Development and implementation of an online patient education programme for children and adolescents with ME/CFS, their parents, siblings, and school personnel: study protocol of the prospective BAYNET FOR MECFS study

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Abstract

Background: The condition of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) poses significant challenges to affected children and adolescents, their social environment, as well as treating physicians, due to the marked impact on quality of life and the absence of causal therapeutic approaches. An aspect of care that has been lacking for these patients involves comprehensive education for them and their social circles.

Objective: This study protocol aims to introduce the goals, study design, and execution and evaluation of the subproject within the BAYNET FOR MECFS project. In it, online patient education programmes are developed for children and adolescents with ME/CFS, their parents, siblings, and school staff in order to enhance independent disease management and knowledge as well as promoting the exchange with other affected individuals.

Methods: In phase I the group-based online education programmes were developed by a multidisciplinary team based on the ModuS concept created by the Competence Network for Patient Education (KomPaS), piloted and finalized. Phase II included the recruiting of participants and implementation of the finalized programs. Due to the restricted physical and cognitive capacity of the affected individuals, the patient education programmes were exclusively designed in a digital format to enable participation. In Phase III the programmes will be evaluated regarding the acceptance, completeness, and satisfaction of the participants. The qualitative assessment covers topics such as individual expectations and individual benefits from the training.In Phase IV the evaluation will investigate the programmes in terms of gain of disease knowledge, improvement in health related quality of live, life satisfaction and family burden.

Results: The programmes were developed, piloted and finalized in phase I lasting from December 2022 to May 2023 with the pilot programmes block lasting from March to May 2023, leading to an adaptation of the concept. The programmes were adjusted in terms of format, content, duration, and schedule to suit the needs of the affected individuals and their social circles. In Phase II, the recruitment of participants for the patient education programme occurred from January to July 2023. A total of two programme blocks for patients and parents and two to three blocks for siblings and school staff were started in May 2023 and were completed in 2023. In Phase III the evaluation started after Phase II and will be concluded by the end of 2024. Phase IV roll out of the program is planned in 2025-2026 (N=150 children and their caretakers) for evaluation of disease knowledge, hrQoL, life satisfaction, family burden including longitudinal evaluation.

Conclusions: The data is intended to contribute to the development of a comprehensive, interprofessional care model for children and adolescents with ME/CFS.

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Conclusion: The data is intended to contribute to the development of a comprehensive, interprofessional care model for children and adolescents with ME/CFS.

Keywords: Patient education; ME/CFS; children; adolescents; ModuS; parents; teachers; siblings; training

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Introduction

Background

ME/CFS is a severe chronic illness that entails significant life changes for those affected as well as their social environment [1, 2]. Estimates suggested that approximately 300,000 people in Germany are affected by ME/CFS, including up to 90,000 children and adolescents [3]. An increase in cases has been observed during the coronavirus disease 2019 (COVID-19) pandemic [4]. Given these numbers, ME/CFS is not a rare disorder [5]. Despite research efforts, the underlying pathophysiology of ME/CFS remains only partially understood [6]. Infections are often identified as the most common triggers [7]. The primary symptoms include profound fatigue that is not improved by rest and can lead to limitations in all areas of school, leisure, and social activities [8]. Another diagnostic criterion is post-exertional malaise (PEM), characterized by a decrease in functional level or exacerbation of symptoms after minimal physical, cognitive, or emotional effort, often described as a "crash." This often occurs with a time delay after exertion and can last from hours to months [8, 9]. Additionally, various forms of muscular pain, joint pain, and headaches, are described, along with sleep disturbances and orthostatic intolerances, which can manifest as postural orthostatic tachycardia syndrome (PoTS) [6, 8, 10, 11]. The disease significantly reduces health-related quality of life (HRQoL) [12]. This reduction is attributed not only to the symptoms themselves but also to their impact on school or occupational participation, resulting in reduced attendance or complete absence from school. Consequently, social isolation frequently occurs [13].

To address knowledge deficits and to empower individuals with ME/CFS to engage in self-management and disease control, the consensus of experts from the European Network on ME/CFS (EUROMENE), which defines diagnostic standards for adults, recommends patient education as part of the therapeutic measures [14]. Patient education programmes have become an integral part of therapy options for children and adolescents with various chronic diseases. The objective of these programmes is to promote the self-management of the individuals and their social environment. Several studies have demonstrated that patient education programs led to increased self-efficacy, disease competence, and satisfaction [15, 16], as well as improved HRQoL and a decrease in disease-specific burden [17]. Additionally, disease-specific symptoms decreased, and the risk of relapses or exacerbations was reduced [18, 19]. One already established and validated concept is the standardized modular training concept ModuS developed by the Competence Network for Patient Education (KompaS) with support from the Federal Ministry of Health [20]. ModuS is available for some less common and rare chronic illnesses for individuals [18, 20], as well as for siblings [21] and parents. The training concept consists of four generic modules and three disease-specific components [20]. The generic modules address psychosocial topics that can apply to all children and adolescents with chronic diseases. The disease-specific modules, on the other hand, provide more detailed information about the aetiology, course, and therapeutic measures for the respective condition. The structure of the ModuS training allows for adaptation to various chronic diseases [20]. Furthermore, these programs can be adjusted to the needs of other groups such as parents, teachers, and siblings [20, 21].

