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RESEARCH ARTICLE

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The lived experiences and significant challenges on lifestyle and weight management facing paediatric patients with Demyelinating Syndromes

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ABSTRACT

Purpose: To explore the perceptions and experiences of children and young people with Demyelinating Syndromes (DS) in living with the condition and maintaining a healthy lifestyle.

Materials and methods: 16 young people with DS took part in semi-structured interviews investigating their perceptions of weight gain, exercise, diet, health, and lifestyle. Interviews were conducted virtually, audio-recorded, and transcribed. Inductive thematic analysis was employed for data analysis. Rigour and credibility were established through detailed immersion, reflexivity and inter-researcher triangulation.

Findings: Five overarching themes were identified: 1) the influence of the diagnosis and condition on the young person's wellbeing, 2) the implication of the treatment, access to services and effects of steroids, 3) the interplay between Physical Activity (PA), diet, lifestyle and DS, 4) challenges to identity and selfhood, and 5) the impact of family and peer support on how the young person navigates their condition.

Conclusions: Diagnosis and treatment appeared to produce a multitude of intersecting effects on the young people interviewed with drastic implications for PA and lifestyle. Those who maintained or improved their PA levels were able to manage their disease course more effectively, despite a lack of information or guidance on PA, nutrition or lifestyle.

IMPLICATIONS FOR REHABILITATION

- This research gives voice to forgotten paediatric populations as they navigate the complex terrain of living with a chronic debilitative autoimmune condition.
- Our data supports the potential benefit of remaining or becoming physically active whilst living with Demyelinating Syndromes (DS).
- Many paediatric patients do not receive appropriate guidance or support outside of medicalised treatments from doctors and nurses.
- Rehabilitation professionals should consider providing a more holistic and comprehensive approach to individuals throughout their DS journey, involving a multi-disciplinary team including consultants, neurologists, physiotherapists, psychologists, nutritionists, and exercise specialists.

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Demyelinating Syndromes; multiple sclerosis; NMOSD; paediatrics; weight; physical activity

Introduction

Multiple Sclerosis (MS) and Neuromyelitis Optica Spectrum Disorder (NMOSD) are both chronic, relapsing, autoimmune conditions characterised by inflammation and damage to the nerves in the brain and central nervous system (CNS) [1,2]. Specifically, the protective myelin sheath that surrounds nerves in the brain and spinal cord is targeted, leading to inflammatory lesions and demyelisation [3–5]. In NMOSD, both the optic nerve and spinal cord can be affected by both myelitis and acute optic neuritis [6,7]. Collectively, they are known as Acquired Demyelinating Syndromes (ADS) or Demyelinating Syndromes

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This article has been corrected with minor changes. These changes do not impact the academic content of the article.

(DS) [5]. Although not recognised as a terminal disease, previous research has shown MS can cause irreversible disability in mid-thirties in individuals with paediatric onset of MS (POMS) [8].

According to Walton et al. [9] approximately 2.8 million people are affected by MS worldwide (35.9 per 100,000 population), with females being twice as likely to develop MS compared to males. In the UK, the MS Society [10] estimates that 130,000 people live with MS, with 130 people being diagnosed per week. Studies suggest that it is the most prevalent, non-traumatic incapacitating disease to affect young adults, with most diagnosis occurring in a person's twenties or thirties [11,12]. Although it can be diagnosed in children, POMS is significantly rarer than adult-onset disease [3]. The MS Society [10] estimates that the number of people with MS aged 10–19 is 160 with a prevalence of 0.02/1000 people in this age category. NMOSD is rarer still [13] and estimated at 0.7–10/1000,000 cases worldwide [14]. Paediatric DS (See Table 1 for a partial typology of conditions), occurs in around 1/100,000 individuals [6].

Despite the rarity of DS in children, these lifelong conditions have long term implications for quality of life, presenting physical, emotional, and psychological challenges. These can have drastic effects, negatively impacting academic performance, participation, and social activities [16]. According to clinical teams, two particularly concerning aspects of these autoimmune inflammatory conditions are that they are often accompanied by drastic weight changes and alterations to body composition. Increased levels of body mass have been attributed to the condition itself, to essential steroid treatments [13,17], to a reduction in physical activity levels [18–20], and disease comorbidities [21,22]. Long-term steroid treatment has been linked to rapid paediatric weight gain and other concomitant adverse effects including hunger, lethargy and bone mineral density changes in other clinical settings [23–27]. Conversely, clinical teams have found that some children with MS experience weight loss. Given the association of body mass with disease outcomes in people with MS (pwMS) and the associated elevated health risks [28,29], body mass changes in children are a cause for concern. Qualitative studies regarding paediatric patient experiences suggest that weight change, barriers to exercise and hunger are among the primary concerns of young people with MS [30,31].

Little is known regarding active management of weight change in paediatric populations and young adults. There is scant research involving these paediatric populations in lifestyle and wellness modifications such as engagement in PA and dietary interventions. Sikes et al. [16] posit that they both may have benefits for paediatric onset of MS. In the adult population, healthy weight maintenance post MS diagnosis is vital for preserving overall health in the short and long term, and has been associated to overall disease progression and response to treatment [19,32]. There are clear guidelines on physical activity (PA) being essential to manage the conditions in adults [18,20,33–36]. By contrast, no consensus on effective dietary intervention or nutritional recommendations for this group has been reached [37,38]. Currently there is no evidenced guidelines for either PA or diet for this paediatric clinical group [4], with accompanying inconsistencies in the specialist Allied Health Professional (AHP) team available to the patient [5]. The present study aims to first, explore the perspectives and perceptions regarding weight gain, health and quality of life, through semi-structured interviews of young people with MS and NMOSD. Second, drawing from the views of these young people, to formulate a list of factors that contribute to weight gain in the paediatric MS and NMOSD patients following steroid treatment. This article may set the stage

Table 1. Typology of demyelinating syndromes.

Disease category	Description
Acute disseminated encephalomyelitis (ADEM)	is a neurological disorder characterised by brief but widespread attacks of inflammation in the brain and spinal cord that damages myelin [15]
Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOG-AD)	is an inflammatory demyelinating condition of the CNS characterised by a monophasic or relapsing course of neurological dysfunction, which does not meet the typical criteria for MS or other known neuroinflammatory conditions [15]
Neuromyelitis Optica Spectrum Disorder (NMOSD) or (NMO)	is an inflammatory demyelinating condition and occurs when the body's immune system reacts against its own cells. This happens mainly in the optic nerves that connect the retina of the eye with the brain and in the spinal cord [7]
Optic Neuritis (ON)	is an inflammatory demyelinating condition of the CNS that results in the loss of vision and is associated with eye pain, loss of colour vision and visual field deficits. It can occur in isolation but often part of ADEM, MOG-AD, MS or NMOSD [15]
Transverse myelitis (TM)	is a rare neurological condition caused by inflammation of the spinal cord. The swelling damages the nerves and can leave permanent scars or lesions [15]
Multiple Sclerosis (MS)	is a chronic, relapsing, autoimmune condition characterised by inflammation and damage to the nerves in the brain and CNS [1]

for next line of research, which could include consideration of the views and positionalities of other stakeholders, such as parents/carers, consultants and other Health Care professionals (HCPs).

Materials and methods

Study design and setting

Ethical approval to conduct this study was received from the NHS Research Ethics Committee and Health Research Agency (21/WM/0010). The interviews reported here are the initial stage of an intervention development study (Clinicaltrials.gov reg: NCT05070286). Key stakeholders (paediatric patients) were invited to take part in a series of interviews to gain perspectives with regards to weight-change, lifestyle, and physical activity in young people with MS, NMOSD, or other DS. Parental consent for minors was sought and approved before any further data collection occurred. The adoption of semi-structured interviews allowed a dynamic and flexible approach towards data collection, ensuring the identified topics were suitably investigated with open discourse being encouraged [39,40].

