health psychology, 20*(1), 5-20.

Bowtell, E. C., Aroni, R., Green, J., & Sawyer, S. M. (2018). Contrasting disclosure practices and experiences of school support for Australian adolescents with cancer, cystic fibrosis and anorexia nervosa: parent perspectives. *International Journal of Inclusive Education, 22*(2), 176-191.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Brigden, A., Shaw, A., Barnes, R., Anderson, E., & Crawley, E. (2020). The child's got a complete circle around him". The care of younger children (5–11 years) with CFS/ME. A qualitative study comparing families', teachers' and clinicians' perspectives. *Health & Social Care in the Community, 28*(6), 2179-2189.

Brigden, A., Shaw, A., & Crawley, E. (2021). “it’sa medical condition… you need to support as much as possible”: a qualitative analysis of teachers’ experiences of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). *BMC pediatrics, 21*(1), 1-9.

Brown, S., & Cox, D. L. (1999). Supporting pupils with chronic fatigue syndrome. *Educational Psychology in Practice, 15*(3), 183-189.

Chew, J., Carpenter, J., & Haase, A. M. (2017). Young People's Experiences of Epilepsy: A Scoping Review of Qualitative Studies. *Health & social work, 42*(3), 167-176.

Chew, J., Carpenter, J., & Haase, A. M. (2019). Living with epilepsy in adolescence—A qualitative study of young people's experiences in Singapore: Peer socialization, autonomy, and self-esteem. *Child: care, health and development, 45*(2), 241-250.

Crawley, E., & Sterne, J. A. (2009). Association between school absence and physical function in paediatric chronic fatigue syndrome/myalgic encephalopathy. *Archives of Disease in Childhood, 94*(10), 752-756.

Dal Canto, G., Pellacani, S., Valvo, G., Masi, G., Ferrari, A. R., & Sicca, F. (2018). Internalizing and externalizing symptoms in preschool and school-aged children with epilepsy: Focus on clinical and EEG features. *Epilepsy & Behavior, 79*, 68-74.

Danguecan, A. N., & Smith, M. L. (2017). Academic Outcomes in Individuals With Childhood-Onset Epilepsy: Mediating Effects of Working Memory. *Journal of the International Neuropsychological Society, 23*(7), 594-604.

Dowsett, E. G., & Colby, J. (1997). Long-term sickness absence due to ME/CFS in UK schools: an epidemiological study with medical and educational implications. *Journal of Chronic Fatigue Syndrome, 3*(2), 29-42.

Elliott, I. M., Lach, L., & Smith, M. L. (2005). I just want to be normal: a qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. *Epilepsy & Behavior, 7*(4), 664-678.

Everett, T., & Fulton, C. (2002). An exploration of secondary school teachers’ beliefs and attitudes about adolescent children with chronic fatigue syndrome. *Support for Learning, 17*(1), 27-33.

Ferro, M. A., Meyer, S. B., Yessis, J., Reaume, S. V., Lipman, E., & Gorter, J. W. (2021). COVID-19-Related Psychological and Psychosocial Distress Among Parents and Youth With Physical Illness: A Longitudinal Study. *Frontiers in Psychiatry, 12*, 761968.

Geraghty, K. (2020). The negative impact of the psychiatric model of chronic fatigue syndrome on doctors’ understanding and management of the illness. *Fatigue: Biomedicine, Health & Behavior, 8*(3), 167-180.

Hareide, L., Finset, A., & Wyller, V. B. (2011). Chronic fatigue syndrome: a qualitative investigation of young patient's beliefs and coping strategies. *Disability and rehabilitation, 33*(22-23), 2255-2263.

Hightower, S., Carmon, M., & Minick, P. (2002). A qualitative descriptive study of the lived experiences of school-aged children with epilepsy. *Journal of pediatric health care, 16*(3), 131-137.

Horton, S. M., Poland, F., Kale, S., de Lourdes Drachler, M., de Carvalho Leite, J. C., McArthur, M. A., . . . Nacul, L. (2010). Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) in adults: a qualitative study of perspectives from professional practice. *BMC family practice, 11*(1), 1-13.

Johnson, E., Atkinson, P., Muggeridge, A., Cross, J. H., & Reilly, C. (2021a). Epilepsy in schools: Views on educational and therapeutic provision, understanding of epilepsy and seizure management. *Epilepsy & Behavior, 122*, 108179.

Johnson, E., Atkinson, P., Muggeridge, A., Cross, J. H., & Reilly, C. (2021b). Inclusion and participation of children with epilepsy in schools: Views of young people, school staff and parents. *Seizure, 93*, 34-43.

Kampra, M., Tzerakis, N., Thomsen, L. L. H., Katsarou, E., Voudris, K., Mastroyianni, S. D., . . . Gatzonis, S. (2017). The challenges that parents of children with epilepsy face: A qualitative study. *Epilepsy & Behavior, 71*, 94-103.

Kitto, L. (2010). Inflammatory Bowel Disease: School Nurse Management. *The Journal of School Nursing, 26*(2), 102-114.

Knight, S. J., Politis, J., Garnham, C., Scheinberg, A., & Tollit, M. A. (2018). School functioning in adolescents with chronic fatigue syndrome. *Frontiers in pediatrics*, 302.