Goal of this study

Currently, there is no standardized education programme for children and adolescents with ME/CFS and their surroundings. Due to the significance of learning and implementing self-directed strategies in the treatment of ME/CFS, such as "pacing," the allocation of energy throughout the day, maintaining good sleep hygiene, and learning and using relaxation techniques, training programs are an essential aspect of care for these patients. The goal of these strategies is to avoid PEM and enhance HRQoL [14]. Moreover, knowledge about the disease is crucial for the comprehensive care of the immediate environment, including family members and school personnel. Therefore, the objective of the project was to develop, implement, and evaluate modular group education programmes for children and adolescents with ME/CFS, their parents, siblings, and teachers.

Nearly all children and adolescents with ME/CFS experience substantial limitations in their (school) activities and social interactions [6]. As a result, in-person group training sessions are not feasible for this patient group. Consequently, in this project, training sessions were developed based on the ModuS concept for digital implementation. Short online sessions offer these individuals the opportunity to participate, even if leaving the house or bed is not possible. This way, they can receive education and connect with other affected individuals. The elimination of travel to and from the programme venue is an additional advantage for this group. Since parents are limited in their time resources due to caring for the affected children and adolescents, handling the bureaucratic aspects associated with the illness, and siblings are also constrained in their time, online formats provide a viable option for participation in education programmes. In the professional realm, online continuing education has become increasingly offered and valued during the COVID-19 pandemic [22]. For school staff, online training is advantageous due to its accessibility and time efficiency.

In the presented study design, the development, implementation, and planned evaluation of the online training model for individuals up to the age of 20 years ME/CFS, their parents, siblings, and school staff are described as part of a new interprofessional care model.

Methods and Results

Study Design

The study is a prospective study without a control group and will be evaluated using qualitative and quantitative analyses. The objective of this study is to conceptualize, implement and evaluate online education programmes based on ModuS for adolescents with ME/CFS, their parents and siblings, as well as school staff. In phase I the online programmes were developed within a multidisciplinary team, piloted and revised. Phase II included the implementation of the finalized programmes. In Phase III the programmes will be evaluated with the primary objective being to investigate the acceptance of participants by assessing the frequency of attendance and responses to the question “Would you recommend the programme to others?” in the online education programmes. Additional objectives will include investigating participants' satisfaction with the programmes, and their rating of its completeness. This will be assessed using quantitative questionnaires. In further interviews with the individual groups participating in the programmes, the themes of individual expectations and benefits will be qualitatively analysed. In Phase IV disease knowledge gain, change in health related quality of life and satisfaction will be investigated within a larger cohort.

Development of the Training Program (Phase I)

Patient Training

In phase I of the education programme development, the needs of individuals with ME/CFS were identified (Figure 1). This was accomplished through consultation with ME/CFS experts and a literature search on the aetiology, symptoms, as well as pharmaceutical and conservative treatment options for ME/CFS in children and adolescents, conducted using relevant databases such as "pubmed," "MEDLINE," and "Cochrane Libraries." Additionally, input was gathered from patient organizations, which provided insights into the most common issues and challenges faced by the affected individuals. The relevant topics were discussed within an interprofessional team comprising members of ME/CFS patient organizations, ME/CFS experienced physicians, psychologists, physiotherapists, and occupational therapists. From these discussions, the content deemed relevant to the affected individuals was selected.

The foundational structure of the training was based on the modules of the ModuS concept [20], with a maximum duration of 45 minutes for training units, complemented by customizable pre- and post-programme materials, taking into consideration the reduced endurance of ME/CFS patients. The concept was pilot-tested in an initial programme block from March to May 2023. Following this, a re-evaluation of the concept was conducted in collaboration with participants, experts, and patient organizations. Based on this feedback, the education programme was revised by the team in terms of flow, time allocation, training materials, and the final version of the education program was developed.

Parent, Sibling, and School Staff Training

In addition to the online education programme for affected children and adolescents, a slightly modified programme concept was developed for parents training. The developmental process was identical to the training programme for adolescents and young adults described above including collaboration with the interdisciplinary team and patient organizations. An education programme specifically designed for minor siblings of affected individuals was also developed. This programme was conceptualized in consultation with individuals affected by the condition and experienced healthcare providers. Another target audience for an online education programme were teachers and school staff. As a significant part of the adolescents' environment, it seemed crucial to inform schools about the condition and collaboratively determine how to support affected individuals in the educational setting, enabling them to continue participating in education and school life. The development process was identical to the training programme for siblings.

After a piloting (March-May 2023) the programmes were re-evaluated, revised and optimized.

Recruitment and Implementation (Phase II)

Recruitment

Our specialized tertiary care center for young people with ME/CFS recruited participants up to 20 years for the online educational training after confirming the diagnosis during a short inpatient stay. Parents were recruited through the selected participants. Siblings and school personnel were informed about the training opportunities through patient organizations, a website, and the affected individuals themselves.

Implementation

Each training session was conducted by two professionals, with at least one of them having completed the patient trainer certification at the basic competence level according to KomPaS. This certification entails knowledge and skills in patient education, as well as didactic tools. A maximum of 14 participants per training block was allowed.

Evaluation (Phase III and IV)

Instruments

The selected measurement instruments comprise validated scores as well as self-developed questionnaires. Epidemiological data include gender, age, and type of school. Educational attainments are also inquired from parents and school staff.