Participant selection and recruitment

Young people with MS or NMOSD, who met eligibility criteria ($n = 18$), were identified by the clinical nurse located at each of the research site hospitals in Oxford and London. This purposeful sampling technique allowed this group of young people to be targeted based on their potential to engage in, and provide greater illumination of the phenomenon [41,42]. After being contacted by the clinical nurse and provided with a patient information package, participants could choose to opt into the study. Of the 18, 17 consented to take part in the study, 2 patients of these were not available to take part in the interviews. 8 out of the 16 participants who took part in the interviews were met in person by the interview lead (KS) during one of the patient's routine consultations with the HCP team. This allowed a rapport to develop ahead of the actual interview.

Inclusion criteria: 10–25-year-old young people having been diagnosed with a Demyelinating Condition prior to age of 18, living in England and Wales, and having the capacity to consent/assent were recruited. The upper age was expanded to include 18–25-year-olds to show a reflection of their childhood experiences into adulthood. It is important to value the perspective of this rare patient group as they transition into the next phase of these lifelong conditions. This also enables greater reflective insight into paediatric services from those who have experienced it recently and illuminates their particular needs and experiences. Notwithstanding the above, the passage from paediatric care to adult care can be a gradual, transitional process, and patients may be seen by paediatric clinicians into their twenties [43].

In addition to MS and NMO, patients also presented with a variety of specific conditions which are illustrated in Table 1. Furthermore, it is the rich texture, depth and quality of the responses that was the overriding consideration here and not just the number of the participants interviewed. Although it is common to use the postpositive notion of data saturation to call a halt to interviewing [44], we, together with others [45,46], rejected this approach. Rather than placing emphasis on the number of participants interviewed [47,48], we concentrated on reviewing and assessing the credibility, resonance, and sincerity of the interview data leading to fullness and thick description.

Data collection and creation

The team created an interview guide with questions being constructed around diagnosis and treatment of the condition(s), nutrition, weight changes, physical activity, overall physical and mental health, and quality of life whilst living with DS. The team psychologist (JD) co-designed questions associated with the targeted behaviours (i.e., mindsets, attitudes or approaches to diet and physical activity). Patient and Public Involvement (PPI) members co-constructed the interview format and methods with the research team. Each interview was conducted by the same researcher (KS) and followed the same format, with questions remaining consistent throughout the study. Example questions are shown in Table 2.

Table 2. Interview topic guide.

Topic theme	Example question
Physical activity and participation	What kind of exercise and activities do you like to do and why do you like to do them?
	Does your condition sometimes make it hard for you to do your sport? Why do you think this is?
	If you are feeling a bit tired, what makes you want to go out and do your sport?
Diet and nutrition	During the day, do you find that you get hungry, or do you find that what you're eating is enough and you feel nice and full after your meals?
	Did they give you any advice at the hospital about what sorts of foods to eat?
	Have your eating habits changed after your diagnosis?
Weight and lifestyle changes	What's you biggest concern about the steroids you've taken?
	Have you noticed any changes in your mood? Can you describe it to me?
	If you think about the changes you've made, are there things that you're happy about with your lifestyle? And are there things that you want to make better?

Interviews with patients were performed virtually through a secure Zoom link, with the interviewer conducting the interview from a secure, private room within a university. Recent findings suggest that video conferencing mediums are effective qualitative data collection methods due to its low cost, easy practicalities, data management controls, and security options [49,50]. However, researchers should be alerted to some of the methodological challenges and evolving ethical concerns specific to virtual interviewing [51]. For example, although virtual interviewing may give researchers and interviewees greater privacy and immediately whilst maintaining physical safety, it may also present an intrusion into a respondent's personal space if conducted in a person's home [51]. The use of synchronous video interviews can be just as valuable as vis-à-vis approaches in developing rapport [52], which negated concerns about authenticity.

Interviewees under the age of 16 years were required to have their parent/carer present, but any parental contribution was scrubbed from the audio recording. Initially, interviews were estimated to take 45–60 min, with actual interview timings ranging from 16 min to 70 min, with an average time of 36 min. A pre-interview questionnaire was administered to the patient to inform the interviewer of patient status prior to starting, and a traffic light system was also introduced to allow the participant to stop the interview if they needed to.

8.5 hours of interview data were elicited and transcribed using Zoom and refined, edited, and re-interpreted by an expert qualitative researcher (AC) in line with the audio recordings. This was required as the transcription software was not accurate; splitting sentences, inserting extraneous time codes, and not sensitive to the nuances of accent, rhythm, and intonation. Accessibility to the audio represented an opportunity for the lead author to get closer to the original, unmediated experience of the interview and draw out initial observations, themes, codes, and annotations on the "cleaned" interview transcript [53]. This is especially important when we move away from the richness of the audio to the stripped down black and white text on a page – there is always a degree of separation or a transformation that researchers need to consider [54].

To maintain the privacy of interviewees, interview data and signed informed consent forms were stored using Oxford Brookes University systems, encrypted, and/or password protected in accordance with university policy. Data (including final transcripts, codes, and themes) were deposited and retained in an appropriate, subject-specific data service or university repository (i.e., RADAR). The research data will be made available for ten years for appropriate open access and re-use with appropriate safeguards. The participants were allocated a participant ID number featuring on all trial documents and any electronic database. Due to the rarity of the conditions, concerted attempts at maintaining anonymity, whilst preserving the richness of the data, have been made [55]. This was assisted with the removal (from the data file) of identifiers, names, and research location that disrupt the connection between individuals and their data [56]. To this end, we join with [57] in choosing participant pseudonyms with integrity, and being mindful of culture, regionality, age, and gender.

Theoretical framework and paradigmatic locations

Qualitative research in general has observed a growing consciousness and increasing awareness of the ethics and politics of representation when used in the social sciences and humanities (e.g. [53,58,59]).

Interestingly, this sensitivity to ethical issues, not only in the conception and operation of research, has concerned some in the biomedical fields in how best to denote the welfare of our participants and the data they generate [60]. This study seeks to use qualitative research methods centred on the interview and a sophisticated analysis of data that illuminates the lived experiences of paediatric patients living with DS to give a rich and meaningful window into their world.

One of the challenges for researchers is to explicate their researcher position, philosophical underpinnings, and paradigmatic allegiances, as both a marker of methodological rigour, and to help others interpret their research more effectively [61]. It is important to consider the grounding principles of research area, where it is located, and the research questions to be answered, before committing to a specific approach to analyse the data [40]. A further issue arises when a multi-disciplinary team with distinct experiences and positionalities relating to the nature of ontology, epistemology and axiology, combine and embark on a shared research endeavour. Each of us on this research team come with a different worldview with preferred paradigmatic allegiances and ways of doing that may clash and disrupt [61].

Taking these complexities together, we settled upon adopting a subtle realist ontological approach to the nature of reality for the participants interviewed, and a subjective epistemological constructionist position in our understanding of knowledge, and how it is created [62]. Subtle realism postulates that an external reality prevails separately from human ideologies and perceptions, but that reality is perceived through our minds and evolved from socially constructed meanings [63]. Hammersley [64] frames subtle realism as sitting between realism and relativism, acknowledging that autonomous, knowable phenomena exist, but rejects the conviction of naïve realism that those phenomena can be accessed directly. Rather, knowledge is framed as actively constructed rather than "out there," waiting to be discovered. Similarly, a social constructionist position advances the notion that all knowledge (and therefore our understanding of reality) is dependent upon human interaction between ourselves, our world, individual perceptions and mediated through a social context [65].

