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Severe and very severe ME/CFS – when healthcare is out of reach: A qualitative study

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Abstract

Severe and very severe myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) causes profound functional impairment and substantial multisystem manifestations, leaving many home- or bed-bound, highly dependent on family/lay caregivers, and often invisible to healthcare. This qualitative study explored healthcare experiences, unmet needs, and barriers to healthcare access among people with severe and very severe ME/CFS, their family/lay caregivers, and healthcare professionals in Austria. Adapted narrative and semi-structured interviews were conducted alongside focus groups and expert interviews with healthcare professionals. Data were analysed using qualitative thematic analysis. Our findings suggest that knowledge gaps, absent or limited transportability, and insufficiently adapted healthcare services restricted access to necessary care, and could even make healthcare itself a risk for deterioration. Family/Lay caregivers frequently assumed coordinative, nursing, and medical responsibilities in the absence of accessible professional support. Improving provision for this population requires models designed around the functional capacities and individual needs of people with severe and very severe ME/CFS, including home-based and outreach care, telemedicine, multidisciplinary coordination, adapted routine and emergency care, and ME/CFS-specific professional education. Future studies should evaluate such models and strengthen research inclusion, particularly of people with very severe ME/CFS.

Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic, multisystem disease[1–3] impairing immune, vascular, neurological, endocrine, metabolic and energy production systems. ME/CFS was formally recognised as a neurologic condition by the World Health Organization (WHO) in 1969[4]. While ME/CFS imposes a substantial disease burden and an especially low quality of life[5], it is one of the most underfunded diseases[6,7]. Partly as a consequence of this, there is no curative treatment available at the moment and recovery rate in adults is assumed to be 5%[3,8]. ME/CFS disproportionally affects the female population[8] with an estimated ratio 3:1. Its defining hallmark feature post-exertional malaise (PEM)[1,3,8,9] constitutes a pathologically impaired physical recovery response with disproportionate and often delayed significant deterioration of the overall health state, accompanied by new or worsening multisystem symptoms. PEM occurs following physical, cognitive, sensory, orthostatic, or emotional exertion that would have been tolerated well prior to disease onset. The PEM-induced deterioration results in prolonged health state decline lasting days, weeks, or longer, and may contribute to progressive functional decline.

Severity classification ranges across a mild, moderate, severe to very severe disease spectrum[8,10–12], with approximately 20–25% of people with ME/CFS classified as severely or very severely affected[8,13–15]. These individuals are predominantly housebound or bedbound, require extensive assistance with activities of daily living, and often experience profound cognitive dysfunction and intolerance to sensory stimulation, communication, and upright posture[3,12,16–19]. In the most severe cases, gastrointestinal dysfunction, swallowing difficulties, and nutritional complications may require highly specialized medical management, e.g., tube feeding[19,20]. Consequently, patients with severe and very severe ME/CFS have substantial and complex healthcare needs and remain heavily dependent on family and other caregivers[12,21].

Despite their considerable disease severity and burden, people with severe and very severe ME/CFS continue to be largely invisible within healthcare systems[12,22] and research[17,23]. Their extreme functional limitations restrict access to standard, non-ME/CFS-specialised healthcare services, while insufficient disease recognition and limited availability of professional expertise further contribute to delayed or inadequate care[3,12,24–27]. Additionally, this patient group is not only medically underserved but also substantially underrepresented in scientific research. This underrepresentation further limits the evidence available to inform clinical practice and healthcare planning for this population. Growing international evidence[22,27,28] indicates that people with ME/CFS face considerable barriers to accessing appropriate healthcare, including fragmented care pathways, limited availability of knowledgeable healthcare professionals, and inadequate diagnostic and supportive services. However, little is known about how individuals with severe and very severe ME/CFS navigate these fundamental problems and experience healthcare within healthcare systems, which mostly do not cater for their needs[17,29].

This is also the case in Austria, despite recent estimates of 14,000 people with severe and very severe ME/CFS[30], a number that has particularly increased in the wake of the COVID-19 pandemic.[31–33] Currently, there is no specialised or outreach treatment for people with severe and very severe ME/CFS within the public secondary or healthcare system, or in the professional nursing system. Only a few private physicians and local donation-funded initiatives treat those with severe and very severe ME/CFS, including via telemedicine; unfortunately, these are also severely overburdened by the high number of patients and complex needs of the disease.

Against this backdrop, this qualitative study seeks to shed light on the severely and very severely affected ME/CFS patient population. As part of the broader multi-perspective, qualitative research project “Adult patients with severe and very severe ME/CFS in Austria. A multi-perspective study.”, we aim in this article to explore the healthcare experiences, unmet healthcare needs, and barriers to

healthcare access of people with severe and very severe ME/CFS and their family/lay caregivers within the Austrian healthcare system. Beyond the Austrian context, examining healthcare access in this particularly underserved population may offer insights relevant to other conditions or healthcare systems seeking to overcome barriers to care for people with profound functional limitations. Finally, by identifying barriers that contribute to healthcare inaccessibility, we aim to inform future service development for this underserved population and their supporting networks.

Methods

Study design and setting

Employing an exploratory qualitative approach, the project was conducted between January 2025 and March 2026. The study included interviews and focus groups with people with severe and very severe ME/CFS, their family/lay caregivers, and healthcare professionals. The qualitative design allowed data collection procedures to be flexibly adapted to the profound functional limitations of people with severe and very severe ME/CFS. The project followed a participatory approach in close collaboration with the Austrian patient organisation Austrian Society for ME/CFS (ÖG ME/CFS). Two members of this society with lived experience of ME/CFS and one family caregiver were regularly involved throughout the research process, contributing to methodological decisions, development of the interview guides, data analysis, and scientific writing. The study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist[34], found in the supplement 1 (S1).