The evaluation forms for the different training sessions are developed based on the training assessment forms for patients by Meng et al. [28] and adapted to the program. These forms include items for assessing the content of the entire education programme as well as specific sessions, the format of the programme, the group dynamic, and the practical usefulness in daily life investigating satisfaction and completeness of the education programmes. Response options are provided on an equivalent scale of 1 to 6, similar to a grading system. Additionally, two open-ended questions are included.

For the assessment of the perceived burden of the disease and health related quality of life, a questionnaire with selected ICF items [23] is completed by patients, the Short form-36 Health Survey (SF-36) [23, 24] and Bell score [25] is completed by patients and their parents and the Large Analysis and Review of European housing and health Status (LARES) [26] and Sibling Perception Questionnaire SPQ [27] is completed by siblings.

The selected ICF items cover domains such as learning, communication, mobility, self-care, household tasks, interpersonal relationships, school/work, and leisure, according to the International Classification of Functioning, Disability and Health (ICF) [23]. The selection of these items is achieved through interdisciplinary team consensus, considering a comprehensive representation of important aspects for the participants.

The SF-36 covers eight areas: physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, mental health, vitality, and social functioning [24].

The SPQ includes questions about interpersonal and intrapersonal difficulties as well as open communication with other caregivers about the disease. Responses are provided on a 4-point Likert scale (0=never, 4=always).

The LARES questionnaire is a screening tool for detecting distress in healthy siblings. It covers topics such as sibling relationships, social integration, family burden, school competence, and knowledge about the illness [26]. Response options are also provided on a 4-point Likert scale (0=never/not at all, 4=always/very strongly).

For Phase IV questionnaires will be adapted/shortened for the roll out.

Procedure

The evaluation will be conducted through quantitative analysis of questionnaires and qualitative analysis of interviews (Figure 2).

During recruitment, participants were invited to consent to receiving quantitative questionnaires. Participants with ME/CFS, who agreed to this, were surveyed at baseline before the start of the online education programme (T0) regarding their participation, HRQoL, and perceived burden using selected ICF participation goals, the SF-36 questionnaire, and the Bell score, to assess the feasibility of the used instruments for Phase IV. The same questionnaires are administered immediately after the training (T1) and again at 6 and 12 months post-training (T2, T3). Since participants have low energy levels, a total of four questionnaire blocks containing 10 questions are sent over two weeks starting at the end of the training (T1). Responses are recorded and sent using a mobile device and will be qualitatively analysed after transcription. Parents complete the SF-36 questionnaire at baseline (T0) and immediately after the training (T1) for external assessment. Additionally, at T1, they receive questionnaires related to training evaluation. School staff are surveyed at baseline (T0) for epidemiological data and receive a training evaluation questionnaire immediately after the training (T1). Siblings are surveyed at baseline (T0) for their epidemiological data and their knowledge about the ME/CFS condition. Their daily burden due to their sibling's chronic disease are also assessed using the LARES and SPQ questionnaires. Following the training (T1), questionnaires are sent to evaluate the training and assess their knowledge about the condition. Additionally, eight weeks after completing the training, the LARES and SPQ questionnaires are administered along with an assessment of the training's impact on their satisfaction.

For the further qualitative investigation of the training program, semi-structured interview guides were developed for school personnel, siblings, and parents within a multidisciplinary team and will be conducted after completion of the programmes. These interview guides aim to capture the impact of the education programme on participants, their individual expectations and individual benefits.

In Phase IV roll out of the program is planned for 150 children and their caretakers for evaluation of disease knowledge, health related quality of life, life satisfaction, family burden and longitudinal evaluation at T-1 (registration), T0 (before start), T1 (after completion), T2 (6 month after completion), T3 (12 month after completion).

Data Processing

The data platform RedCap is used for sending out questionnaires and storing data. A separate database was created for each survey, containing the corresponding questionnaires. If the training participants agreed to participate in the survey and provided their email, their information was entered into the databases. Questionnaires are sent as links in emails at the designated time points. Each study participant is assigned an ID and is linked to their corresponding email address in a separate document, stored in a way that only study staff with access to this file can trace back the identity. Linking will only occur for combining the SF-36 self-assessment and external assessment by the participants and their parents. All other questionnaires will be stored and analysed anonymously. In case of missing or incomplete questionnaire responses, participants will be sent reminder emails after one week. Audio files containing responses from participants to questionnaire sections can be uploaded and stored using the clinic's internal data exchange program "fex". Transcription backups will be stored exclusively on secure clinic's server. The analysis will be conducted solely using pseudonymized data.

Statistical Analysis

The study follows an exploratory approach. The goal will be to receive responses from 30 participants for the quantitative surveys, which, according to calculations, would provide sufficient statistical power to assess acceptability measured by the variable “Would you recommend the programme to others?” on a scale from 1-6 and dichotomized (1-2 = high acceptance, 3-6 = low acceptance). Based on the edukids study where staff was trained on diabetes [29], a comparable proportion of 87% with high acceptance is assumed. A sample size of 30 people is sufficient to estimate the proportion of individuals with high acceptance of the training at 87% with a precision of 12% (half the width of the 95% confidence interval according to the Wilson score). The quantitative questionnaire data will be analysed using SPSS software (Version 29.0.1.1). The questionnaires from different training programs will be analysed separately.

Epidemiological data of participants as well as satisfaction, usefulness, completeness of the modules, knowledge gain and acceptance in form of attendance rate in the different training programmes will be represented through descriptive analyses such as means and standard deviations. For categorical variables such as gender and severity of disease, results will be presented using relative and absolute frequency statements. Perceived burden of disease will be assessed through various specific questionnaires (SF36, Bell, LARES, SPQ) and will be analysed through descriptive statistics. Changes in these variables before and after the programmes will be analysed using statistical tests for dependent samples such as t-test.