In this research, we sought to sensitively explore the different positionalities and experiences of paediatric patients with MS and NMOSD, acknowledging that all human social life is meaningful and that the lived experiences of these patients are unique, partial, and formed in relation to their interaction with the world, other people, values, beliefs, and emotions [62]. The present study is an attempt to privilege the voices of a hitherto overlooked patient group, which may lead to novel insights, and a deeper understanding of what it is like to live in their world(s).

Data analysis

We adopted the inclusion of a-priori knowledge and used an inductive thematic analysis [66] to read into the data and draw out specific themes and patterns. We followed the procedure outlined in Table 3 as shown below:

RTA differentiates itself from other forms of thematic analysis in that it explicitly recognises the researchers' role in meaning making and knowledge production [45]. Within this approach, codes are seen to represent the subjective identification of patterns within a given dataset (see Table 4):

All data were manually coded and organised by the lead author (AC). This process occurred over many months and involved peer debriefing with other members of the research group. Here we engaged

Table 3. Phases of (reflexive) thematic analysis [45,66,72].

Phase	Activity
1	*Immersion into transcripts and audio data*. This was an extended activity that facilitated a deep dive into the individual worlds of each participant. Each transcript was re-written, edited or refined in accordance to the audio data.
2	*Generating initial codes*. This systemic process allowed a deeper immersion into the data set, where raw data were given tags or conceptual categories.
3	*Searching for and generating themes*. This stage involved identifying patterns in the data set, considering them for quality and rigour in relation to the research questions and intensions of the paper
4	*Reviewing themes*. There was an ongoing analysis and consideration of themes to see if they 'worked' with the coded extracts (Level 1) and the entire data set (Level 2). This is where the 'thematic' map was produced.
5	*Defining and naming themes*. This was a recurrent process that moved back and forth between the data set, categories and stories being told.
6	Producing and writing the report. This stage was centred around a selection of vivid, compelling extract examples with a final analysis of selected extracts and relating back of the analysis to the research question and literature.

Table 4. Examples of coded data sets.

Speaker	Interview data	Codes
Patient	Well, the first attack knows when I was first admitted; I couldn't move the whole right side of my body, I could, I couldn't move my eyes were blurry and everything. I think, after a week, I was able to finally move my toes, my legs and everything, so I just had to they had to help me hold one side of my body and help me walk around with it. They did have some physiologist (sic physiotherapist?) as well to help me; they brought me to another room and they would have two bars on the side of me, so I can hold on to them and make sure I can walk by myself or anything just making sure that I can start walking. And they would do that I think every week for that one month…	Paralysis/loss of neurological control. Vision impaired Physical control slowly returned. Value of physio. Hugely debilitating acute phase.
Interviewer	Though sorry. Were you in hospital for a month time?	
Patient	yeah The first time yeah.	
Interviewer	Sorry, the second time?	
Patient	Oh yeah. . And then the second time… nothing really happened to my body, just throwing up and then it just made my hands just shake and everything, but we just didn't know what was happening, they said it was a relapse and at that point they had to bring up my steroid tablets again. Then, after that everything goes fine, but they said I shouldn't do too much work for my right side of my body, because it will be too much pressure for it and because my hand will just start shaking for no reason.	Peculiarities of symptoms Caution with exercise…
Interviewer	And at the moment, now currently, on the right side of your body, has it returned to kind of baseline, or do you still have some weaknesses in there?	
Patient	yeah I do have some weaknesses, yeah because sometimes it feels normal but most of times I can't really lift as much as I used to before. It would be too much and then I'll have to get someone else to help me.	Residual effects of condition.

in iterative meaning-making, assessment of categories from the transcripts and individually reviewed various drafts of the manuscript [67]. Continuous feedback from the research group helped to interrogate the initial findings of the lead author, identify blind spots or suggest alternative interpretations of the data, thus enhancing trustworthiness. This method of data analysis yielded five overarching themes: 1) the influence of the diagnosis and condition on the young person, 2) the implication of the treatment, access to services and effects of steroids, 3) the interplay between physical activity (PA), diet, lifestyle, and DS, 4) challenges to identity and selfhood, and 5) the influence of family and peer support.

Quality and trustworthiness within qualitative research

Central to the tenets of conducting quality research, maintaining methodological rigour and owning issues of transparency is, in how we, the researchers, position ourselves, own our own voices; in addition to making decisions about data, including representation and legitimacy of the text [40,68,69]. These aspects are inextricably tied up with the processes and politics of undertaking research, which themselves are subject to the operations of power within and between the researchers, the research question and the participants [47,70]. Furthermore, these aspects overlap with the need to be ethically reflexive throughout the research process, and not just treated as a tick-box exercise at the start [48]. For example, through interacting with the participants and actively involving them in the co-creation of data, we argue that we have heard their voices and have attempted to resonate them in this paper. At the same time, we are sensitive to the politics of representation, the asymmetric power relationship between ourselves and the participants, and the ethical responsibilities we have in deciding how to read the data, what to include, and what to leave out [47]. Therefore, for us, we borrow from Markula and Silk [70] who argues that the centrality of the researcher is integral to the research process as we are instrumental in co-creating the ontological landscape and topography of the research endeavour.

These elements have ramifications for reflexivity, honesty and transparency, which themselves feed into notions of rigour and trustworthiness. Throughout the different phases of the research process, we have attempted to integrate data analysis and sense-making as a non-linear, imbricated activity that is sufficiently entangled in an iterative process and looping hermeneutics [71]. By engaging with multiple levels of data, regular bouts of meaning making, coding and theme development [72] we have not treated data analysis as an add-on process, for that causes an artificial separation between the rest of the research process. Instead, regular interaction *via* zoom meetings, phone calls, and WhatsApp

Table 5. Participant demographics.

Pseudonym	DS	Age range (years)
Dante	Neuromyelitis Optica Spectrum Disorder (NMOSD or NMO)	18–19
Alfie	Neuromyelitis Optica Spectrum Disorder (NMOSD or NMO) [caused by Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOG-AD)]	10–11
Kai	Neuromyelitis Optica Spectrum Disorder (NMOSD or NMO)	12–13
Jordan	Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOG-AD)	12–13
Florence	Transverse Myelitis (TM)	10–11
Tahlia	Neuromyelitis Optica Spectrum Disorder (NMOSD) + Aquaporin-4 (APQ4)	14–15
Blake	Acute disseminated encephalomyelitis (ADEM) + Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOG-AD)	12–13
Claude	Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOG-AD)	16–17
Imogen	Relapsing remitting Multiple Sclerosis (MS)	14–15
Leon	Relapsing remitting Multiple Sclerosis (MS)	16–17
Layla	Relapsing remitting Multiple Sclerosis (MS)	16–17
Eloise	Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOG-AD)	22–23
Nadia	Neuromyelitis Optica Spectrum Disorder (NMOSD or NMO)	18–19
Margot	Multiple Sclerosis (MS)	16–17
Rosalind	Multiple Sclerosis (MS)	18–19
Charlie	Optic Neurosis (ON)	14–15

messages between the lead author (AC) and JD demonstrated an active consideration of the developing themes and subthemes of the data. This lengthy iterative process and allied writing sessions then informed larger vis-à-vis meetings with the rest of the team adding additional steer. These interactions have allowed us to sustain a form of inter-investigator reliability and keep data analysis firmly in view [67].

Findings

This section draws out the sensibilities, emotions and perspectives of the participants who have acted in concert with us to craft a story that explores the lived experiences and significant challenges on lifestyle and weight management for paediatric patients with DS. To assist with evoking a sense of the participants and giving extra credence to their voices, we have produced a brief biography in Table 5.