Lambert, V., Gallagher, P., O'toole, S., & Benson, A. (2014). Stigmatising feelings and disclosure apprehension among children with epilepsy. *Nursing Children and Young People (2014+), 26*(6), 22.

Lewis, A., & Parsons, S. (2008). Understanding of epilepsy by children and young people with epilepsy. *European Journal of Special Needs Education, 23*(4), 321-335.

Lum, A., Wakefield, C., Donnan, B., Burns, M., Fardell, J., & Marshall, G. (2017). Understanding the school experiences of children and adolescents with serious chronic illness: a systematic meta-review. *Child: care, health and development.*

Lyons, A. C., & Chamberlain, K. (2006). *Health psychology : a critical introduction*: Cambridge University Press.

McEwan, M. J., Espie, C. A., Metcalfe, J., Brodie, M. J., & Wilson, M. T. (2004). Quality of life and psychosocial development in adolescents with epilepsy: a qualitative investigation using focus group methods. *Seizure, 13*(1), 15-31.

Mecarelli, O., Messina, P., Capovilla, G., Michelucci, R., Romeo, A., Beghi, E., . . . Boniver, C. (2015). An educational campaign about epilepsy among Italian primary school teachers. 2. The results of a focused training program. *Epilepsy & Behavior, 42*, 93-97.

Ministry of Education. (2022, May 12). *Specialist schools.* Retrieved from https://www.education.govt.nz/school/student-support/special-education/specialist-schools-for-students-with-high-needs/

Ministry of Education. (2021, October 21). *Strategies to support learning.* Retrieved from https://www.education.govt.nz/school/health-safety-and-wellbeing/student-and-staff-health/health-conditions-in-education-settings-supporting-children-and-young-people-2/strategies-to-support-learning/#sh-fatigue%20support

Ministry of Education. (2021, May 07). *Students with learning support needs.* Retrieved from https://www.education.govt.nz/school/student-support/special-education/

Ministry of Education. (2022, May 28). Supporting ākonga with health conditions. Retrieved from https://www.education.govt.nz/school/health-safety-and-wellbeing/student-and-staff-health/health-conditions-in-education-settings-supporting-children-and-young-people-2/#sh-fatigue%20support

Ministry of Education. (2022, April 28). *Types of schools and year levels.* Retrieved from https://www.education.govt.nz/school/new-zealands-network-of-schools/about/types-of-schools-and-year-levels/#sh-correspondence%20school

Nicholas, D. B., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. M. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health and Quality of Life Outcomes, 5*(1), 28.

Nijhof, L. N., Nijhof, S. L., Bleijenberg, G., Stellato, R. K., Kimpen, J. L., Pol, H. E. H., & van de Putte, E. M. (2016). The impact of chronic fatigue syndrome on cognitive functioning in adolescents. *European journal of pediatrics, 175*(2), 245-252.

Parslow, R. M., Harris, S., Broughton, J., Alattas, A., Crawley, E., Haywood, K., & Shaw, A. (2017). Children's experiences of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a systematic review and meta-ethnography of qualitative studies. *BMJ open, 7*(1), e012633.

Parslow, R. M., Shaw, A., Haywood, K. L., & Crawley, E. (2017). Important factors to consider when treating children with chronic fatigue syndrome/myalgic encephalomyelitis

(CFS/ME): perspectives of health professionals from specialist services. *BMC pediatrics, 17*(1), 43.

Pinquart, M., & Teubert, D. (2011). Academic, physical, and social functioning of children and adolescents with chronic physical illness: A meta-analysis. *Journal of pediatric psychology, 37*(4), 376-389.

Porter, J., Georgeson, J., Daniels, H., Martin, S., & Feiler, A. (2013). Reasonable adjustments for disabled pupils: what support do parents want for their child? *European Journal of Special Needs Education, 28*(1), 1-18.

Rehm, R. S., Fisher, L. T., Fuentes-Afflick, E., & Chesla, C. A. (2013). Parental advocacy styles for special education students during the transition to adulthood. *Qualitative health research, 23*(10), 1377-1387.

Reilly, C., Atkinson, P., Das, K. B., Chin, R. F., Aylett, S. E., Burch, V., . . . Neville, B. G. (2014). Academic achievement in school-aged children with active epilepsy: A population-based study. *Epilepsia, 55*(12), 1910-1917.

Reilly, C., & Ballantine, R. (2011). Epilepsy in school-aged children: more than just seizures? *Support for Learning, 26*(4), 144-151.

Renzetti, T., Calabrese, C., Pietrafusa, N., Pannacci, I., Rainò, R., Giuffrida, A., . . . Vigevano, F. (2020). Management of epileptic seizures in school-age children: educational project dedicated to school staff. *Epilepsy & Behavior, 105*, 106951.

Roberts, J., & Whiting, C. (2011). Caregivers of school children with epilepsy: findings of a phenomenological study. *British Journal of Special Education, 38*(4), 169-177.

Rowe, K. (2020). Paediatric patients with myalgic encephalomyelitis/chronic fatigue syndrome value understanding and help to move on with their lives. *Acta Paediatrica, 109*(4), 790-800.

Rowe, P. C., Underhill, R. A., Friedman, K. J., Gurwitt, A., Medow, M. S., Schwartz, M. S., . . . Rowe, K. S. (2017). Myalgic encephalomyelitis/chronic fatigue syndrome diagnosis and management in young people: a primer. *Frontiers in pediatrics, 5*, 121.