A significance level of $p \leq 0.05$ will be assumed for all procedures.

Qualitative Analysis

In the qualitative analysis of interviews, an exploratory analysis of themes related to individual benefits and satisfaction will be pursued, but saturation is not a specific target.

The interviews with parents, siblings, and school staff will be conducted using semi-structured interview guides. The questions will be developed through collaboration between the interdisciplinary teams, with input from external researchers with expertise in qualitative analysis, in multiple discussion rounds. Due to the dispersed geographical distribution of the participants, all interviews will be conducted online and recorded. The recordings will be pseudonymized and transcribed verbatim. The analysis will be conducted using the MAXQDA software. The creation of categories were both deductive, based on the themes outlined in the interview guide, and inductive, derived from the data. The qualitative content analysis method by Kuckartz [30] will be used as a guideline. After an initial analysis of the material, all transcripts will be independently analysed once again by another person, and categories will be formed using the same process. The analyses and categories from both iterations will be discussed within the team, and the material will be reanalysed based on the revised categories. The analyses were regularly discussed and debated within an interdisciplinary team consisting of physicians, psychologists, physiotherapists, social workers, and occupational therapists. Upon reaching consensus, a category handbook will be created, and the results will be presented using hierarchical code-subcode models and word clouds.

Ethical considerations

The study was conducted in accordance with the Declaration of Helsinki. The Ethics Committee of the university hospital of the Technical University of Munich approved the BAYNET FOR ME/CFS study (2023-1-S-KH). The Ethics Committee of the Julius-Maximilians-University approved the conduct of the training evaluation on 08/11/2023 (71/23). Written informed consent will be obtained after recruitment from the participants or a parent or legal guardian for participating children under 18 years. It is reiterated that participation is voluntary and that there will be no consequences if they do not participate or complete the study. The confidentiality and privacy of the participants' information is protected by deidentifying the data and through the use of a secure, encrypted, and password-protected database for storage.

Results

Piloting

All programmes were pilot-tested in an initial programme block from March to May 2023 within phase I. Participants were recruited through patient organization and advertising through the institute's website. In total 8 patients and their parents, 5 siblings and 59 school staff participated in the piloting. Participants who took part in piloting were not able to participate in the finalized online education programmes.

Finalized online education programmes

In total four programmes were developed to young individuals with ME/CFS, their parents, siblings and school staff. In the final version for the online education programme for young individuals with ME/CFS the generic modules of introduction and disease management were placed at the beginning and end of the programme following the ModuS curriculum (Table 1). Contents were condensed and shortened due to the limited endurance of patients. Additionally, for each unit, short practical sequences were held alongside theoretical input, and group discussions. Theoretical content was regularly and repeatedly reflected upon with the affected individuals, individual barriers will be identified, and collaborative solutions developed within the group. Presentations were created in consultation with patient organizations for each programme unit, along with a comic story. With an adequate time before the education programme sessions, the participants can familiarize themselves with the respective topics using these comics and/or short videos/podcasts and familiarise themselves with the content beforehand through small tasks. For the post-session phase, the content of each unit is summarized in an age-appropriate comic, which will be provided to the participants for reflection and as a reminder.

All online programme units for the affected individuals were conducted in the early afternoon and scheduled for 45 minutes. Participants had the option to end the session earlier due to exhaustion at any time. Throughout the project, two training blocks consisting of twelve sessions each were conducted, with a total of 24 participants. Each training unit was led by two trainers, with at least one certified as ModuS patient trainer. The objective was to empower the affected individuals to become "experts" of their own condition.

For the parents’ online education programme, in addition to information about ME/CFS, care strategies and therapy, social, legal and educational topics were included. The units were tailored to the needs of parents (Table 2). The focus lied on current treatment approaches and information about pacing, as well as relaxation and breathing techniques as main pillars of ME/CFS therapy. Parents were provided the opportunity to address emotionally distressing experiences related to ME/CFS. The parental programme consisted of four evening sessions. Similar to the affected patients, the parent programme was conducted online, with a duration of 1.5 hours per session.

In addition to conveying information about the disease, the siblings programme focused on the experiences of siblings and provides them with an opportunity to exchange their thoughts. The ModuS sibling workshop served as a template for this programme and was condensed to fit into an online programme over the time frame of one afternoon. For school staff, an online education programme was developed, delivering information about the ME/CFS and its symptoms, as well as the possibilities for the educational involvement of affected individuals outside of regular classes.

Both the sibling and school staff trainings comprised a 90-minute online session conducted in the evening via an conventional online platform.

Implementation of the education programmes

The goal of 30 patients was not reached since some patient had already participated in in-hospital trainings in the past and did not want to take part. Recruitment of siblings was unexpectedly low, despite advertising through various channels. In total 24 young patients with ME/CFS and their parents, as well as 8 siblings and 51 school staff were recruited to this study between January 2024 and June 2024. They agreed to participate in the programmes as well as in the evaluation. The online education programmes containing a total of two programme blocks for patients and parents and two to three blocks for siblings and school staff started in May 2023, with completion by the end of October 2023. All participants have been surveyed at baseline (T0) before the beginning of the programmes as part of the evaluation and will be continued to be evaluated, concluding by the end of 2024. Data analyzation will begin after completion of the programmes and is expected to last to the end of 2024.