Five overarching themes were identified: 1) the influence of the diagnosis and condition on the young person's wellbeing, 2) the implication of the treatment, access to services and effects of steroids, 3) the interplay between physical activity (PA), diet, lifestyle and DS, 4) challenges to identity and selfhood, and 5) the impact of family and peer support on how the young person navigates their condition. These themes, and a further 13 subthemes were identified and presented in Figure 1.

Influence of diagnosis and condition on the young person

The young people interviewed offered a variety of responses to how the attacks, diagnosis and the syndromes in general had affected them. This is in keeping with the diverse conditions themselves and whole host of symptoms that may preset in a variety of forms, severity and temporality [15].

Psychological distress

This analysis resulted in the first subtheme of psychological distress being identified as a major element affecting the young person. This was expressed *via* anger, fear, and concern for the future which was also intermixed with negative mood, depression, anxiety, and vulnerability [73]. To illustrate, when asked about any mood changes since diagnosis, Dante offers "I feel like I'm more I anxious now, and also sometimes I feel I can be really sad. I have moments that I'm really sad…. ." Dante's response suggests the condition presents some serious psychological challenges and negative emotional states which originate from the impact of his diagnosis. Looking ahead he is "…anxious about my future and how it's gonna be when I'm older. And then I start saying things like why did it happen to me, and how can I prevent that"? This anxiety extends into his lifestyle where he says that he takes comfort in fast food and makes poor diet choices when he is desolate. An otherwise keen gym goer, Dante reports that anxiety acts as a barrier to exercise and prevents him from leaving the house. To mitigate this, he undertakes home exercises and physical activity to mediate his mental state.

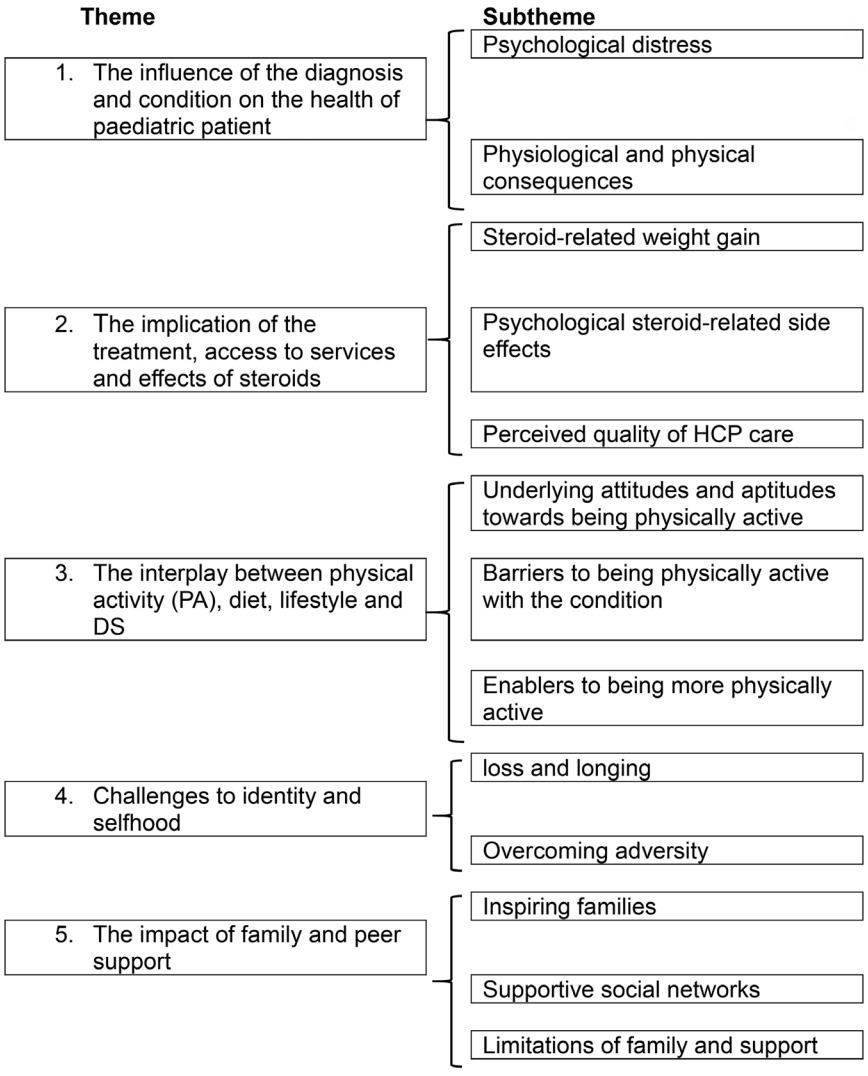

Figure 1. Thematic diagram of themes and subthemes.

Anxiety, worry and fear from diagnosis and its implication for life also play out in other patients:

> I was really upset a lot of the time and crying a lot and like worrying and things like that. [Then] I saw this psychiatrist and she told me to do this mindfulness group, like how to control your worrying and things like that. (Tahlia)

For this patient, the distress of the condition was helped by access to psychological support and that mindfulness strategies when deployed sensitively can be really effective. This was by no means representative of experiences across the cohort, thus demonstrating both multiple patient views and inconsistences between provision of care between NHS Trusts. For example, there was no support for Eloise, and the anxiety of diagnosis was compounded by the fear of being vulnerable to other illnesses, leading to social isolation and acting as a barrier to her favourite (and only) exercise:

> … even though I love swimming, I haven't swum in many years, because there was always like a sort of scare about (…) being immuno-compromised. And actually, when I was diagnosed, that was a big thing; I was too scared to go out in public.

Furthermore, not only did Eloise find the attack itself and being hospitalised for so long profoundly arduous, she "… found it really difficult to sort of talk about, then come to terms with sort of living with MOG". Similarly, other young patients reported difficulties. For example, Kai, a talented athlete who was diagnosed at the age of 10 years says that he "… get[s] a bit upset sometimes, because I know what

happened to me, but during my attack I've got quite angry, but mostly upset because I knew what was going on". As researchers, we cannot reach into the interior realities of participants with total assurance [39], but what may be implied certainly resonates with us. For these young people, DS have real psychological effects that echo throughout their life course to date.

Physiological and physical consequences

The second sub theme focused on the significant serious physical consequences of the initial attack. Most of the respondents related the catastrophic and terrifying acute phase as this MOG-AD patient relates:

> It was quite, quite serious, and I don't remember much of it to be fair … I became paralyzed from the chest down and then I was on a ventilator for three days, and then from then my swallowing went. (Claude)

The severity of the acute phase including the terror of paralysis was echoed by Rosalind:

> I was waking up because I was sitting my GCSEs at the time with really, really bad pins and needles and cold legs… And it got to a point that I couldn't feel like my chest, and my legs. Then I went on a walk with my friend, and I was just falling over. Then I was paralyzed from the neck down for a few months, and then … once I was stable, I had plasma transplant and loads of steroids.

Other patients added to this, relating stories about the long rehabilitation phase that these dramatic events presented:

> I couldn't move the whole right side of my body (…) my eyes were blurry and everything. I think, after a week, I was able to finally move my toes, my legs and everything. They had to help me hold one side of my body and help me walk around with it. They did have some physiotherapists as well to help me; they brought me to another room and they would have two bars on the side of me, so I can hold on to them and make sure that I can start walking. And they would do that I think every week for that one month. (Nadia)

Many patients reported a wide range of chronic physical consequences of living with and recovering from attacks and relapses. These included poor sensation and numbness, lack of balance and co-ordination, bladder and bowl issues, vestigial pain and weakness, and chronic and specific fatigue. Nadia indicates that her biggest worry is going back to hospital or "having another relapse, and then having to do the whole [recovery] thing over again". Similarly, Rosalind spoke about the frustration of living with a chronic condition, reflecting on how she felt it has adversely affected her cognition and dealing with other people's assumptions of chronic fatigue "… it's not just being tired, it's like being just exhausted; I can't get out of bed".