Participants and eligibility criteria

Three participant groups were included to capture multiple perspectives: people with severe and very severe ME/CFS, caregivers, and healthcare professionals. For all three groups, eligible participants had to be aged ≥18 years, residing in Austria, and fluent in German or English at the time of data collection. All participants were required to provide information on their age, sex/gender, and place of residence and to provide written informed consent. In addition, group-specific eligibility criteria applied:

People with ME/CFS (group 1) were eligible if they had a formal diagnosis of ME/CFS by a physician. Eligibility assessment included completion of the FUNCAP27 (FC27) questionnaire[35], supplemented by three additional items from the FUNCAP55 (FC55) questionnaire[35], and the Munich-Berlin Symptom Questionnaire (MBSQ), which incorporates the Canadian Consensus Criteria. The additional FC55 items were: “Brushing your teeth without assistance” from the personal hygiene/basic functions domain; “Making a simple cold meal, such as a sandwich or cereal” from the activities at home domain; and “Speaking a few words” from the communication domain. A FC27 score ≤2.5 was required for classification as severe ME/CFS and a score ≤1.0 for classification as very severe ME/CFS.

Caregivers (group 2) were eligible if the person they substantially cared for was aged ≥18 years at the time of data collection and had a formal diagnosis of ME/CFS. In addition, they were required to provide information on the person with severe and very severe ME/CFS they cared for, including completion of the FC27 questionnaire, supplemented by the three additional FC55 items described above, and the MBSQ. The same FC27 thresholds were applied to classify the severity of ME/CFS in the person cared for.

Healthcare professionals (group 3) were eligible given written confirmation of professional experience in caring for people with severe and very severe ME/CFS. Eligible professionals were from the fields of medicine, nursing, and allied health professions.

Sampling and recruitment

For groups 1 and 2, recruitment was conducted through public calls on social media platforms disseminated through the networks of the organisations ÖG ME/CFS and the Association of Family Caregivers (IG-Pflege) as well as through private self-help groups, purposive sampling, and snowballing. For group 3, potentially eligible healthcare professionals were approached through the research team's professional networks, including networks of team members with expertise in the care of people with ME/CFS, and through public calls on social media.

Due to the high response rate in groups 1 and 2, participant selection was subsequently conducted by the research team. The selection aimed to achieve a gender distribution of approximately 3:1 women to men, in line with the gender distribution reported in the scientific literature[1,8], while also aiming for geographical representation across Austria and the inclusion of people with very severe ME/CFS. A target sample size of 8–12 participants per group was predefined in the study protocol, considering anticipated data saturation and the challenges associated with recruiting and including people with severe and very severe ME/CFS.

For group 3, the recruitment strategy initially aimed to include six to 12 physicians and five to eight nursing professionals, in accordance with the study protocol, anticipated data saturation, and feasibility considerations. The group was ultimately expanded to include a further four to eight healthcare professionals from relevant therapeutic fields, including dietetics, occupational therapy, physiotherapy, psychology, and psychotherapy.

Data collection

For participants in groups 1 and 2, a combination of narrative and semi-structured interviews[36] were used. Semi-structured questions addressed five specific topics in group 1: "Introduction and Personal Narrative" (including life before severe and very severe ME/CFS, the course of illness to date, individual perceptions of severe and very severe ME/CFS, and a typical day); "Symptom Management" (including emergency situations); "Professional Care Experiences"; "Interactions with Professionals and Family Caregivers"; "Improvements in Nursing and Care" (including ideas for improving care); followed by an open section (see interview guides in Supplement 2). For group 2, six topics were asked: "Introduction and Personal Narrative"; "Medical and Nursing Care at Home"; "Challenges and Gaps in Care"; "Symptom Management and Prevention of Exacerbations"; "Support for Family Caregivers", "Need for Training and Information"; followed by an open section (see interview guides in Supplement 2).

To ensure that interviews were accessible to people with severe and very severe ME/CFS, data collection was flexibly adapted to participants' individual needs. For participants with very severe ME/CFS, the interview guide could be reduced to three brief questions. Participants could choose between interviewer-led interviews (online or, for participants based in Vienna, in person), audio self-recordings based on a previously provided interview guide, or a combination of both. This resulted in an individualised approach for each participant, ranging from interviewer-led interviews conducted across several sessions to self-recorded interviews completed in segments over several months, or a combination of both. Interviews could be paused or stopped at any time and continued on another day. For one very severely affected participant with a FC27 score of 0.0, the interview was conducted by proxy through a family caregiver, communicating via single words and non-verbal cues. A second planned proxy interview involving a person with a FC27 score of 0.0 was discontinued by mutual agreement to avoid jeopardising the participant's health. Interviewer-led sessions lasted an average of 31 minutes (in the range of 21–50 minutes) per part and, where required, were conducted in up to four separate parts, with appointments ranging from twice weekly to once weekly. Three participants – two severely and one very severely affected – chose audio self-

recording, resulting in five to ten separate recordings per participant, with individual recordings' mean duration of 19 minutes (ranging from two to 58 minutes). The longest self-recorded interview extended over a period of three months. Due to health concerns, one severely affected participant switched to audio self-recording after completing one online interview. One very severely affected participant opted to conduct the interview across three separate appointments at their home in Vienna. In total, more than 17 hours of interview recordings were collected for group 1.

Appointments with caregivers (group2) were predominantly conducted online; one interview took place at the Medical University of Vienna (MUV) and two took place at the participants' home in Vienna or in a geographically close area. The interviews lasted an average of 95 minutes (in the range of 53 to 144 minutes), totalling more than 19 hours of recorded data for group 2.