Participants had the option to agree to interviews during recruitment. Out of those, three participants attending school and three participants not attending school were recruited for interviews after completion of the programme, along with parents who consented to interviews. For siblings and school staff, six individuals who agreed to interviews were randomly selected after completion of the programme.

In Phase IV roll out of the program is planned in 2025-2026 for 150 children and their caretakers to investigate disease knowledge, health related quality of life, life satisfaction, family burden and longitudinal evaluation

Discussion

Overview

Currently, only a few specific and regionally limited healthcare options are available for children and adolescents with ME/CFS. Education programmes for both patients and their social environment represent an initial step towards providing unified care for these patients. The aim of this study is to design, implement, and evaluate an online education programme for children and adolescents with ME/CFS, as well as for their social environment including parents, siblings, and school personnel. The training programmes are developed based on the ModuS training concept [20] and aim to empower participants for self-management of the disease and to provide a comprehensive understanding of the disease as well as promoting exchange among those affected.

Primary findings

In contrast to typical standardized education concepts, the ME/CFS education programmes for all target groups were designed as online offerings. For patients, online sessions provided the opportunity to participate in programmes even when leaving the house or bed is not possible. Offering the training programme online, adolescents could receive a disease specific education, and had the chance to connect with other affected individuals. Additionally, the programme sessions could be followed from various positions, such as lying down, which reduces physical exertion. With possibly declining energy resources of the participant during the session, a shortened participation was feasible. The need to commute to and from the venue was eliminated, further easing the burden on this group. With most electronic devices like PCs, laptops, and mobile phones equipped with cameras, virtual introductions, and direct interactions among participants were still possible. Hence, the core advantage of this patient education program, which is interaction and networking, remained intact in the digital format.

For parents, who are constrained by the care of affected children and adolescents as well as the bureaucratic demands associated with the disease, the online format offers a way to participate in education programmes. Parents can benefit from the absence of time-consuming travel and the flexibility of joining from different locations. Similarly, for siblings, the goal is to minimize the barrier to participation. Online programmes allow them to easily connect, enabling even younger siblings to participate without relying on parental support for mobility.

In the professional realm, online events have become commonplace, especially due to the COVID-19 pandemic, and are now frequently offered and appreciated [22]. Thus, the education programme for school staff was also designed as online sessions to ensure maximum reach, given the accessibility and time efficiency of this format.

The design of the education programmes took into consideration the individual needs of each participant, aside from the digital format. ME/CFS is typically associated with significant fatigue and reduced concentration spans [14]. As a result, the units of the education programme for patients have to be kept short and combined with minimally taxing practical exercises. Therefore, each unit lasted only 45 minutes. Considering the risk of PEM associated with ME/CFS [6], participants were prompted to assess their energy levels at the beginning, end of each unit and were given a short break midway to prevent overexertion. If participants report a low energy level, they were informed about the option to end the session on their own. No participant was excluded by the trainers due to low energy levels, as self-management of one's own resources was a key learning objective of the training.

Given the time limitations during the units, preparatory and follow-up materials, including podcasts, are developed for each training session. The advantage of this approach is that participants can review these materials at their own chosen time, based on their energy levels. Materials were presented visually as comics to ensure comprehension for children and adolescents, avoiding long text passages. Videos and podcasts facilitate information absorption in line with multisensory learning.

The ModuS curriculum was originally developed for rare or chronic diseases [20]. The positive impact on disease management and HRQoL has been confirmed multiple times [16, 31].

The concept's modular structure, offering predefined topics with high flexibility, facilitates the customization of content to address the specific requirements of individuals with ME/CFS and their social environment. Efforts were made to select content that held the greatest significance for ME/CFS patients, parents, siblings, and school staff.

Consistent with the ModuS concept, the training for patients extended beyond medically relevant subjects to encompassed psychosocial themes that are common across chronic diseases [20].

The training sessions for parents were developed to encompass crucial aspects such as navigating the child's illness, communicating it in a child-friendly manner, and accessing specialized medical support [6]. The disease imposes various burdens on parents [32, 33], which can significantly impact the daily life of the family. Therefore, the programme not only covered disease origins and treatment but also dedicated an entire session to disease management. Furthermore, parents of ME/CFS patients often lacked information about social legal aspects [32], which was also incorporated into the programme sessions through collaboration with social pedagogues. This approach aimed at providing a comprehensive understanding of the various dimensions of managing ME/CFS and its impact on families.

The content for the sibling training was selected based on the unique challenges faced by siblings of children with chronic illnesses. Chronic illnesses within the family can lead to burdens for this group as well [34]. Feelings of shame, jealousy, and anxiety might arise [6]. There can also be a redistribution of resources, such as time spent with parents, increased family stress, and social challenges [35]. This training focuses primarily on providing a child-friendly explanation of the illness. Additionally, it aims to foster an understanding of the disease and empathy for the affected family member. For the sibling training, the focus was on facilitating interaction among affected siblings and creating a platform for them to communicate their needs, questions, uncertainties, and fears.