Implication of treatment, access to services and effects of steroids

The way in which life-saving medications (including steroid treatments) intersected with the approach of the HCPs, patient disposition towards treatment, access to services, and the level of information and guidance provided had profound effects on the patients themselves. These had further implications for how the individual responded to their DS conditions, and were compounded by inconsistences in the system and a lack of coordinated, wrap-around care between different elements of the NHS.

Steroid-related weight gain

One of the most prominent effects was the dramatic weight gain experienced by many of the patients as a consequence of steroids:

> So, I gained *a lot of* weight, I think I gained about two- and a-bit stone that summer? And I think it was something that really, really affected me and because I was in a wheelchair, I wasn't really moving, because obviously I was paralyzed. And my *face* from the steroids was massive, like your face really, really, really swells up. And I just felt really bloated and swollen. (Rosalind)

Although the steroids are essential for managing the condition effectively [5,73], they had significant visible effects on body composition which were distressing to these young people as Rosalind intimates.

At a time when a person's self-identity is forming, with one's ego and sense of self-worth being bound up to the physical presentation of self, adolescents and young people are acutely sensitive to the gaze of others [31]. Just like Rosalind above, just over a third of participants drew reference to "moonface," which is where the discernible side effects of steroid weight-gain are most prominent and distressing. Jordan reflects with disenable unease "And when I was on steroids, I think I did gain weight, but mainly in my face. And I think it was definitely easier to gain weight".

Previous studies have demonstrated that weight change is linked to patients responding to a dramatic increase in hunger levels that steroids induce [13,17]. This was mirrored with the majority of interviewees in our research declaring that they experienced increased food intake due to hunger "I've definitely had an increased appetite. I was eating a lot more (…) now I'm trying to control it" (Tahlia). Rather than judging patients for not adequately controlling their calorific intake and/or maintaining recommended activity levels, we probed the participants to explore related mechanisms for weight gain. What follows is an account of real anguish caused by physiological changes to perceptions of hunger:

> I couldn't feel full, which was the weirdest thing because I would have an entire meal, the complete meal, and like genuinely have like my belly protruding like I was so full. And I would cry because I feel like I'm starving. (Eloise)

Given the well-known consequences of steroids, most patients were forewarned about changes to their satiation levels by their HCPs. Nonetheless, this appeared to be the limit of advice given directly to the young person, with little or no dietary guidance provided about how to best manage their nutrition and increased cravings in a healthy manner. Some were just told to increase water intake or to avoid fatty foods, but with no real signposting. Furthermore, Layla was totally uninformed about the potential consequences of steroids in the first place and left to work it out for themselves:

> I don't recall ever hearing about weight management or exercise. I think, maybe because I was at the time, a healthy weight. I was quite slim… they didn't even tell me at the time that steroids has a lot of weight gain, and I actually found out through a friend who had taken steroids about that like as a side effect, but then I like quite rapidly noticed it myself, and then looked into it.

A common element throughout was that interviewees were unhappy with the lack of guidance and really welcomed the idea of more information from HCPs. Several spoke about how this information would have ameliorated the weight gain "Well, it would have been helpful to know just like what types of food to eat, rather than me just snacking all the time, to be honest" (Imogen).

Psychological steroid-related side effects

In addition to these concerns, some patients spoke candidly about how they perceived steroids to have psychological side effects that negatively influences their disposition and increases fatigue. Layla offers "I think the steroids had made me a bit moody and I was really tired, like I really wanted to sleep all the time". Jordan emulates this position offering "I think the steroids definitely made me more tired and (…) a bit more sensitive to stuff, but then afterwards I think now I'm obviously I'm off the steroids, that doesn't make me feel as bad". How much of the low mood and increased fatigue can be associated directly to steroids is not clear, as it could also be attributed to the stress of staying in hospital, anxieties over the diagnosis, and effect of the condition itself.

However, for some patients the effect of steroids were unequivocal, significant and frightening:

> I got really depressed, and so it was sort of like, I had been really euphoric and like high (at first) on the steroids, and then it was for so long that when I went down, it was like sort of everything was grey again. And it was a little like this grey cloud had sort of tinted the world, and I was really, not in a good place and the sort of reality of my condition set in. The fatigue sort of revealed itself and just a lot yeah sort of went downhill… (Layla)

Layla offers us a lucid depiction of how extended exposure to IV steroids can have significant psychological effects affecting many aspects of a patient's perception of reality, mood, and even personality. For some patients who were lucky enough to have access to mental health or psychological counselling, this was a godsend with patients appreciating how these sessions allowed them to make sense of their

feelings and support their mental health challenges. Kai mentioned that he could request an appointment *via* his mother anytime he wished for, and Imogen was able to access counselling two years after diagnosis. For others, this support was not forthcoming, and it reflects the inconsistences in the UK healthcare system. It took a lot of courage for Eloise, to speak so candidly about her illness and her poor experience of therapy:

> The NHS is not very resource heavy with mental health stuff, so it took me like two years to get seen by anyone. I got this ACT (Assertive Community Treatment) service, which was like talking therapy and I found that quite unhelpful because it was a very general counselling service, which was really not tailored to people with chronic illnesses. Like, to the point where one of my therapists said that I was too ill for therapy, which I think is ridiculous to say to someone, like super disheartening and also, inappropriate.

Eloise continued to open up about her extreme psychological steroid-related side effects and her difficulties in coming to terms with her depression associated with her DS. After years, she attributed her disturbing thoughts and suicidal tendencies to steroids, and she started taking anti-depressants. She remains hopeful that "once I get off steroids, I'll be myself again because the steroids changed my personality". Both Layla and Eloise spoke the most eloquently about their problematic diagnosis journey, ineffective support offered and perceived devastating psychological effects of steroid treatments, but in contrast, many interviewees were quite taciturn. Perhaps, as a result of their age, the younger respondents lacked the appropriate vocabulary to express their concerns, or they did not want to talk about these issues to a stranger.

Perceived quality of HCP care

Where the interviewees appeared to have the most positive experiences regarding their treatment was with their physiotherapists. Although the patients did recall some contact between themselves and consultants, they often did not remember much due to the severity of their illness during initial or subsequent attacks. Instead, patients were able to build up constructive relations with physiotherapists, which resulted from hands on, effective progress with their rehabilitation. When asked about who was most instrumental in their recuperation, Claude celebrated the impact of his physio:

> So yeah, they're good at exercise. They sort of get your core working and it's all working on that balance and stuff because at that point, I wasn't able to walk or anything and sitting up on the edge of the bed, that was quite hard.

Kai mentioned that he would see his physio every month and was provided with exercises to do himself at home, which got progressively more difficult. He appears to have a positive working relationship with his clinical team and so prioritises his exercises. However, most patients did not report that they received any guidance about physical activity levels, or how much exercise they should do, but they may have been more unwell and may not have remembered. Kalb et al. [74] recommends $\geqslant$150 min/week of exercise and/or $\geqslant$150 min/week of lifestyle physical activity (for chronic disorders) if symptoms and comorbidities allow, yet our research suggests that clinicians may not be promoting the guidelines, despite the body of research exhorting the benefits of being active [18,36,75].

Interplay between physical activity (PA), diet, lifestyle and DS

The question how exercise and/or PA intersects with diet, lifestyle and the condition itself manifested in a multitude of ways, demonstrating complex, heterogenous relationships between elements.