For group 3, data collection was preferably conducted in focus groups, aiming to facilitate dynamic discussions and primarily to identify shared challenges, innovative practices, and specific care needs that might not emerge in individual interviews. Focus groups comprised a maximum of four participants per appointment and were divided into three subgroups: physicians, nursing professionals, and allied health professionals. Where healthcare professionals were unable to attend a focus group, individual interviews were conducted. Based on the interview guides for groups 1 and 2, healthcare professionals were asked about their professional experiences in caring for people with severe and very severe ME/CFS, including their perception of disease severity, professional care provided at home, their situation, challenges and (urgent) needs in their professional role, gaps in healthcare, symptom management and prevention of worsening, experiences with healthcare cooperation, and an open section (see interview guides in Supplement 2). Focus groups lasted, on average 104 minutes (in the range of 78-125 minutes) and individual interviews 54 minutes (in the range of 48-59 minutes), totalling more than 14 hours of audio recordings.

All online interviews and focus groups were recorded via WebEx using the MUV's data-protection-compliant WebEx access to enable participation regardless of place of residence. Interviews conducted at participants' homes, at the MUV, or by telephone were audio-recorded using an audio recording device. Participants who opted for audio self-recording already had suitable recording devices, for example due to their professional background, and were provided with individual password-protected data storage via the MUV's ownCloud account to upload their recordings.

After each interview, the respective interviewer (all employees at MUV in the related project) prepared an interview diary, partly incorporating field notes. Following the interviews and focus groups, all recordings were transcribed verbatim and pseudonymised by members of the research team using the transcription software Tucan.ai and Amberscript. In cases of acoustic ambiguity or unclear passages, the respective transcript passages were double-checked against the audio recording by another member of the research team. In addition, transcripts were periodically cross-checked by a second team member to ensure transcription accuracy.

Data analysis

All verbatim interview and focus group transcripts were imported into ATLAS.ti for thematic analysis following the approach described by Braun and Clarke[37,38]. The analysis combined inductive and deductive approaches: key themes and patterns were initially identified inductively from the data, while deductive analysis was guided by literature and the research objectives.

Three researchers (VH, SW, ACM) were involved in coding the interview and focus group data. The codebook was applied across the dataset while remaining open to the addition of new codes where existing codes did not adequately capture relevant content. Groups of related codes were then

allocated among team members for further analysis, with findings subsequently discussed and integrated across the research team.

Preliminary findings were presented to study participants in two online webinars in December 2025, one adapted to the extent possible to the functional capacities of participants with severe (and very severe) ME/CFS (approximately 20 minutes with a limited number of slides) and one for family/lay caregivers (approximately 60 minutes). Following the presentation, participants were invited to comment on the preliminary findings and provide feedback on whether these reflected their experiences.

Ethical considerations

The Ethics Committee of the MUV approved the study (EK No. 1614/2024). The overarching project was conducted in accordance with the Declaration of Helsinki (1964). All participants provided written informed consent. Where a person with severe and very severe ME/CFS had granted a healthcare proxy (Vorsorgevollmacht), informed consent could be provided by the authorised caregiver on their behalf.

Participants in groups 1 and 2 received a €10 voucher as compensation for their participation.

Given the often challenging and emotionally demanding nature of the interview situations and resulting data, members of the research team regularly exchanged experiences and reflections throughout the study. These discussions, complemented by two supervised sessions led by a psychologist, supported researcher well-being and ongoing reflexivity regarding the research process.

Results

Description of the participants

Group 1 consisted of 12 people with severe (9) and very severe (3) ME/CFS. Participant characteristics are shown in Table 1.

Number of participants	12
Sex/Gender, female:male	10:2
Mean age, years (total range)	40 (22-58)
Number of severely affected	9
Number of very severely affected	3
Mean FC27 score of severely affected (total range)	1.7 (1.2-2.3)
Mean FC27 score of very severely affected (total range)	0.6 (0.0-0.9)

Table 1: Characteristics of participants with severe and very severe ME/CFS.

Group 2 comprised 12 family/lay caregivers for people with severe and very severe ME/CFS. Their demographic characteristics and the disease severity of the persons they cared for are shown in Table 2.

Number of participants	12
Sex/Gender, female:male	7:5
Mean age, years (total range)	55 (31-80)
Number of caregivers with severely affected care recipients	4
Number of caregivers with very severely affected care recipients	8

Mean FC27 score of severely affected care recipients (total range)	1.6 (1.1-2.3)
Mean FC27 score of very severely affected care recipients (total range)	0.4 (0.0-0.9)

Table 2: Characteristics of caregivers and the severity of ME/CFS in the person they cared for.

Four participants in each of Groups 1 and 2 (one third of each group) formed four care recipient–caregiver pairs.

In group 3, a total of 22 healthcare professionals who had experience working with people with severe and very severe ME/CFS took part in the focus groups or interviews. These included eight physicians from the fields of dentistry, anesthesia, pediatrics, internal medicine, psychiatry, general medicine, palliative medicine, or laboratory medicine. Six registered nurses (Diplomierte Gesundheits- und Krankenpflege, DGKP) and one nursing assistant (Pflegefachassistenz, PFA) were interviewed, five of whom provide care for severely and very severely affected ME/CFS patients and two of whom work as case managers. The seven interviewees practicing from allied health professions represented the disciplines of psychology/psychotherapy, occupational therapy, physiotherapy, and dietology.