Sankey, A., Hill, C. M., Brown, J., Quinn, L., & Fletcher, A. (2006). A follow-up study of chronic fatigue syndrome in children and adolescents: symptom persistence and school absenteeism. *Clinical Child Psychology and Psychiatry, 11*(1), 126-138.

Serdari, A., Tsalkidis, A., Tripsianis, G., Vadikolias, K., Chatzimichael, A., Piperidou, C., & Livaditis, M. (2009). Epilepsy impact on aspects of school life of children from different cultural populations in Thrace, Greece. *Epilepsy & Behavior, 15*(3), 344-350.

Shiu, S. (2001). Issues in the education of students with chronic illness. *International journal of disability, development and education, 48*(3), 269-281.

Similä, W. A., Nøst, T. H., Helland, I. B., & Rø, T. B. (2021). Factors related to educational adaptations and social life at school experienced by young people with CFS/ME: a qualitative study. *BMJ open, 11*(11), e051094.

Similä, W. A., Rø, T. B., & Nøst, T. H. (2021). Experiences Among School Personnel and School Nurses on Educational Adaptations for Students With CFS/ME: A Qualitative Interview Study. *Frontiers in pediatrics*, 1317.

Snead, K., Ackerson, J., Bailey, K., Schmitt, M. M., Madan-Swain, A., & Martin, R. C. (2004). Taking charge of epilepsy: the development of a structured psychoeducational group intervention for adolescents with epilepsy and their parents. *Epilepsy & Behavior, 5*(4), 547-556.

Stephens, C. (2008). *Health promotion : a psychosocial approach*: Open University Press.

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. *The SAGE handbook of qualitative research in psychology, 2*, 17-37.

Tillett, A., Glass, S., Reeve, A., & Burt, A. (2000). Provision of health and education services in school children with chronic fatigue syndrome. *Ambulatory Child Health, 6*(2), 83-89.

Tollit, M., Politis, J., & Knight, S. (2018). Measuring School Functioning in Students With Chronic Fatigue Syndrome: A Systematic Review. *Journal of School Health, 88*(1), 74-89.

Tomoda, A., Miike, T., Yamada, E., Honda, H., Moroi, T., Ogawa, M., . . . Morishita, S. (2000). Chronic fatigue syndrome in childhood. *Brain and Development, 22*(1), 60-64.

Van Hoof, E., De Becker, P., & De Meirleir, K. (2006). Pediatric chronic fatigue syndrome and munchausen-by-proxy: A case study. *Journal of Chronic Fatigue Syndrome, 13*(2-3), 45-53.

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in healthy and patient populations. *Medical care*, 800-812.

Vickers, M. H. (2000). Stigma, work, and “unseen” illness: A case and notes to enhance understanding. *Illness, Crisis & Loss, 8*(2), 131-151.

Winger, A., Ekstedt, M., Wyller, V. B., & Helseth, S. (2014). ‘Sometimes it feels as if the world goes on without me’: adolescents' experiences of living with chronic fatigue syndrome. *Journal of Clinical Nursing, 23*(17-18), 2649-2657.

Yang, L., Lu, Q., Tang, W., Ji, J., Tang, P., Jiang, Y., . . . Quan, Y. (2021). Teachers’ experiences of managing children with epilepsy in school: A qualitative study. *Epilepsy & Behavior, 121*, 108039.

Appendix A

Example ME/CFS Questionnaire

Start of Block: Information Page

Info_pg

The Support Provided by School Systems to Children and Youth with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Epilepsy:

A Parental Perspective

Information Sheet

Researcher(s) Introduction

This research is being conducted by Kirstin Bierre for the fulfilment of the requirements for the degree of Master of Science in Psychology with endorsement in Health Psychology. The academic supervisors involved are clinical psychologists Dr Don Baken and Dr Kirsty Ross (Massey University, School of Psychology). Please read this Information Sheet carefully before deciding whether or not to participate.

Project Description and Invitation

We know that being unwell can affect children and young people's ability to attend and participate in school. However, very little is known about this in New Zealand and our school systems. This project aims to investigate the support provided by New Zealand school systems to students with myalgic encephalitis (ME)/chronic fatigue syndrome (CFS) and Epilepsy.

We would like to invite you to participate by filling in a questionnaire asking about your child or youth with ME/CFS or epilepsy and their schooling experiences. This will hopefully broaden our understanding of the support provided by New Zealand school systems to children and youth with ME/CFS and epilepsy, contributing to existing literature.

Participant Identification and Recruitment

You have received this invite because it has been distributed by an ME/CFS or epilepsy organisation (i.e., national organisation or Facebook group).

Selection Criteria

We are looking for participants who: Are parents/caregivers of children/youth with ME/CFS or epilepsy Have a child/youth with ME/CFS or epilepsy that is primary or secondary school aged who has experience with the New Zealand education system **Exclusion Criteria** Parents/caregivers of children/youth with ME/CFS or epilepsy who do not have experience with the New Zealand education system **Project Procedures**

We will ask for general demographic information about yourself and your child/youth with ME/CFS or epilepsy (non-identifiable information only); your child/youth's specific health-related needs (such as their symptoms) when at school; which aspects of their condition impact on schooling; which aspects of schooling are affected; and what measures the institution takes to support your child/youth with such implications.