Underlying attitudes and aptitudes towards being physically active

To foreground this theme, we felt it appropriate to explore some of the underlying attitudes to PA and lifestyle where participants displayed a variety of attitudes from exercise enthusiasts to indifference along a continuum. Several participants were self-declared PA devotees who played a variety of sports several times a week:

> Yeah, I'm quite sporty, I play football, roller hockey, and I go swimming. [Sports] just make me *happy*! I enjoy seeing a lot of my friends there and it's one of those things where I feel like I'm good at it, and I enjoy it! (Blake)

He emphasises the intense joy he gets from participating and acknowledges the social benefits of being physically active. Many participants like Tahlia and Blake emphasise the fun element, and others like Kai, Jordan and Leon have got to high performance levels in their sports. Several like Margo and Rosalind are moderately active, and some would love to be more active, but a lack of facilities prevents them taking part. By way of contrast, Eloise is not particularly "sporty," but derives her exercise from other means:

> Okay um it sounds silly, but like I think gardening is like the most active thing I do, yeah! I think that's the thing that gets me sweating the most. (…) I find it really hard to do any running. And even walking so, even semi medium amounts of time is quite difficult. So, not that I avoid walking, but it is not my choice of exercise - it's more like a medium to get from A to B.

Barriers to being physically active with DS

The diagnosis, treatment and rehabilitation also had profound effects on the young person's activity levels and variety of exercises they could do. Together with an appreciation of diet and healthy food choices, some battled to regain their original activity levels, but others floundered. Some of the barriers to improving PA and diet included limited access to facilities, knowledge of suitable nutrition, concomitant effects of steroids on mood and weight gain, underlying lifestyle habits, fear of relapse, anxiety, chronic fatigue, pain and other varied significant effects of living with relapsing or remitting, progressive autoimmune chronic conditions. Imogen offers an insight into her situation when she had a severe relapse resulting in enforced bed rest:

> I was just hungry, and I was just eating because I thought I couldn't be active, because I had a left side weakness. And I had like a splint for a while and so I couldn't be active, so I was just eating.

Other major barriers to exercise included fear of bringing on symptoms. For Layla this was particularly significant as the condition has had a paralysing effect on her activity due to perceived limitations of MS and lack of support from HCPs. She relates that she "had bladder problems because of it, then if I run, sometimes I urgently need to go to the toilet. So, I don't really want to do exercise because of that reason". Linked to this is the lack of support, information and guidance about what sort of PA is suitable for that particular DS which impacts confidence levels, exacerbating the fear of instigating another attack. Alternatively, Nadia wants to exercise, but a lack of guidance limits how she exercises within the confines of her NMO:

> I only would do probably 15 or 20 minutes. I don't go above that because that's when I'll start shaking, my hands will start shaking and feeling exhausted. Most times when that happens, I'll get dizzy as well, not really lifting up too much stuff probably only … at least say the highest it probably go three or four kg so far that I can lift up.

These young people have made repeated calls for coordinated plans and direction for their rehabilitation beyond physiotherapy and medication, and our findings suggest that this cohort are significantly affected by a lack of information around diet and nutrition. Several participants reflected that they made poor food choices if they were unhappy or had low mood, which then adds to their anxieties about further weight gain.

Enablers to being more physically active with DS

By way of contrast, several said that they had made conscious and positive changes to their diet in an attempt to control their weight gain and manage their condition more effectively. Claude, a recently diagnosed 16-year-old NMO patient recounts his epiphany "So, from what's happened has made me think that I need a better sort of food intake, because what I was eating wasn't really beneficial for my body". He talks about eating a more balanced diet with a lot of fruit and vegetables. Furthermore, Claude has paired this with a concerted effort to complete exercises set by his physiotherapist and has steadily increased his capacity for exercise in a serious attempt to regain health and fitness. What is apparent is his drive and motivation appears to come from within – he is intrinsically motivated and takes ownership for his progress.

Similarly, Dante has started to go to the gym four times a week in an attempt to become more active. He feels like exercise gives him a sense of autonomy and is becoming more confident, in addition to him losing his steroid-weight and becoming physically stronger. This sense of transformation is encouraging, and Dante is keen to emphasise the positive value of PA. By incorporating breathing exercises, yoga and a new commitment to improving diet, Dante feels like he is driving his own progress. He still suffers from anxiety, but by seeking out training programmes online and researching and implementing better food choices, he is "coming out from the dark side and can see." Likewise, Jordan at 12–13 years old understands the link between PA and mental health and well-being; for him staying active "just keeps you healthy and is a great stress reliever as well"! Several interviewees discussed the positive effects that being physically active has on mood and combating fatigue, which is mirrored in the literature [74,76]. Tahlia muses "I just think that when I'm there and with my friends, I have a kick about and think I'll just completely forgot about feeling tired and [feeling] not that great and it will make me feel more happy".

Several participants reported debilitating effects of exhaustion, preventing further PA. For example, Blake, a very sporty ADEM and MOG-AD patient, relates how fatigue and migraines affect his balance leading to increased falls in hockey as a consequence of living with the condition. Due to his personal motivation and strength of character, he perseveres with his sport, as he says it helps him manage his condition better. Similarly, Leon, a gifted footballer, takes the position that being very fit and physically active is essential to mitigate against the debilitative effects of MS:

> Well, cos I do so much sport, they (the HCPs) said I'm probably one of the fittest people they have on the on the medication. So, they said because I'm so healthy, that it's probably like the treatment has the best circumstances to work to be as effective as it can. So that sort of settled a lot of nerves, any doubts in the treatment.

Despite the debilitating effect COVID restrictions had on sport, Leon continued to train on his own terms, being self-directed and single minded in his approach to football and applying his GCSE PE knowledge about correct nutrition, training and recovery effectively. He refuses to be cowed by MS and offers inspirational advice by "… showing people what can be done if healthy lifestyle and being active is followed (…) as it can help you live without being impacted by your MS." Alternatively, Eloise offers a more subtle explanation for her motivation to become more active, lose weight and become as she reflects that she is "so young and I feel like an old woman a lot of the time". She attributes her new motivation to the brain chemistry (mental health) changes that result from exercise:

> I think, you feel alive when you do move because it gives you these endorphins, and the lighter I am, the more I can move and I'm so heavy! But it's really hard to do anything, and so, when I can like fly upstairs, I'll feel young again!

Other participants related their own epiphanies committing to a healthier lifestyle. Rosalind was able to lose the two stone she put on in hospital by changing her routine, committing to healthy food choices and finding motivation from charity work:

> I raised money for MS during lockdown, so I'd do 10,000 steps a day and then that was my thing. And then that sort of kick started me being a bit more healthy and just trying to make healthy healthier food choices and just like not stress.

Perhaps being engaged in her own rehabilitation and displaying autonomy she was able to change her path and walked her way back to a healthier lifestyle [77]. Nadia too is proud of the progress she has made with her weight loss, and Layla attributes her healthier disposition to dancing classes, becoming vegetarian, and paying attention to protein.

Challenges to identity and selfhood

Living with and managing these inflammatory, unpredictable, remitting and/or progressive DS posed particular challenges to the participants' sense of identity and selfhood, with responses varying in form and intensity.

Loss and longing

Some articulated a sense of loss and sadness for the person they were as the condition manifested itself on the young person. Rosalind picks up the story:

> I used to love ceramics, and I used to do it all the time, but I went back to it after MS and I found that just my way of thinking and my brain like, I couldn't control my hands in the way that I wanted to. I find it a lot more difficult than before, and it sort of upset me because that was something I always loved, and I just felt like I couldn't do it anymore.