Interview and focus groups results

Regarding experiences, unmet needs, and barriers within the Austrian healthcare system, the analysis of the transcripts from all three participating groups revealed five dominant themes that are interrelated:

Knowledge gaps regarding ME/CFS and their consequences. Across all participant groups, gaps in knowledge about ME/CFS were described as a major barrier throughout the healthcare pathway. People with severe and very severe ME/CFS and their caregivers reported extensive efforts to acquire disease-specific knowledge independently through the internet, patient forums, and personal networks, and subsequently bring this knowledge to healthcare professionals, as relevant information and expertise were often perceived as insufficiently available within the healthcare system:

"We had to learn everything ourselves, work it out for ourselves, and search for answers on the internet and in forums. (..) No one could help us."
Person with severe ME/CFS_12

This knowledge gap was mentioned as contributing to prolonged and patient-driven diagnostic pathways. Repeated consultations and diagnostic detours, including recommendations for psychotherapy and physical exercise before ME/CFS was recognised, were reported:

"Just like so many others. So, she went from pillar to post – the typical medical odyssey that everyone's familiar with anyway. Everyone told her she should go to psychotherapy and, of course, do exercise, which she then did. Naturally, it only made everything worse."
Caregiver_6

Participants described regularly having to identify their symptoms of ME/CFS themselves and then seek out the few healthcare professionals whom they perceived as having relevant expertise. Access to whom depended on financial resources and, given limited capacity and high demand, sometimes on luck.

For people with severe and very severe ME/CFS and their caregivers, repeatedly acquiring and communicating disease-specific knowledge despite limited energy and resources constituted an additional burden. The ability to acquire and communicate such knowledge thus became a prerequisite for navigating healthcare.

Across participant groups, physical activation, exercise, and graded increases in activity without adequate consideration of PEM were described as inappropriate and, in some cases, associated with substantial deterioration. People with severe and very severe ME/CFS and caregivers consequently described having to assess, modify, or resist professional recommendations themselves, shifting responsibility for protection against potentially harmful care onto people affected and caregivers. Negative healthcare experiences also contributed to the avoidance of healthcare services, further limiting some participants' engagement with healthcare:

"But at that point, I was so traumatized by medical interactions that I was really reluctant to see a doctor."
Person with very severe ME/CFS_2

Alongside these knowledge gaps, people with severe and very severe ME/CFS and caregivers described experiences of mistrust, disbelief and medical gaslighting, a colloquial term describing the dismissal or minimization of patients' symptoms and concerns by healthcare professionals. Their accounts included dismissal or minimisation of symptoms, psychologisation of somatic symptoms, and questioning or rejection of the ME/CFS diagnosis altogether. Participants described being perceived as unwilling, lazy, or responsible for their own illness, and reported that their accounts of symptoms and limitations were sometimes disregarded even when supported by medical documentation. Attempts by patients or caregivers to communicate disease-specific information were also described as being dismissed or ridiculed. These experiences extended beyond encounters with individual healthcare professionals and, in some cases, affected access to medical procedures, sick leave, or appropriate consideration of documented comorbidities and risks. One participant with very severe ME/CFS, who had previously worked as a healthcare professional, described experiencing disbelief and devaluation within the healthcare system despite their professional background, as well as encountering resistance when attempting to obtain appropriate, needs-adapted care.

Another participant described contrasting experiences across healthcare encounters:

"How is it that one person takes you seriously and simply does their job competently, without feeling personally offended by my underlying condition in any way? And the other one questions everything, just because she doesn't like seeing that diagnosis on paper."
Person with severe ME/CFS_6

Healthcare professionals likewise described lack of education regarding ME/CFS in their studies and the need to develop expertise through self-directed learning. This often involved research outside working hours, adding to their professional workload. One professional stated: "That means you have to work it all out yourself." Informal professional networks were described as an important means of compensating for these gaps. At the same time, healthcare professionals reported that limited ME/CFS knowledge remained widespread across healthcare settings and professional groups.

Overall, knowledge gaps about ME/CFS affected all participant groups, placing substantial responsibility for acquiring and communicating disease-specific knowledge on people with severe and very severe ME/CFS, caregivers, and individual healthcare professionals, while contributing to inappropriate care, mistrust, and disengagement from healthcare.

Inaccessible healthcare: Home- and bed-boundedness and limited transportability. Being home- or bed-bound and having limited or no capacity to travel substantially restricted access to healthcare. Across all participant groups, transport was described as often unfeasible or requiring extensive preparation, while some people with very severe ME/CFS were considered unable to tolerate transport at all. Necessary journeys could require transport in a supine position, sedation, sensory protection, and support from their caregivers and healthcare professionals and were, in some cases, associated

with subsequent further deterioration. Attending appointments could require substantial preparation and rest beforehand as well as prolonged recovery afterwards.

Even when transport was possible, the ability of people with severe and very severe ME/CFS to access healthcare depended on whether they could tolerate the entire process of receiving care. Long waiting times, prolonged appointments, upright positioning, movement within healthcare facilities, repeated communication and examinations, and exposure to light, noise, and other sensory stimuli were described as additional sources of exertion. Participants described considerable variation between healthcare settings, with one participant contrasting being immediately provided with a quiet place to lie down in one setting with having to remain seated for hours in a bright and highly stimulating environment in another. Another participant attributed a permanent deterioration to an outpatient procedure that involved a three-hour waiting period:

"But this biopsy permanently worsened my condition. Since this biopsy. I was very severe afterwards. I had to wait there for three hours in the outpatient clinic. It really wasn't manageable."
Person with very severe ME/CFS_3

Even extensive adaptations did not necessarily make healthcare safely accessible. Participants described deterioration following appointments despite measures such as transport in a supine position, opportunities to rest, or minimised waiting times. One participant with severe ME/CFS reported that an appointment outside their home, despite transport in a supine position and almost no waiting time, was followed by a permanent deterioration after which they were no longer able to leave their living area. In another case, a caregiver described several weeks of PEM following a cardiology appointment despite extensive preparation, rest, and the possibility to lie down during the appointment; the person was subsequently no longer able to leave their room.