We estimate that the questionnaire will take approximately 5 mins to 15 mins to complete depending on the number of schools being reported.

Once you have completed the online questionnaire and you have selected submit, the questionnaire will be automatically uploaded to the researcher.

Data Management

The data from the completed questionnaires will be analysed and the subsequent findings will be reported in the thesis written by Kirstin Bierre. It is our intention that findings will also be presented at conferences and written up into a peer reviewed journal. We hope that these findings will help inform a better understanding of the support offered by New Zealand schooling systems for students with ME/CFS, and epilepsy. Data will be analysed and reported in group format and individuals will not be able to be identified.

If you wish to receive a summary of these findings you will be given the opportunity to provide an email address which will NOT be linked to the questionnaire you have completed, ensuring anonymity.

All data will be secured in a secure database

Participant's Rights

You are under no obligation to accept this invitation. Completion and return of the questionnaire implies consent. If you decide to participate, you have the right to: *decline to answer any particular question; ask any questions about the study at any time during participation; withdraw from the study up until the questionnaire responses have been submitted; be given access to a summary of the project findings when it is concluded*

Researcher(s)/Project Contacts

If you have any questions or queries regarding this project, please don't hesitate to contact the following:

Researcher
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This research project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Professor Craig Johnson, Director (Research Ethics), telephone 06 356 9099, extn 85271, email humanethics@massey.ac.nz.

End of Block: Information Page

Start of Block: Instructions

Instr_hdr Instructions

Instr_1
Thank you for participating in this study. This questionnaire consists of a series of questions about your child/youth with ME/CFS and their experiences of the New Zealand school system.

The questionnaire should only require 5-15 minutes of your time, depending on which school systems you have experienced.

The data obtained will be analysed and findings will be reported in a thesis and presented at future conferences. We hope that these findings will help inform a better understanding of the support offered by New Zealand schooling systems for students with ME/CFS.

Please complete all the sections that are relevant to you, but, you have the right to not answer any particular question.

Many thanks for your assistance with this survey, we at Massey University greatly appreciate it.

End of Block: Instructions

Start of Block: Consent

Appr_hdr Respondent Consent

Appr_inf Thank you for participating in this questionnaire. Your participation implies consent. You have the right to decline to answer any particular question.

Consent I have read and understood the information sheet for this study and consent to collection of my responses.
(Please click on the 'Yes' choice if you wish to proceed.)

○ Yes (1)

○ No (2)

End of Block: Consent

Start of Block: Screen for NZ Education

NZ_Ed Have you and the child/youth with ME/CFS you care for had experience in the educational system in New Zealand?

○ Yes (1)

○ No (2)

Display This Question:

If Have you and the child/youth with ME/CFS you care for had experience in the educational system in... = No

NZ_Ed_no We are sorry, but we are only interested in the experiences of people who have been involved with the New Zealand educational system, thank you for your interest.

End of Block: Screen for NZ Education

Start of Block: Respondent demographics (RD)

RD_inf It is useful for us to have a broad understanding of the people who are completing this survey. These first questions will help with that.

RD1 What is your gender?

- ○ Male (1)
- ○ Female (2)
- ○ Non-binary (3)
- ○ Other (please specify) (4) ____

RD2 What is your age?
(please select the number of years)

▼ Less than 15 (1) ... 100 (86)

RD3 What is your ethnicity?
(please select as many as apply)

☐ New Zealand European/ Pākehā (1)

☐ New Zealand Māori (2)

☐ Pacific Islander (3)

☐ Asian (4)

☐ Middle Eastern/Latin American/African (5)

☐ Other (please specify) (6) ____

End of Block: Respondent demographics (RD)

Start of Block: Child/youth demographics (CD)

CD_inf It would be good to have some understanding about your child/youth with ME/CFS before we ask about your impression of their educational experience.

CD1 What is your child/youth's gender?

○ Male (1)

○ Female (2)

○ Non-binary (3)

○ Other (please specify) (4) ____

CD2 How old is your child/youth with ME/CFS?

▼ Less than 3 (1) ... 20 (18)

CD3 What is your child/youth's ethnicity?
(please select as many as apply)

☐ New Zealand European/ Pākehā (1)

☐ New Zealand Māori (2)

☐ Pacific Islander (3)

☐ Asian (4)

☐ Middle Eastern/Latin American/African (5)

☐ Other (please specify) (6) ____

End of Block: Child/youth demographics (CD)

Start of Block: Health related questions (HR)

HR_inf *We understand that your child/youth's ME/CFS and schooling experiences are unique to your child/youth and that these questions may not cover everything. As a result, there will be an opportunity at the end of this questionnaire for you to elaborate on your experiences.*

HR1 Does/did your child/youth experience ME/CFS symptoms that impact/impacted on schooling?