Limitations

This study has several limitations. Firstly, the number of participants is limited and their participation in the programme and the evaluation voluntary. This may result in a disproportionate representation of less severely affected patients, who might be more capable of taking part in the programme and the evaluation potentially biasing the responses. Furthermore, this might lead to higher acceptance rates compared to more severely affected patients who might be less capable of participating due to the severity of the disease. However, we plan to address this by conducting interviews and qualitative analyses by including different degrees of disease burden of patients to incorporate these results into the overall assessment. Secondly, patients were only recruited through one centre, which may disproportionately represent patients from a specific region. Nonetheless, this is the only centre in Germany for young patients with ME/CFS, ensuring accurate diagnosis and adherence to the inclusion criteria. Lastly, the evaluation of the program is conducted immediately after its completion. Therefore, no statement regarding the long-term effects of the programs can be made in Phase I-III.

Conclusions

The present study protocol describes the study design, goals, conceptualization, and implementation of newly developed online training programmes for individuals up to the age of 20 years with ME/CFS, their parents, siblings, and school staff. The aim of the training is to promote disease knowledge and empower affected individuals to manage their own condition. Particularly in the case of ME/CFS, individuals may experience significant limitations in social participation due to their restricted mobility. Online training programmes can support not only the affected individuals in their self-management of the disease but also contribute to social participation through interactions with other affected individuals.

However, the impact of the disease extends to the social environment, including parents, siblings, and school personnel. A notable deficit in knowledge exists here as well, which the training programs, as part of an interprofessional care model, aimed to address. The newly established interdisciplinary training program following the ModuS principle for ME/CFS can thus make a valuable contribution to raising awareness about the condition and providing regional coverage, significantly enhancing the care of children and adolescents with ME/CFS.

After positive evaluation, plans are underway to establish train-the-trainer programmes to enable the widespread offering of ME/CFS training programs as part of a standardized care model for affected children and adolescents. The high demand for the previous pilot training programmes highlights the need, not only among affected individuals but also among parents, school staff, and siblings. In the future, multiple training blocks are envisioned to be offered throughout the year, contributing to comprehensive care. These programmes will be adjusted and improved based on initial evaluations.

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J.S., U.B. and B.V. conceptualized and designed the study. U.B. acquired funding and coordinated the BAYNET FOR MECFS project. J.S. coordinated the education programme. All authors participated in developing the online education programmes. J.E., M.S., J.S., N.S., N.R., V.D., L.S., J.T., K.D. and K.W. conducted the pilot tests. All authors contributed to the subsequent revisions of the education programmes. F.K. drafted the manuscript. All authors have read, revised, and approved the final manuscript.

Data availability

The data sets analyzed during this study are available from the corresponding author upon reasonable request.

Conflict of interest

All authors declare that they have no conflict of interest.

References

1. Webb CM, Collin SM, Deave T, Haig-Ferguson A, Spatz A, Crawley E. What stops children with a chronic illness accessing health care: a mixed methods study in children with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME). BMC Health Serv Res. 2011 Nov 11;11:308. PMID: 22078101. doi: 10.1186/1472-6963-11-308.
2. Garralda ME, Rangel L. Impairment and coping in children and adolescents with chronic fatigue syndrome: a comparative study with other paediatric disorders. J Child Psychol Psychiatry. 2004 Mar;45(3):543-52. PMID: 15055373. doi: 10.1111/j.1469-7610.2004.00244.x.
3. Aufbau eines multizentrischen, altersübergreifenden, klinischen ME/CFS-Registers (MECFS-R) sowie einer multizentrischen, altersübergreifenden ME/CFS-Biobank (MECFS-Bio) mit Auswertung der epidemiologischen, klinischen Versorgungsdaten aus dem MECFS-R. . In: Gesundheit Bf, editor. 2022.
4. Komaroff AL, Bateman L. Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? Frontiers in Medicine. 2021 2021-January-18;7. doi: 10.3389/fmed.2020.606824.
5. Valdez AR, Hancock EE, Adebayo S, Kiernicki DJ, Proskauer D, Attewell JR, et al. Estimating Prevalence, Demographics, and Costs of ME/CFS Using Large Scale Medical Claims Data and Machine Learning. Frontiers in Pediatrics. 2019 2019-January-08;6. doi: 10.3389/fped.2018.00412.
6. Myalgische Enzephalomyelitis / Chronic Fatigue Syndrome (ME/CFS): aktueller Kenntnisstand. In: Gesundheit Bf, editor. Köln: Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen; 2023.
7. Chu L, Valencia IJ, Garvert DW, Montoya JG. Onset Patterns and Course of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Front Pediatr. 2019;7:12. PMID: 30805319. doi: 10.3389/fped.2019.00012.
8. Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue S, Board on the Health of Select P, Institute of M. The National Academies Collection: Reports funded by National Institutes of Health. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington (DC): National Academies Press (US); 2015. doi: 10.17226/19012
9. Bested AC, Marshall LM. Review of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: an evidence-based approach to diagnosis and management by clinicians. Reviews on Environmental