The difficulties associated with reaching and tolerating healthcare also affected responses to acute health problems and potential emergencies. People with severe and very severe ME/CFS, caregivers, and healthcare professionals described situations in which hospital care was avoided or considered only when circumstances became critical because transport and hospital attendance were expected to cause substantial deterioration. A caregiver described the resulting concern about potential emergencies:

"But there was actually this sense of panic. What would we do if she had to go to hospital? And that's not a nice feeling, because everyone knows that's not an option. Yes, you can't take her to hospital for just any reason. Only in an absolute emergency. Her condition would get so much worse."
Caregiver_4

Participants therefore described difficult decisions about whether an acute health problem justified the risks associated with ambulance transport and hospital care. One participant described this dilemma:

"When there's an allergic reaction or something like that, [...] I have to weigh whether I might experience severe deterioration due to the emergency situation, or severe permanent deterioration from the ambulance transport and hospital stay. Those are extremely difficult decisions that one normally shouldn't have to make."
Person with severe ME/CFS_5

Thus, home- and bed-boundedness and limited transportability could make accessing healthcare itself a health risk. Inaccessibility extended beyond the ability to physically reach healthcare facilities to the

ability to tolerate the conditions under which care was provided, leaving participants to weigh the need for medical care against the potential for deterioration associated with accessing it.

Systemic healthcare failures affecting people with severe and very severe ME/CFS. Across participant groups, existing healthcare structures were predominantly described as lacking adaption to the situation of people with severe and very severe ME/CFS. Although participants also reported individual examples of appropriate and highly valued care, these were described as exceptions, often depending on individual healthcare professionals who were willing and able to adapt usual routines. Difficulties were reported across all levels of the healthcare system – primary, specialist, inpatient, outpatient, nursing, and allied healthcare. They also extended beyond ME/CFS-specific treatment to the insufficient management of other health problems and routine healthcare needs, including dental and gynaecological care. As one caregiver described:

"There aren't really any routine check-ups anymore, as it were. Yes, well. What else? Well, if there are things like that which are just incredibly worrying, then we'll just have to wait and see."
Caregiver_10

Primary care was described as particularly important because general practitioners (GPs) could provide referrals and prescriptions, coordinate specialist recommendations, support administrative procedures, and offer home visits in some federal states. However, access to and quality of these services varied considerably. Some participants described supportive GPs who acknowledged their own knowledge gaps, cooperated with specialists, and adapted care (e.g. low-stimulus care), whereas others reported difficulties obtaining home visits, telemedical consultations, prescriptions, referrals, or implementation of specialist recommendations. In some cases, healthcare professionals or services declined further involvement because the required care was perceived as too complex and time-consuming. One participant with very severe ME/CFS described their GP practice withdrawing from their care:

"The [GP practice] actually terminated our treatment contract. It was simply too complicated for them."
Person with very severe ME/CFS_3

Similar structural barriers were described in hospital and emergency care. In some cases, participants reported that hospitals were unable to accommodate the needs of people with severe and very severe ME/CFS. One caregiver described a situation in which hospital admission was declined because appropriate facilities were reportedly unavailable:

"The ambulance crew then spent I don't know how long on the phone with the hospital and the doctors and so on, and they said they couldn't take her because they didn't have the facilities for people like that."
Caregiver_5

A physician confirmed the lack of applicable treatment options in hospital as follows:

"It's not just the transport itself, but we've gone through the whole scenario: the A&E department, waiting in A&E. If you tell someone 'ME/CFS', I can ring whoever I want. I don't have those options in hospital; it's just not going to happen. So it's simply not possible."

Healthcare professional, medicine

The limitations of routine healthcare services became particularly apparent when complex or acute medical treatment was unavoidable. Participants described situations in which ME/CFS-specific information and individual precautions were communicated in advance but were not consistently implemented or transferred between healthcare professionals. In case of an acute appendectomy, one

participant reported that neither ME/CFS nor the relevant comorbidity, mast cell activation syndrome, was familiar to the anaesthesia team. Although specialist information and direct access to treating experts were provided, recommended precautions were reportedly not taken as planned, and the participant subsequently experienced severe complications:

"It was very, very stressful in the hospital because the anaesthesia team knew neither ME/CFS nor mast cell activation syndrome [...]. [A specialist] wrote us a medical report and [another specialist] would have been available by telephone. However, the hospital did not want to know or hear about it. [...] It was initially promised that they would follow [the recommendations in the medical report, but before the operation I found out that no preparatory measures [...] had been taken."
Person with severe ME/CFS_6

Rehabilitation was another healthcare setting in which participants described standard treatment approaches as insufficiently adapted to ME/CFS. People with severe and very severe ME/CFS and caregivers regularly reported health deterioration following rehabilitation interventions, particularly those involving physical activation or exercise. For some, this deterioration was substantial, as illustrated by this participant's experience:
"So since then I've needed a wheelchair as well. I went in walking, just like everyone else does, and came out in a wheelchair."
Person with very severe ME/CFS_3

Healthcare professionals described comparable difficulties arising from within the healthcare system. Established professional routines and skills often did not translate to the care of people with severe and very severe ME/CFS, requiring highly individualised approaches and leaving some professionals uncertain about how to provide care without exacerbating symptoms. This was particularly apparent in professional nursing, where routine positioning, personal care, communication, and activation could conflict with limited tolerance of exertion and sensory stimuli of people with severe and very severe ME/CFS. A nursing professional described this discrepancy as follows:

"Everything I learned during my training – in positioning, assistance, even ergonomic working – I could completely forget."
Healthcare professional, nursing

Routine healthcare settings were similarly described as insufficiently equipped to accommodate people with severe and very severe ME/CFS. Dental care was one example: while regular examinations generally required attendance at a dental practice, home-based dental care was described as exceptional and constrained by equipment and established professional routines. A healthcare professional highlighted how people with severe and very severe ME/CFS consequently remained largely outside ordinary dental practice:

"I think that in my field this whole illness is an enormous blind spot, because people who are severely affected simply do not come. A regular dentist never sees them."
Healthcare professional, medicine

Participants also described a lack of continuity and comprehensive services across sectors. Specialist services were frequently reported as operating at capacity, while home-based and telemedical care remained inconsistently available. Although telemedicine enabled some participants to access healthcare without leaving home and allowed healthcare professionals to assess acute problems remotely, these options were described as depending on individual providers rather than being routinely embedded within healthcare structures. Overall, participants reported a substantial lack of

comprehensive care structures across Austria, with service provision relying largely on individual or local initiatives rather than a coordinated nationwide approach.

Family and other caregivers compensating for systemic gaps in healthcare. Across all three participant groups, caregivers emerged as central actors in maintaining healthcare when professional services were unavailable, inaccessible, or insufficiently adapted to people with severe and very severe ME/CFS. Beyond assistance with daily activities, they organised and administered medications, monitored health parameters, coordinated care, and communicated with healthcare professionals, frequently becoming the primary interface with the healthcare system.

Caregivers often had to acquire disease-specific medical and nursing knowledge themselves, with little professional guidance on managing severe symptoms, medication, or changing care needs:

"Of course, it's a huge challenge for family members to cope with that situation. You end up having to take on the nursing and medical care, so to speak, even though you don't really know how."
Caregiver_11

Their responsibility increased during phases of deteriorating health and could extend into potentially life-threatening situations. One family described having to manage a rapid transition to complete care dependency "without any help". When profound weakness subsequently made chewing and swallowing increasingly exhausting, they felt compelled to consider artificial nutrition but reported that the required hospital-based intervention was not possible:

"In the end, thankfully, we managed without it […] but we were at the point where we would have needed it. But it was clear that there was no healthcare facility where this could be provided. […] It simply wasn't available."
Caregiver_1

Other caregivers described difficulties obtaining professional support for acute medical problems, including severe breathing difficulties and persistent infections, leading one caregiver to summarise: "We are afraid of an emergency!" Healthcare professionals confirmed this dilemma. In one case, scenarios such as myocardial infarction or fracture had been discussed with a caregiver because emergency transport was considered incompatible with the condition of the person with very severe ME/CFS:

"Basically, what we agreed on is that we all hope it never comes to that […] that an acute situation occurs."
Healthcare professional, medicine

In this case, if transport and hospital care remained inaccessible, symptom-oriented care at home was described as the only feasible option, potentially including end-of-life care. Caregivers thus carried responsibility for recognising and responding to health deterioration with limited professional backup, while also organising services, communicating on behalf of the affected person, and advocating for necessary interventions:

"I'd like to be able to hand over this responsibility, because I'm bearing it all on my own. All on my own."
Caregiver_7

These responsibilities were accompanied by uncertainty, limited capacity to attend to their own health needs, difficulties combining caregiving with paid employment, and social isolation.

Overall, gaps in accessible and appropriate healthcare shifted substantial responsibilities onto caregivers, who frequently became responsible for maintaining care even during acute and potentially life-threatening situations.

The main, closely interconnected, factors contributing to inadequate or inaccessible healthcare, as identified across the three participant groups, are summarised in Table 3.

Main factor	**Identified key aspects**
Knowledge gaps regarding ME/CFS	Limited professional knowledge; inappropriate interventions; disbelief and dismissal of symptoms
Inaccessible healthcare	Home- and bed-boundedness; limited transportability; inability to tolerate conventional healthcare settings
Insufficiently adapted healthcare structures	Inadequate routine, specialist, rehabilitation, hospital and emergency care; limited flexibility and continuity
Family/Lay caregivers compensating for systemic gaps	Assumption of coordinative, nursing and medical responsibilities; limited or absent professional support

Table 3: Factors contributing to inaccessible or inadequate healthcare for people with severe and very severe ME/CFS.

Envisioning better healthcare for severe and very severe ME/CFS: suggestions by the participants. Across all three participant groups, suggestions for improving healthcare centred on the need for specialised services that could accommodate the profound and fluctuating limitations associated with severe and very severe ME/CFS. A prominent request among people with severe and very severe ME/CFS and caregivers was for healthcare to be available at home. Participants called for home visits not only from GPs but also from medical specialists and allied healthcare professionals, as well as for mobile nursing and diagnostic services such as blood draws. This extended beyond ME/CFS-specific treatment to routine and preventive healthcare, including dental and gynaecological care. Telemedicine was considered an important complementary approach, particularly when leaving the home was not feasible. Healthcare professionals similarly advocated outreach models involving medical, nursing, and allied healthcare professionals, with some proposing multidisciplinary mobile teams or hospital-at-home approaches.