○ Yes (1)

○ No (2)

Display This Question:

If Does/did your child/youth experience ME/CFS symptoms that impact/impacted on schooling? = Yes

X→

HR2
What are the main ME/CFS symptoms that impact/impacted on schooling?
(Select as many as apply)

☐ Physical fatigue (1)

☐ Mental fatigue (2)

☐ Post-exertion fatigue (3)

☐ Orthostatic intolerance (symptoms upon standing upright) (4)

☐ Pain (muscle and joint) (5)

☐ Headaches (6)

☐ Pharyngitis/sore throat (7)

☐ Adenopathy/swollen lymph nodes (8)

☐ Gastrointestinal distress (9)

☐ Neurological problems (eg., Sensitivity to light and noise) (10)

☐ Cognitive impairment/difficulties (11)

☐ Sleep disturbance (12)

☐ Reduced concentration (13)

☐ Depression (14)

☐ Anxiety (15)

☐ Other (please elaborate) (16) ____

Page Break

HR3 Are there health care needs related to ME/CFS that impact/impacted on schooling?

○ Yes (1)

○ No (2)

Display This Question:

If Are there health care needs related to ME/CFS that impact/impacted on schooling? = Yes

HR4 What are the main ME/CFS health care needs that impact on schooling?
(Select as many as apply)

☐ Anti-epileptic medications (1)

☐ Sleep aids (2)

☐ Pain medications (3)

☐ Other medications (4)

☐ Diet restrictions (5)

☐ Pacing (6)

☐ Need for shorter/reduced school days (7)

☐ Responding to unpredictable functioning (e.g., sudden fatigue, incontinence, orthostatic intolerance etc) (8)

☐ Emergency response to seizures (9)

☐ Control of sensory stimulation (10)

☐ Hospitalisation (11)

☐ Medical appointments (GP, Specialist, Nurse, Dietician, Physiotherapist, Counsellor etc) (12)

☐ Other (please elaborate below) (13) ____

Page Break

HR-inf2 Please answer the next question in relation to the school environment.

HR5 How often have you or your child/youth experienced negative attitudes, in the form of prejudice and discrimination, in response to their health condition?

○ Always (1)

○ Often (2)

○ Sometimes (3)

○ Rarely (4)

○ Never (5)

HR4 If you feel that there is something else you would like to add about your child/youth’s health please do so here ...

____

____

____

____

____

End of Block: Health related questions (HR)

Start of Block: Health Outcome questions (HO)

HO1 **Attendance**
How many hours would/does your child/youth attend in an average week? (with full-time attendance with no absences being 30 or more hours per week)

○ 0-3 (0)

○ 4-6 (1)

○ 7-9 (2)

○ 10-12 (3)

○ 13-15 (4)

○ 16-18 (5)

○ 19-21 (6)

○ 22-24 (7)

○ 25-27 (8)

○ 28-30 (9)

○ 30+ (10)

HO2 **Academic Performance**
Please rate your perception of your child's academic performance at school

○ Excellent (1)

○ Above average (2)

○ Average (3)

○ Below average (4)

○ Very Poor (5)

Page Break

HO_inf **Quality of Life**
Please rate your perception of these aspects of your child/youth’s life

HO3 Your child/youth’s **Physical health**

- ○ Excellent (1)
- ○ Above average (2)
- ○ Average (3)
- ○ Below average (4)
- ○ Very Poor (5)

HO4 Your child/youth’s **Mental health**

- ○ Excellent (1)
- ○ Above average (2)
- ○ Average (3)
- ○ Below average (4)
- ○ Very Poor (5)

Page Break

HO5 Your child/youth's **Social relationships**

- ○ Excellent (1)
- ○ Above average (2)
- ○ Average (3)
- ○ Below average (4)
- ○ Very Poor (5)

HO6 Your child/youth's **Sense of meaning and purpose**

- ○ Excellent (1)
- ○ Above average (2)
- ○ Average (3)
- ○ Below average (4)
- ○ Very Poor (5)

HO7 If you feel that there is something else you would like to add about your child/youth's **health outcomes** please do so here ...

____

____

____

____

____

End of Block: Health Outcome questions (HO)

Start of Block: Impact on Schooling Questions (IS)

X→

IS1 Please indicate the areas of schooling that are impacted on by the following aspects:
(Select those that apply by clicking on the appropriate boxes; select as many as apply)

	Child/youth's ME/CFS **symptoms** (1)	Child/youth's ME/CFS **health care needs?** (2)	**Prejudice/Discrimination** (3)
⊗ No Impact / None (IS1_1)	☐	☐	☐
Enrolment (IS1_2)	☐	☐	☐
Attendance (IS1_3)	☐	☐	☐
Participation (IS1_4)	☐	☐	☐
Concentration (IS1_5)	☐	☐	☐
Work completion (IS1_6)	☐	☐	☐
Academic performance (IS1_7)	☐	☐	☐
Socialisation (IS1_8)	☐	☐	☐
Student teacher relationships (IS1_9)	☐	☐	☐
Emotional distress (IS1_10)	☐	☐	☐
Other (please elaborate below) (IS1_11)	☐	☐	☐

Page Break

IS2 To what extent do you think your child/youth's ME/CFS impact/impacted on schooling?

○ Not at all (1)

○ Very Little (2)

○ Somewhat (3)

○ To a Great Extent (4)

IS3 If you feel that there is something else you would like to add about your child/youth's **health on schooling** please do so here ...

____

____

____

____

____

End of Block: Impact on Schooling Questions (IS)

Start of Block: School (Scl)

Scl_inf1 We are particularly interested in your experience of the education system in supporting your child/youth with ME/CFS. The following questions will ask about that.