Health. 2015;30(4):223-49. doi: 10.1515/reveh-2015-0026.
10. Malone LA, Morrow A, Chen Y, Curtis D, de Ferranti SD, Desai M, et al. Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of postacute sequelae of SARS-CoV-2 infection (PASC) in children and adolescents. Pm r. 2022 Oct;14(10):1241-69. PMID: 36169159. doi: 10.1002/pmrj.12890.
11. Lim EJ, Ahn YC, Jang ES, Lee SW, Lee SH, Son CG. Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). J Transl Med. 2020 Feb 24;18(1):100. PMID: 32093722. doi: 10.1186/s12967-020-02269-0.
12. Kingdon CC, Bowman EW, Curran H, Nacul L, Lacerda EM. Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls. Pharmacoecon Open. 2018 Dec;2(4):381-92. PMID: 29536371. doi: 10.1007/s41669-018-0071-6.
13. Roxanne MP, Nina A, Danielle B, Alison S, Kirstie LH, Esther C. Adolescent’s descriptions of fatigue, fluctuation and payback in chronic fatigue syndrome/myalgic encephalopathy (CFS/ME): interviews with adolescents and parents. BMJ Paediatrics Open. 2018;2(1):e000281. doi: 10.1136/bmjpo-2018-000281.
14. Nacul L, Authier FJ, Scheibenbogen C, Lorusso L, Helland IB, Martin JA, et al. European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE): Expert Consensus on the Diagnosis, Service Provision, and Care of People with ME/CFS in Europe. Medicina (Kaunas). 2021 May 19;57(5). PMID: 34069603. doi: 10.3390/medicina57050510.
15. Schmidt S, Herrmann-Garitz C, Bomba F, Thyen U. A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults. Patient Educ Couns. 2016 Mar;99(3):421-8. PMID: 26597543. doi: 10.1016/j.pec.2015.10.024.
16. Menrath I, Ernst G, Lange K, Eisemann N, Szczepanski R, Staab D, et al. Evaluation of a generic patient education program in children with different chronic conditions. Health Educ Res. 2019 Feb 1;34(1):50-61. PMID: 30535075. doi: 10.1093/her/cyy045.
17. Menrath I, Ernst G, Szczepanski R, Lange K, Bomba F, Staab D, et al. Effectiveness of a generic transition-oriented patient education program in a multicenter, prospective and controlled study. Journal of Transition Medicine. 2018;1.
18. Szczepanski R, Jaeschke R, Spindler T, Ihorst G, Forster J. Preschoolers' and parents' asthma education trial (P2AET)--a randomized controlled study. Eur J Pediatr. 2010 Sep;169(9):1051-60. PMID: 20300774. doi: 10.1007/s00431-010-1173-z.
19. Ahnert J, Müller J, Löffler S, Vogel H. Patienten- und Elternschulungen bei Neurodermitis. Monatsschrift Kinderheilkunde - MONATSSCHR KINDERHEILK. 2010 06/01;158:586-91. doi: 10.1007/s00112-010-2169-5.
20. Ernst G, Szczepanski R. Modulares Schulungsprogramm für chronisch kranke Kinder und Jugendliche sowie deren Familien „ModuS“. 2020.
21. Ernst G, Klein L, Kowalewski K, Szczepanski R. [I'm still here - Training for the Siblings of Chronically Ill or Handicapped Children]. Klin Padiatr. 2020 Aug 6. PMID: 32767293. doi: 10.1055/a-1214-6624.
22. Schulenburg K. Anforderungen an berufliche Fortbildungen in Zeiten der Covid-19-Pandemie. Public Health Forum. 2021;29(1):61-3. doi: doi:10.1515/pubhef-2020-0101.
23. World Health O. International classification of functioning, disability and health : ICF. Geneva: World Health Organization; 2001.
24. McHorney CA, Ware JE, Jr., Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care. 1993 Mar;31(3):247-63. PMID: 8450681. doi: 10.1097/00005650-199303000-00006.
25. Bell D. The doctor's guide to chronic fatigue syndrome: understanding, treating and living

with CFIDS. Boston: Da Capo Lifelong Books; 1995.
26. FamilienBande S. LARES Geschwisterkinder. Augsburg2009-2022 [cited 2023 11.08.2023]; Available from: https://www.stiftung-familienbande.de/lares.html.
27. Lobato DJ, Kao BT. Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. J Pediatr Psychol. 2002 Dec;27(8):711-6. PMID: 12403861. doi: 10.1093/jpepsy/27.8.711.
28. Meng K, Seekatz B, Roßband H, Worringen U, Faller H, Vogel H. Entwicklung eines standardisierten Rückenschulungsprogramms für die orthopädische Rehabilitation. Rehabilitation (Stuttg). 2009 2010/01/12;48(06):335-44. doi: 10.1055/s-0029-1239575.
29. Inhouse-Schulungsprogramm für Betreuer – Deutsche Diabetes Stiftung unterstützt Projekt „Edukids“ an der Charité. Diabetes aktuell. 2016;14(03):114-6.
30. Kuckartz U. Qualitative Inhaltsanalyse. Methoden, Praxis, Computerunterstützung. 69 469 Weinheim: Beltz Verlagsgruppe; 2018. ISBN: 9783779946830.
31. Ernst G, Menrath I, Lange K, Eisemann N, Staab D, Thyen U, et al. Development and evaluation of a generic education program for chronic diseases in childhood. Patient Educ Couns. 2017 Jun;100(6):1153-60. PMID: 28109650. doi: 10.1016/j.pec.2017.01.001.
32. Nehring I, Riedel C, Baghi L, Moshammer-Karb T, Schmid RD, Kries Rv. Psychosoziale Lage von Familien mit chronisch kranken Kindern: Eine Befragung betroffener Eltern in Selbsthilfegruppen. Gesundheitswesen. 2014;77:102-7.
33. Wiedebusch S, Muthny FA. Eltern von chronisch kranken Kindern. Monatsschrift Kinderheilkunde. 2009;157(9):903-10. doi: 10.1007/s00112-009-1996-8.
34. Rowe PC, Underhill RA, Friedman KJ, Gurwitt A, Medow MS, Schwartz MS, et al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer. Frontiers in Pediatrics. 2017 2017-June-19;5. doi: 10.3389/fped.2017.00121.
35. McKenzie Smith M, Pinto Pereira S, Chan L, Rose C, Shafran R. Impact of Well-being Interventions for Siblings of Children and Young People with a Chronic Physical or Mental Health Condition: A Systematic Review and Meta-Analysis. Clin Child Fam Psychol Rev. 2018 Jun;21(2):246-65. PMID: 29450764. doi: 10.1007/s10567-018-0253-x.