Participants also called for specialised structures that could coordinate care across disciplines and healthcare settings. People with severe and very severe ME/CFS and caregivers proposed central points of contact with ME/CFS expertise that could maintain an overview of individual healthcare needs, coordinate diagnostics and treatment, and facilitate access to appropriate specialists. Healthcare professionals similarly emphasised multidisciplinary care and proposed case management to help prioritise healthcare needs when numerous symptoms and specialties were involved:

"Which symptoms are affected, which specialisations are needed? What is the order of priority? I think case managers are often needed to say, okay, there are 18 symptoms now, but this and this need to be addressed first."
Healthcare professional, medicine

Rather than being limited to outpatient services, participants envisaged specialised structures that could connect home-based, outpatient, and inpatient care. Healthcare professionals proposed regional specialised outpatient services that could also provide expertise to healthcare professionals outside specialist centres, while participants across all groups described a need for specialised inpatient options when hospitalisation was required. Suggested adaptations included small or dedicated units with single rooms, reduced light and noise, individualised medical and nursing care, dietary options adapted to individual needs, and adequate staffing. As one caregiver described:

"There should really be a ward specifically for people with [ME/CFS], with doctors and nurses who know what they need, where they can really have quiet, and with staff who are trained in this disease."
Caregiver_5

Across these different settings, flexibility and adaptation to the individual capacity and fluctuating health status of people with severe and very severe ME/CFS emerged as an overarching requirement. Participants called for minimised waiting times, flexible appointments that could be cancelled or rescheduled at short notice, low-stimulation healthcare environments, and care adapted to individual functional and sensory limitations. This need for flexibility was particularly evident in discussions of professional nursing care. The amount and timing of assistance required varied considerably between individuals and according to fluctuations in health status, making services based on fixed schedules difficult to use. This included personal hygiene and food and fluid administration, including intravenous fluids, which often required prolonged periods with intermittent breaks and had to be accommodated during night time hours due to disrupted sleep–wake cycles. Participants additionally emphasised ME/CFS-specific nursing practices, including infection precautions and minimising conversation and other sensory stimulation. As one participant with very severe ME/CFS summarised:

"The care that's given has to be as flexible and dynamic as this disease is."
Person with very severe ME/CFS_2

Finally, improvements in disease-specific knowledge among healthcare professionals were considered fundamental to making these models of care feasible and safe. Participants called for education and continuing professional training across medical, nursing, allied healthcare, emergency, and hospital services. Adequately funded research was also considered necessary to improve diagnosis and treatment. People with severe and very severe ME/CFS and caregivers particularly emphasised the need for professionals to understand disease-specific management, including medication, to believe and take them seriously, and to engage with them respectfully. Healthcare professionals likewise called for training across professions and settings, alongside greater interprofessional exchange and networking to share expertise.

Taken together, suggestions across all participant groups reflected a need for healthcare structures that could adapt to the individual and fluctuating capacities of people with severe and very severe ME/CFS, recognising that their profound functional limitations render existing models of care largely inaccessible. The key suggestions for improving healthcare are summarised in Table 4.

Main area	**Suggested improvements**
Home-based and outreach healthcare	Home visits; mobile diagnostic services; mobile healthcare provision by medical, nursing, and allied health professionals; telemedicine
Specialised and coordinated care structures	Multidisciplinary services; case management; coordination between home-based, outpatient and inpatient care
Flexible and individually adapted care	Flexible appointments; low-stimulation environments; adaptation to functional and sensory limitations
Improved disease specific knowledge	Professional education and training across healthcare disciplines and settings

Table 4: Suggested improvements in healthcare for people with severe and very severe ME/CFS

Discussion

Our findings demonstrate profound unmet medical and nursing needs as well as interrelated barriers to healthcare for people with severe and very severe ME/CFS and their family/lay caregivers in Austria. Across the gathered perspectives, limited or inaccurate knowledge about the disease among healthcare workers, restricted transportability, and healthcare structures being insufficiently adapted to severe functional and sensory limitations markedly compromised access to appropriate and safe care. These barriers extended beyond ME/CFS-specific care to routine and acute healthcare, and were repeatedly associated with healthcare avoidance. Family/Lay caregivers frequently compensated for these systemic gaps by assuming extensive coordinative, nursing, and medical responsibilities. Overall, these findings stand in marked contrast to established elements of quality healthcare[39,40], including effectiveness, safety, people-centredness, timeliness, equity, integration, and efficiency, pointing to fundamental shortcomings in both the accessibility and quality of healthcare for people with severe and very severe ME/CFS in Austria.

Furthermore, poor-quality healthcare generally can contribute to preventable morbidity and impose additional costs on individuals, healthcare systems, and societies[39,41]. In our study, several participants described substantial and often persistent deterioration following healthcare interventions that were insufficiently adapted to ME/CFS[17], with some participants reporting a subsequent progression from mild or moderate to severe disease. Previous studies have shown that particularly rehabilitation approaches involving activation or exertion beyond individual limits are inappropriate for people with ME/CFS[42,43]. In one striking case, a participant reported entering a rehabilitation setting able to walk but leaving dependent on a wheelchair following severe functional decline. Healthcare that is not adapted to the characteristics of ME/CFS, particularly its hallmark feature PEM and individual exertion limits, may itself become a source of additional health burden, consistent with previous research[43–45]. Notably, recent findings from Germany showed reduced functional status in 45% of participants following an ME/CFS-adapted inpatient rehabilitation programme[46], underscoring the need for careful implementation and evaluation of healthcare interventions for ME/CFS. This is supported by findings from a Norwegian specialised care service for severely and very severely ill ME/CFS patients. 25% improved probably because the health care professionals prioritised to prevent PEM in these severely affected ME/CFS patients[19].