Scl_inf2 As mainstream schools and other education institutions, such as regional health schools and/or Te Kura, are quite different, we will ask about your experience of these institutions separately, first asking about mainstream schooling, then, IF you have had experience with another institution type, we will ask about these experiences second.

X→

Scl1 Has your child/youth been involved with mainstream schooling while they have been unwell with ME/CFS?

○ Yes (1)

○ No (2)

Display This Question:

If Has your child/youth been involved with mainstream schooling while they have been unwell with ME/... = No

X→

Scl1b Why has your child/youth not been involved with a mainstream school?

○ Child/youth was diagnosed before school age so went straight into another education institution, such as Regional health schools and/or Te Kura. (1)

○ Other (please elaborate below) (2) ____

End of Block: School (Scl)

Start of Block: Mainstream School (MS)

MS_inf We are particularly interested in the mainstream school that your child/youth has spent the most time involved with whilst having this diagnosis. This may be a current or past enrolment. Please answer the following mainstream school questions in relation to this.

X→

MS1 Is your child/youth still currently involved with this institution?

○ Yes (1)

○ No (2)

Display This Question:

If Is your child/youth still currently involved with this institution? = No

MS2 Why did you move your child/youth from this school/institution?
(Select as many as apply)

☐ They were too sick to attend (1)

☐ Fatigue made attendance difficult (2)

☐ There was a more supportive institution (3)

☐ This school/institution was not supportive (4)

☐ The school/institution didn’t have the resources to support my child (5)

☐ Demand of transporting for partial school days (6)

☐ Moved to different schooling area (7)

☐ Moved from primary to secondary level education (8)

☐ Discrimination from staff (9)

☐ Discrimination from peers (10)

☐ Another non-health related reason (11)

☐ Other (please elaborate below) (12)

____

MS3 If you feel that there is something else you would like to add please do so here ...

____

____

____

____

____

End of Block: Mainstream School (MS)

Start of Block: MS Disclosure (Dcl)

Dcl_1 Is/was this institution informed of your child/youth's ME/CFS?

○ Yes (1)

○ No (2)

Skip To: Dcl_4 If Is/was this institution informed of your child/youth's ME/CFS? = No

Page Break

X→

Dcl_2 Is/was this institution made aware of the impact of your child/youth's ME/CFS on schooling?

○ Not at all aware (1)

○ Partially aware (2)

○ Fully aware (3)

Display This Question:

If Is/was this institution made aware of the impact of your child/youth's ME/CFS on schooling? = Partially aware

Or Is/was this institution made aware of the impact of your child/youth's ME/CFS on schooling? = Fully aware

X→

Dcl_3 Who informed the institution of the impact of your child/youth's ME/CFS on schooling?
(Select as many as apply)

☐ You or other parent/guardian (1)

☐ General practitioner (GP) (2)

☐ Specialist (3)

☐ Other medical professional (4)

☐ Previous educational professional (5)

☐ Other (please elaborate below) (6)

____

Page Break

Display This Question:

If Is/was this institution informed of your child/youth's ME/CFS? = No

Or Is/was this institution made aware of the impact of your child/youth's ME/CFS on schooling? = Not at all aware

Or Is/was this institution made aware of the impact of your child/youth's ME/CFS on schooling? = Partially aware

Dcl_4 Why was/has this institution not (been) made fully aware of the impact of ME/CFS on schooling? *(Select as many as apply)*

☐ Not necessary (1)

☐ Private information (2)

☐ Fear of discrimination (unfair treatment, exclusion, bullying etc) (3)

☐ Have not gotten around to it (4)

☐ Lack of specific medical expertise (5)

☐ No reason (6)

☐ Other (7) ____

Dcl_5 If you feel that there is something else you would like to add please do so here ...

____

____

____

____

____

End of Block: MS Disclosure (Dcl)

Start of Block: MS Support (Sppt)

Sppt1
Please indicate the kinds of support provided by the school, the kinds of support used by your child/youth, and the kinds of support you believe your child/youth needs/needed

(Please answer in relation to your child/youth's ME/CFS; Please indicate those that apply by clicking on the appropriate boxes; Select as many as apply)

	<u>Support provided by the school</u> (1)	<u>Support used by your child/youth</u> (2)	<u>Support Needed</u> (3)
None (Sppt1_1)	☐	☐	☐
Help with treatments (medication administration, diet restriction …) (Sppt1_2)	☐	☐	☐
Opportunities to rest (Sppt1_3)	☐	☐	☐
Opportunities to study from home (Sppt1_4)	☐	☐	☐
Flexible attendance (Sppt1_5)	☐	☐	☐
Space to rest (Sppt1_6)	☐	☐	☐
Additional learning resources (Sppt1_7)	☐	☐	☐
Flexible toilet breaks (Sppt1_8)	☐	☐	☐
Help with accidents (Sppt1_9)	☐	☐	☐
Teacher aid (Sppt1_10)	☐	☐	☐
Tutoring (Sppt1_11)	☐	☐	☐
Catch-up lessons (Sppt1_12)	☐	☐	☐
Online Learning (Sppt1_13)	☐	☐	☐
Extensions (Sppt1_14)	☐	☐	☐

Exam flexibility (Sppt1_15)	☐	☐	☐
Curriculum flexibility (Sppt1_16)	☐	☐	☐
Adequate communication with home/parent or caregiver (Sppt1_17)	☐	☐	☐
Responsive to emergencies (Sppt1_18)	☐	☐	☐
Responsive to bullying (Sppt1_19)	☐	☐	☐
Counselling (Sppt1_20)	☐	☐	☐
Positive attitudes and understanding (Sppt1_21)	☐	☐	☐
Inclusion initiatives (where appropriate) (Sppt1_22)	☐	☐	☐
Other (please elaborate below) (Sppt1_23)	☐	☐	☐

Page Break

Sppt2 To what extent do you think this institution supports/supported your child/youth with the impact their ME/CFS has/had on schooling?