For Rosalind, not being as proficient as she was, demonstrates the limitations and hardships of MS in terms of engaging in personally meaningful activities. She intimates that she has lost something of herself with this blow to her self-confidence. Additionally, she feels that this loss was exacerbated by the significant weight gain, which adversely affected her self-worth and value. Progressing to sixth form after her relapse, she was sensitive to the critical gaze of her peers and having to walk with a crutch "*threw* my confidence completely I'd say". Eloise relates to this saying that her rapid weight gain and her bladder and bowl issues challenged her in coming to terms with profound changes to her appearance and adapting to disabilities. Not only is she feeling like she is being "othered" by peers, but she despairs at her physical transformation and loss of fitness:

> Its just really difficult (…) the transition to like not being able to fit into clothes, and I think the thing that really got me is walking up the stairs became this really difficult task. Just going upstairs just in my home, I would be out of breath, I'd have to sit down. That just was like so shocking to me like, how can I struggle with something that's so common?

Perhaps the most profound challenge to identity comes from Eloise who related a terrifying account of how steroids changed her personality and invoked a psychotic, alienating experience:

> … so, in hospital they gave me like the intravenous steroids, and I had like an episode (which I've never had before). I had an episode of depersonalization which was really scary, was like really dissociative, and …. yeah that was a really scary time because I was like in hospital and I just had this really weird out of body experience.

Overcoming adversity

Despite these profound challenges, others demonstrated immense positivity and resilience in overcoming adversity:

> The NMO can be bad sometimes, but it also can be a thing that can motivate you on being the best version of yourself if you want to improve yourself. And also, like I'm learning that is not the end of the world sometimes and even, if you like have the condition you can still do the things that you enjoy doing, yeah. (Dante)

Rather than being limited by the condition, Dante refuses to be beaten or defined by it. In this moment he takes on the challenge. Kai echoes this position in overcoming adversity:

> I always loved my gymnastics and because I've competed at quite a high level, I were quite good at it. So, I thought I need to get back at it, I need to do it again. I never let anything defeat me because I wanted to go back, and I really enjoyed it!

This adolescent takes his intrinsic motivation and drive in rejecting the label of a chronic paediatric patient, but instead relishing the challenge to succeed. He adopts a realist perspective in always looking ahead and "… to carry on," not giving into self-pity. However, rather than running the risk of attributing too much agency to these remarkable young people, we turn our attention to the final theme of the influence of family and peer support.

The influence of family and peer support

This theme captured the support offered by family and extended networks surrounding the young person. This support manifested itself as both enabling and restrictive in terms of influencing access and opportunity for PA, eating habits and mental wellbeing.

Inspiring families

The first subtheme, inspiring families and parental influence was markedly pronounced in creating the social environment of the family, its values, beliefs, attitudes and customs. Many of the respondents were grateful to their parents in inspiring them to become more active, with Layla and Eloise (who were not particularly active at diagnosis) benefiting from their mothers acting as powerful role models and exercise companions, "my mom is a really big gym fanatic, and she says, "oh let"s go!' and she's really encouraging and its quite fun for me" (Layla). Eloise was grateful to her mother for joining her in online classes during the COVID pandemic where she enjoyed the camaraderie of being part of an online community. In addition, Kai, Jordan and Florence all profited from their parent's support and encouragement in continuing their varied sporting interests, which was also strengthened by sibling involvement [78]. The strength of the family unit in promoting activity for healthy living and managing the condition appears to be very influential, with Kai's mother and brother taking an altruistic role in helping him undertake his physiotherapy activities.

Supportive social networks

Specifically for Kai, the circles of influence ripple out from family to include a second subtheme of wider social networks involving close cooperation between family, physiotherapist, and gymnastics coach where they would "work together to get me a regime to get back into doing it (competing)." In a similar vein, Imogen pays homage to her swim coaches:

> … because I had good people around me, I felt like I could stop when I wanted to, and have a break, when I felt like I needed it, which was really good. So I did, and then I would continue going after that.

Participants were also appreciative of their peers and friends, with several emphasising the value of social interaction and collective engagement from their sports. By illustration, Jordan who has made most of his friends through gymnastics, reflects on how they are motivated to go training when they are tired:

> I think it's kind of more fun when I get there, even though obviously you have to do a lot, [its] still fun to go and socialize as well and when I'm there it's not never as bad as when I'm thinking about how much effort is going to be!

Florence speaks about her enjoyment about "being part of a team" and the fellowship it engenders when she plays hockey, especially with her sister. In these young people, these activities appear to promote positive self-thoughts, empowering them by mitigating the weight and anxieties of living with DS. Support networks are also very influential in encouraging those who are not very active to increase their PA. Layla got quite animated as she related how her dancing lessons acted as a facilitator for exercise she relishes:

> … so it's a big group of us and we like to hang out a lot as well, so it's just fun! Because your friends are there, and like you can mess around sometimes, but you're still getting something out of it. And then our teacher's quite funny - we've known her since we were little, so it's very enjoyable.

For those who are involved with exercise promotion with certain disease groups, having opportunities to undertake different forms of exercise that do not always involve a gym environment could enable PA and so facilitate the management of their disease course and/or reduce associated co-morbidities.

A further example of how peer group support is invaluable also comes from Florence where she expresses how speaking to other young people with DS can be cathartic:

> I know this one girl that's the same age as me and she also has MS as well, so we like to keep in touch. Then there's also paediatric MS online group and like with video call sort of every three months. And when you do get to interact with a lot of other young people, sort of from about like nine to 18, who also have the same condition and you get like their experiences, I think it's really, really good.

Dante substantiates this relating that he made a friend on Instagram who also has NMO, and they communicate *via* texts. He values having someone who is living with the condition to share experiences, thoughts and feelings with, and he benefits from her insights "she can explain me things that maybe I'm

not aware of. Or how to cope with things when I'm feeling sad or anxious". Eloise corroborates the value of having a concerted network of similarly affected young people but offers a caveat that most online support MS groups are for middle-aged people on Facebook with whom she cannot relate to: "…having a place targeted to young people would be really helpful because it just felt like I was being grouped together with people I had very little in common with. And that sort of made me less likely to get support". Due to the rareness of these conditions in paediatric populations [3,13], however, not all participants knew about or could draw upon the support that this kind of relationship could offer and felt isolated.

Limitations of family and support

Despite these significant positive influences of family and peer support, there does appear to be limitations to this assistance. Whereas several interviewees credited their parents in maintaining or developing positive attitudes to PA, Nadia emphasised the powerlessness of her mother in wanting to do more but being confused about how she could help her daughter. Some interviewees reported that their parents were either apathetic towards exercise or actively dissuaded them from PA in the fear that exercise may cause a relapse. Furthermore, other stakeholders had an impact on the young person. Tahlia offered that her clinicians said she could carry on with football, "but not to do too much," which is vague, unhelpful and does not inspire confidence.

Correspondingly, some interviewees spoke knowledgably about the importance of good nutrition, but were also subject to unhealthy dietary choices if they were not responsible for making their own meals. Older respondents mentioned the difficulties in adhering to their own diet if they were surrounded by family members eating more tempting foods. The home environment becomes vital for inculcating good dietary habits, which could be improved with direct access to a dietician and better nutritional advice for patients and parents. We advocate for DS patients to receive integrated care that goes beyond the medicalisation of the autoimmune condition, including a focus on PA promotion, psychological counselling and mental wellbeing, healthy nutrition advice, social opportunities and a more effective link between the specialist hospitals and local services.