Knowledge gaps about ME/CFS appear to have consequences throughout the healthcare pathway, beginning with a delayed diagnosis – currently estimated at approximately five years in Austria[13] – and potentially to substantial underdiagnosis internationally[8,47]. A striking paradox is that people with severe and very severe ME/CFS and their family/lay caregivers often have to develop and communicate disease-specific expertise themselves, while their knowledge and credibility are simultaneously questioned or dismissed. This resonates with previous Norwegian studies about ME/CFS reporting insufficient professional knowledge, disbelief and lack of acknowledgement, impaired patient–provider relationships, and subsequent healthcare avoidance[17,48]. Psychologisation and stigma may reinforce these dynamics[49], as perceived psychological and controllability-related attributions have been associated with poorer health and social outcomes[50]. Notably, healthcare professionals in our study themselves acknowledged gaps in formal ME/CFS education and the need for self-directed learning. Knowledge gaps may therefore contribute not only to delayed or inappropriate diagnosis and care, but also to erosion of trust and ultimately withdrawal from healthcare. Against this backdrop, previous research[51] has highlighted ME/CFS-specific education as important for addressing professional misunderstanding and fostering informed and compassionate care.

For people with severe and very severe ME/CFS, these barriers are compounded by a fundamental problem of functional healthcare inaccessibility. Formally available services may remain effectively inaccessible when their utilisation requires transport, prolonged upright positioning, waiting,

communication, or sensory exposure beyond individual tolerance. Similar barriers and extensive unmet care needs have been reported among people with severe and very severe ME/CFS in Norway[17]. Our findings further suggest a potentially self-reinforcing process of invisibility: those with the greatest functional limitations and healthcare needs may be least able to access conventional services and consequently remain largely unseen by the healthcare system. This is particularly concerning in Austria, given scarce specialised services and the limited availability of home-based and outreach care reported by participants. Similar structural invisibility has been described internationally and may extend to research, where conventional procedures can impede participation of those most severely affected[52,53].

The consequences of functional inaccessibility extend beyond affected individuals themselves, as family/lay caregivers frequently become the interface between people they care for and an otherwise difficult-to-access healthcare system. Their responsibilities go beyond conventional informal caregiving and include coordinating care, acquiring and communicating medical knowledge, monitoring symptoms, managing treatments, and, in some cases, responding to potentially critical situations. Caregivers thus function as an informal healthcare infrastructure, bridging gaps where formal healthcare structures do not adequately reach people with severe and very severe ME/CFS. Our findings therefore suggest a *de facto* transfer of healthcare responsibility from formal services to the private sphere of families and personal circles. This not only places substantial burden on caregivers but may also create inequities between those who can rely on family support and those who cannot.

The present study provides extensive multi-perspective qualitative insights into the experiences of people with severe and very severe ME/CFS, their family/lay caregivers, and healthcare professionals from different fields. Qualitative research methods tailored to the individual needs and capacities of this underrepresented patient group facilitated their participation and inclusion in research, representing a key strength of this study. The continuous involvement of people with lived experience further supported its relevance and appropriateness. However, several limitations should be considered. Despite substantial adaptations to facilitate participation, people at the most severe end of the disease spectrum remained difficult to include and may therefore be underrepresented. Recruitment through patient organisations, social media, self-help groups, and personal networks may also have introduced selection bias. Interview participants were predominantly highly educated, and eligibility required proficiency in German or English. Consequently, individuals facing additional linguistic, socioeconomic, or other barriers may be underrepresented. Access to healthcare professionals was challenging due to the limited availability of those with clinical experience in the field of ME/CFS, largely due to their extensive workloads. This was particularly evident in the case of nursing professionals, who were scarce due to the small number of individuals specialising in ME/CFS.

Our study demonstrates substantial and interrelated barriers to appropriate and safe healthcare for people with severe and very severe ME/CFS in Austria. Those with the greatest healthcare needs may be least able to access existing services, while family/lay caregivers frequently compensate extensively for resulting gaps in formal healthcare. Improving healthcare for this population requires services designed around patients' functional capacities and individual needs rather than relying solely on existing structures. Priorities include accessible home-based and outreach care, telemedicine, multidisciplinary coordination, adaptations of routine and emergency care to individual functional and sensory limitations, and ME/CFS-specific education across healthcare professions. Future research should evaluate the feasibility, safety, effectiveness, and implementation of adapted or new services, and further develop inclusive research approaches that enable meaningful participation of people with very severe ME/CFS, who remain particularly underrepresented in both healthcare and research.

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Author Contributions

K.H. and S.W. designed the study, and K.H., S.W. and V.H. conceptualized the research questions. S.W., V.H. and A.H. developed the interview guides. V.H., S.W. and A.C.M. conducted the interviews and focus groups, curated the transcripts and developed the coding framework. V.H., A.H., S.W., A.C.M. and L.M. analyzed the qualitative data. K.H. and A.H. provided methodological guidance and ethical oversight. K.H. secured funding and supervised the project. V.H. wrote the original draft of the manuscript. A.H., S.W., A.C.M., L.M., O.D.S., S.L.G. and K.H. critically revised the manuscript for important intellectual content. All authors reviewed and approved the final manuscript for submission.

Competing Interests Statement

The authors declare no competing interests.

Data Availability Statement

The interview and focus group transcripts generated and analysed during this study are not publicly available due to ethical and data protection restrictions aimed at safeguarding participant

confidentiality. Given the small and highly specific study population and the sensitive nature of the information collected, sharing individual-level data could pose a risk of participant re-identification, even after pseudonymisation. Illustrative and de-identified data excerpts (such as representative quotes) supporting the findings are provided within the article. Enquiries regarding data availability may be directed to the corresponding author and will be evaluated on a case-by-case basis, subject to applicable ethical and legal requirements.

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