○ Not at all (1)

○ Very little (2)

○ Somewhat (3)

○ To a great extent (4)

○ ME/CFS does not impact on schooling (5)

Page Break

Display This Question:

If To what extent do you think this institution supports/supported your child/youth with the impact... = Not at all

Or To what extent do you think this institution supports/supported your child/youth with the impact... = Very little

Sppt3 What do you think stopped the institution from supporting your child/youth?
(select as many as apply)

- ☐ We have not told them about the diagnosis (1)
- ☐ Disease was not taken seriously by educational professionals (2)
- ☐ Disease was not taken seriously by the institution (3)
- ☐ Educational professionals did not understand needs (4)
- ☐ Educational professionals forgot about the needs of my child/youth (5)
- ☐ Educational professional too busy to keep attending to the chronic nature of the condition (6)
- ☐ Educational professionals were not flexible (7)
- ☐ Institutional rules did not allow for flexibility (8)
- ☐ Funding limitations (9)
- ☐ Other (please elaborate) (10) ____

Page Break

Sppt4 Do you feel satisfied with the current level of help/support provided by the school in question?

○ Very dissatisfied (1)

○ Dissatisfied (2)

○ Neither (3)

○ Satisfied (4)

○ Very satisfied (5)

Sppt5 The school/educational professionals could benefit from training and education on your child/youth's health condition?

○ Strongly agree (1)

○ Agree (2)

○ Neither agree nor disagree (3)

○ Disagree (4)

○ Strongly disagree (5)

Sppt6 If you feel that there is something else you would like to add about the support provided to your child/youth please do so here…

____

____

____

____

____

End of Block: MS Support (Sppt)

Start of Block: Regional Health School (RHS) and others

RHS1 Has your child/youth been involved with another education institution that is not mainstream schooling i.e., Regional Health School/s (RHS) and/or Te Kura?

○ Yes (1)

○ No (2)

Display This Question:

If Has your child/youth been involved with another education institution that is not mainstream scho... = No

RHS2 Why has your child/youth not been involved with another education institution i.e., RHS or Te Kura?

○ Did not know about these education institutions (1)

○ Child/youth does not meet the criteria (2)

○ Enrolment process too difficult (3)

○ Do not see this as necessary (4)

○ Do not believe that such education institutions could meet your child/youth's needs (5)

○ Other (please elaborate below) (6) ____

Display This Question:

If Has your child/youth been involved with another education institution that is not mainstream scho... = Yes

RHS3 Would you like to answer questions about your child/youth's involvement with another education institution i.e., RHS and/or Te Kura?

○ Yes (1)

○ No (2)

Page Break

Display This Question:

If Has your child/youth been involved with another education institution that is not mainstream scho... = No

RHC_C
As you have not had experience with ‘other’ education institutions i.e., RHS and/or Te Kura the questionnaire is concluded.

Thank you for taking the time to participate in this research. We at Massey University greatly appreciate your contribution.

Display This Question:

If Has your child/youth been involved with another education institution that is not mainstream scho... = Yes

And Would you like to answer questions about your child/youth’s involvement with another education in... = No

RHS_D This concludes the questionnaire. Thank you for taking the time to participate in this research. We at Massey University greatly appreciate your contribution.

End of Block: Regional Health School (RHS) and others

Start of Block: Regional Health School Use

RHSU_inf We are particularly interested in the institution that your child/youth has spent the most time enrolled with. This may be a current or past enrolment. Please answer the following questions in relation to this school.

X→

RHSU_1 Is your child/youth still currently involved with this institution?

○ Yes (1)

○ No (2)

Display This Question:

If Is your child/youth still currently involved with this institution? = No

X→

RHSU_2 Why did you move your child/youth from this school/institution?
(Select as many as apply)

☐ They were too sick to attend (1)

☐ Fatigue made attendance too difficult (2)

☐ Lack of flexibility around attendance (3)

☐ There was a more supportive institution (4)

☐ This school/institution was not supportive (5)

☐ This institution was not a good fit for my child/youth (6)

☐ The school/institution didn’t have the resources to support my child (7)

☐ There was the expectation that this was a temporary schooling situation (8)

☐ Ill-suited or inadequate teaching staff (9)

☐ Demand of transporting for partial school days (10)

☐ Discrimination from staff (11)

☐ Discrimination from peers (12)

☐ Another non-health related reason (13)

☐ Other (please elaborate below) (14) ____

RHSU_3 If you feel that there is something else you would like to add please do so here ...

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End of Block: Regional Health School Use

Start of Block: RHS Disclosure

X→

RHS_Dcl_1 Is/was this institution informed of your child/youth’s health condition?