Discussion

Diagnosis and treatment of these chronic, relapsing, autoimmune diseases that often have serious implications for quality of life, health and wellbeing, are explored in this paper. Hearing these young people's stories and giving an account of how they negotiate their condition(s), allows us, the researchers to live for a moment in their world [62]. This was both humbling and profound. Disturbing though these stories are and frightening for the young people and their families who experience them, it is crucial that research gives voice to these underrepresented or marginalised patient groups in the hope that they may instigate greater insights into their lived experiences [31,47]. Due to the rarity of these conditions, we are not seeking to generalise to wider society *per se*, but are offering thoughts on the challenges of living with chronic long-term conditions. This paper acknowledges the fortitude and resilience of these young people in the face of adversity.

The data elicited a diversity of responses and perspectives for the young people living with DS. Specifically, our findings had multiple intersecting physical, emotional, psychological, and social dimensions, suggesting that these the paediatric patients are not a homogenous group, but instead require bespoke treatment and intervention. Particularly important for our findings is the significance of being supported to be physically active, keep a healthy and balanced diet, and adopt a positive lifestyle that maintains social relationships and incorporates notions of wellness. Individuals who were supported were better able to be healthy despite the condition. These findings corroborate previous research exploring barriers and facilitators of health behaviours in adult [75,78] and paediatric DS populations [16]. Furthermore, they substantiate the importance of adopting health behaviours that not only facilitate the active management of the DS, but promote physical and psychological wellbeing that contributes to the holistic development of the young person overall [5,79]. Consequently, those participants who managed to be more active often attributed their motivations to the perceived benefits to their mental health [75]. This illustrates the need for systematic, tailored, and more informed interventions for this patient group.

Just as holistic, wrap around or integrated care is an essential aspect of treatment for children with cancer [80], we join with Smith et al. [5] in calling for a child-centred and holistic support within treatment and management of DS that involves multi-disciplinary teams including consultants, neurologists, physiotherapists, dieticians, psychologists, and exercise scientists working together to support patients and their families. Our data suggests a lack of a coordinated care or a patchwork of approaches in which psychological support is scant, under resourced and varied in healthcare provision in England and Wales, despite the higher prevalence of emotional and psychiatric disorders in this population [5]. Rather than to roundly critique provision, the rarity of the conditions means that there are only a few specialist centres (with some care being provided locally) leading to this patchwork effect. For Dante, Kai, and Tahlia, having access to some psychological support was key, but Imogen had to wait two years before she could benefit from counselling or psychiatric treatment. Furthermore, Imogen and Eloise's slide into depression, psychosis, and alienation was testament to absent or inadequate treatment with devastating effects. Future research may seek to explore the views and experiences of HCPs and parents/carers of paediatric patients with DS for further perspectives as how to optimise care in people living with DS often far removed from specialist centres.

These diverse findings have implications for the way that young people with DS are diagnosed and treated to better understand the impact these conditions have on their health, lifestyle, and PA choices (and vice versa). A major aspect was the desire for better support and guidance regarding diet, nutrition, and PA to help them manage steroid-induced weight changes, mood swings, fatigue and other debilitating symptoms of DS. This is in concert with the literature that supports the positive and protective effects of exercise in patients with DS [18,20,33–36]. Despite this consensus, patients responded to the challenges of living with DS in multiple ways. Specifically, patients tended to fall into three distinct groups, namely some who were very active prior to being diagnosed with a DS and were highly motivated to strive for activity maintenance after diagnosis and treatment. Some patients were not physically active either pre- or post-diagnosis and struggled to manage their disease course with concomitant effects on their mental and physical health. A third group were moderately active before the condition manifested itself, but then struggled to maintain activity levels or weight management after. Some of these patients then experienced an epiphany leading to a significant change in their lifestyle and physical activity levels. These changes elicited a range of health benefits and improvements to quality of life.

The data suggested a range of both facilitators and barriers to being physically active with associated behavioural or emotional responses to the diagnosis, treatment, and effects of the conditions. Some of these facilitators included the positive effects of family on diet and lifestyle, peer support, and motivational disposition, whereas barriers included fatigue, stress, fear of physical activity, alienation from their own bodies, fear of exercise exacerbating symptoms, or limited access to relevant resources or sources of information. These findings are consistent in the literature [30,31,78). We suggest that inhibiting barriers are interconnected and exacerbated through the lack of information and guidance around appropriate PA and nutrition provided by HCPs, with any guidance for exercise being framed mostly as cautionary. This was mostly seen in patients who were not particularly active, but those who were significantly active appeared empowered to make their own decisions.

Limitations

As with all empirical research we recognise that there are study limitations. For example, there may be bias in the sample recruited, as we did not seem to enlist those individuals with extreme weight gain. Our study attracted those who were willing to discuss health issues and not necessarily patients who were obese, had poor nutritional health, and/or adverse attitudes to PA. However, our sample does have enough heterogeneity and appears to represent a large proportion of those with these rare conditions in the UK. Furthermore, this may represent a further limitation, as due to the very small number of paediatric patients with DS, we only had a very small pool of potential recruits. In addition, there may be bias in the interview data collected as those individuals under the age of 16 years had their parent present which may have inhibited or influenced the young people's responses [54]. Parental attendance, however, is in line with complying with NHS Research Ethics Committee and Health Research Agency

requirements. Furthermore, we acknowledge that the interviews were managed and subsequent data analysed by adult researchers, which may have influenced the participant's narratives and ways that they presented their accounts [31]. On reflection, the interviewer (KS) spent considerable time and effort developing a respectful and encouraging rapport with respondents, both prior to and during the interview encounter [39]. As a result, most interviewees seemed relaxed, open, willing to discuss their lives with DS, and did not give the impression of being constrained by parental presence or adult questioning.

Recommendations/future directions

Despite the known difficulties in the medical treatment of children or adolescents with DS [81], we argue that if holistic, integrated care is to become truly multi-disciplinary, then we need to invite dieticians, physiotherapists, and exercise scientists to the AHC team. Although, the World Health Organization's [82] recommended PA guidelines for children and adolescents is $\geq$ 60 min per day is well documented, there are no PA guidelines for DS in this population. This further substantiates the need for bespoke, personalised treatment that considers the neuroprotective aspects of exercise [83], the importance of resistance exercise [18] and the aerobic effects leading to a reduction the combined effects of co-morbidities [74]. There is a real sense of frustration which we present as a missed opportunity for parents/carers to become more confident in how best to help their child manage their condition through positive changes to their lifestyle. This is essential given that fatigue, depression, and obesity disproportionately affects children with DS [84], further inhibiting their ability to manage their condition.

Rather than offering specific and bespoke practical clinical guidance to AHC teams, this exploratory study seeks to give voice to concerns of the patients themselves. Future research could focus on the co-creation of intervention studies between researchers, clinicians, and AHC professionals in concert with patients. This could include research into the perspectives of HCPs, and parents and carers of paediatric patients towards providing more integrative holistic care. Our study has highlighted the potential benefits of supported physical activity, positive nutrition, extended social networks and enacted well-being. We call for more research into structured/unstructured physical activity and dietary support, and how this may be operationalised in paediatric settings for DS.

A further recommendation is that interviewees called for access to support groups that were made up of their contemporaries, rather than most online groups involving older people. This might help counter feelings of alienation and despair by contributing towards a more robust mental state, which could assist with adhering to a healthy lifestyle [31]. Those who maintained or improved their physical activity levels, were able to manage their disease course more effectively [3]. They took ownership of their condition, perceiving they had greater control over their symptoms and were committed to "get their body back". Thus, we feel that after hearing the voices of the participants, coordinated intervention by committed multi-disciplinary teams of AHPs is essential. Nonetheless, despite some of these positive stories, these young people are dealing with significant physical, emotional, and psychological challenges as they navigate adolescence and early adulthood with a chronic, debilitative autoimmune condition.

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Author contributions

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