○ Yes (1)

○ No (2)

Skip To: RHS_Dcl_4 If Is/was this institution informed of your child/youth’s health condition? = No

Page Break

RHS_Dcl_2 Is/was this institution made aware of the impact of your child/youth’s health condition on schooling?

○ Not at all aware (1)

○ Partially aware (2)

○ Fully aware (3)

Display This Question:

If Is/was this institution made aware of the impact of your child/youth’s health condition on school... = Partially aware

Or Is/was this institution made aware of the impact of your child/youth’s health condition on school... = Fully aware

RHS_Dcl_3 Who informed the institution of the impact of your child/youth’s ME/CFS on schooling? *(Select as many as apply)*

☐ You or other parent/guardian (1)

☐ General practitioner (GP) (2)

☐ Specialist (3)

☐ Other medical professional (4)

☐ Previous educational professional (5)

☐ Other (please elaborate below) (6)

____

Page Break

Display This Question:

If Is/was this institution informed of your child/youth's health condition? = No

Or Is/was this institution made aware of the impact of your child/youth's health condition on school... = Not at all aware

Or Is/was this institution made aware of the impact of your child/youth's health condition on school... = Partially aware

RHS_Dcl_4 Why was/has this institution not (been) made fully aware of your child/youth's health condition/health related needs?
(Select as many as apply)

- ☐ Not necessary (1)
- ☐ Private information (2)
- ☐ Fear of discrimination (unfair treatment, exclusion, bullying etc) (3)
- ☐ Have not gotten around to it (4)
- ☐ Lack of specific medical expertise (5)
- ☐ No reason (6)
- ☐ Other (7) ____

RHS_Dcl_5 If you feel that there is something else you would like to add please do so here ...

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End of Block: RHS Disclosure

Start of Block: Regional health Schools - Support

RHS_Sppt_1
Please indicate the kinds of support provided by the school, the kinds of support used by your child/youth, and the kinds of support you believe your child/youth needs/needed

(Please answer in relation to your child/youth's ME/CFS; Please indicate those that apply by clicking on the appropriate boxes; Select as many as apply)

	Support provided by the school (1)	Support used by your child/youth (2)	Support Needed (3)
None (1)	☐	☐	☐
Help with treatments (medication administration, diet restriction …) (2)	☐	☐	☐
Opportunities to rest (3)	☐	☐	☐
Opportunities to study from home (4)	☐	☐	☐
Flexible attendance (5)	☐	☐	☐
Space to rest (6)	☐	☐	☐
Additional learning resources (7)	☐	☐	☐
Flexible toilet breaks (8)	☐	☐	☐
Help with accidents (9)	☐	☐	☐
Teacher aid (10)	☐	☐	☐
Tutoring (11)	☐	☐	☐
Catch-up lessons (12)	☐	☐	☐
Online Learning (13)	☐	☐	☐
Extensions (14)	☐	☐	☐

Exam flexibility (15)	☐	☐	☐
Curriculum flexibility (16)	☐	☐	☐
Adequate communication with home/parent or caregiver (17)	☐	☐	☐
Responsive to emergencies (18)	☐	☐	☐
Responsive to bullying (19)	☐	☐	☐
Counselling (20)	☐	☐	☐
Positive attitudes and understanding (21)	☐	☐	☐
Inclusion initiatives (where appropriate) (22)	☐	☐	☐
Other (please elaborate below) (23)	☐	☐	☐

Page Break

RHS_Sppt_2 To what extent do you think this institution supports/supported your child/youth with the impact their ME/CFS has/had on schooling?

○ Not at all (1)

○ Very little (2)

○ Somewhat (3)

○ To a great extent (4)

○ ME/CFS does not impact on schooling (5)

Page Break

Display This Question:

If To what extent do you think this institution supports/supported your child/youth with the impact... = Not at all

Or To what extent do you think this institution supports/supported your child/youth with the impact... = Very little

RHS_Sppt_3 What do you think stopped the institution from supporting your child/youth?
(select as many as apply)

☐ We have not told them about the diagnosis (1)

☐ Disease was not taken seriously by educational professionals (2)

☐ Disease was not taken seriously by the institution (3)

☐ Educational professionals did not understand needs (4)

☐ Educational professionals forgot about the needs of my child/youth (5)

☐ Educational professional too busy to keep attending to the chronic nature of the condition (6)

☐ Educational professionals were not flexible (7)

☐ Institutional rules did not allow for flexibility (8)

☐ Funding limitations (9)

☐ Other (10) ____

Page Break

RHS_Sppt_4 Do you feel satisfied with the current level of help/support provided by the school in question?

○ Very dissatisfied (1)

○ Dissatisfied (2)

○ Neither (3)

○ Satisfied (4)

○ Very satisfied (5)

RHS_Sppt__5 The school/educational professionals could benefit from training and education on your child/youth's health condition?

○ Strongly agree (1)

○ Agree (2)

○ Neither agree nor disagree (3)

○ Disagree (4)

○ Strongly disagree (5)

RHS_Sppt_6 If you feel that there is something that we have not covered and/or you wish to elaborate on any of the experiences we have asked about please do so here…

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End of Block: Regional health Schools - Support

Start of Block: End

End This concludes the questionnaire. Thank you for taking the time to participate in this research. We at Massey University greatly appreciate your contribution.

End of Block: End

Appendix B

Findings presented within a socio-ecological model