Abbreviations

COVID-19: coronavirus disease 2019
EUROMENE: European Network on ME/CFS
HRQoL: health-related quality of life (HRQoL)
ICF: International Classification of Functioning, Disability and Health
KompaS: Competence Network for Patient Education
LARES: Large Analysis and Review of European housing and health Status
ME/CFS: myalgic encephalomyelitis/chronic fatigue syndrome
PEM: post-exertional malaise
PoTS: postural orthostatic tachycardia syndrome
SPQ: Sibling Perception Questionnaire
SF-36: Short Form-36 Health Survey

Table 1: Overview of units of the online ME/CFS education programme for children and adolescents with ME/CFS based on the ModuS curriculum[a,b].

ModuS Modules[c]	**Modules description**	**Programme units**	**Content**	**Methods/ Materials**	**Profession of trainer**
0 + I + II[b]	Introduction and motivating education about the illness, treatment, and prognosis	1) Introduction	Introduction, team presentation, group formation, disease education, symptoms, introduction to pacing diary	Training materials, group discussion, surveys	Physician
III + IV	Skills and motivation for low-symptom intervals and skills for regulating and avoiding acute crises: emergency management	2-3) Breathing and relaxation exercises and strategies	Reflection on previously known relaxation strategies, importance and benefits of relaxation techniques, teaching of relaxation and breathing exercises (diaphragmatic breathing, body scan, progressive muscle relaxation, guided imagery)	training materials, breathing exercise, survey	Physio-therapist
II + IV	Motivating education about the illness, treatment, and prognosis and skills for regulating and avoiding acute crises: emergency management	4-5) PEM/Crash	Reflection on individual stressors, definition of PEM (post-exertional malaise), strategies for managing PEM, exercise for applying pacing to prevent PEM	Training materials, group discussion, surveys	Occupational therapist
III + IV	Skills and motivation for low-symptom intervals ans skills for regulating and avoiding acute crises: emergency management	6-7 Pacing	Definition of pacing, pacing rules, energy-saving techniques, development of individual pacing strategies	Training materials, survey, group discussion	Occupational therapist
III + IV	Skills and motivation for low-symptom intervals asd skills for regulating and avoiding acute crises: emergency management	8-9) Additional therapies	Current medication treatment options, main pillars of ME/CFS therapy, treatment options for sleep disorders, circulatory issues, pain, brain Fog	Training materials, survey, group discussion	Physician
V	Disease management within the family system	10-11) Disease management	Current emotional energy drains, teaching emotion regulation strategies, practice for recognizing one's own emotional capacity	Training materials, survey, individual work, group	Psychologist

				discussion	
VI	Conclusion	12) Open discussion	Formulating personal goals for the future, feedback opportunities, conclusion	Survey, group discussion	Physician

[a] Blue = generic modules, gray = diagnosis-specific modules; [b] unit includes topics from both cross-disease and disease-specific modules; [c] all modules are conducted by two trainers, the session leading profession is shown in the table, either a physician or a psychologist participated in all sessions to guarantee the continuity of the programme.

Table 2: Overview of modules of the online ME/CFS education programme for parents of children and adolescents with ME/CFS based on the ModuS curriculum[a,b].

ModuS module	**Module description**	**Programme units**	**Content**	**Methods/ Materials**	**Profession of trainer**
0 +I +II + V[b]	Introduction and motivational education on illness, treatment, and prognosis, disease management within the family system	1) Disease pathogenesis and coping	Introduction, team introduction and training structure, explanation of ME/CFS pathophysiology and symptoms, presentation of the 5-phase-model of illness coping and coping strategies	Training material, small group activities, surveys	Physicians and psychologists
III + IV	Skills and motivation for low-symptom intervals and skills for regulating and avoiding acute crises: emergency management	2) Breathing and relaxation exercises and strategies & Pacing	Importance and benefits of relaxation techniques, teaching relaxation and breathing exercises (diaphragmatic breathing, body scan, muscle relaxation, guided imagery)	Training material, breathing exercise, survey	Physiotherapists and occupational therapists
II + IV + V[b]	Motivational education about the illness and skills for regulating and avoiding acute crises: emergency management and disease management within the family system	3) Therapy options & management of disease	Presentation of conservative treatment measures for the most common symptoms of ME/CFS, reflection on individual family challenges, effects of chronic stress, guidance for dealing with stress and promoting emotional stability, reflection on challenges and strategies for dealing with the social environment	Training material, survey, group work	Physicians and psychologists
III + IV	Skills and motivation for low-symptom intervals and skills for regulating and avoiding acute crises: emergency management	4) Social legal aspects & school	Information on social legal entitlements, presentation of various educational participation options	Training material	Social workers

[a] blue = generic modules, gray = diagnosis-specific modules; [b] unit includes topics from both cross-diseases and disease-specific modules

Supplementary Files

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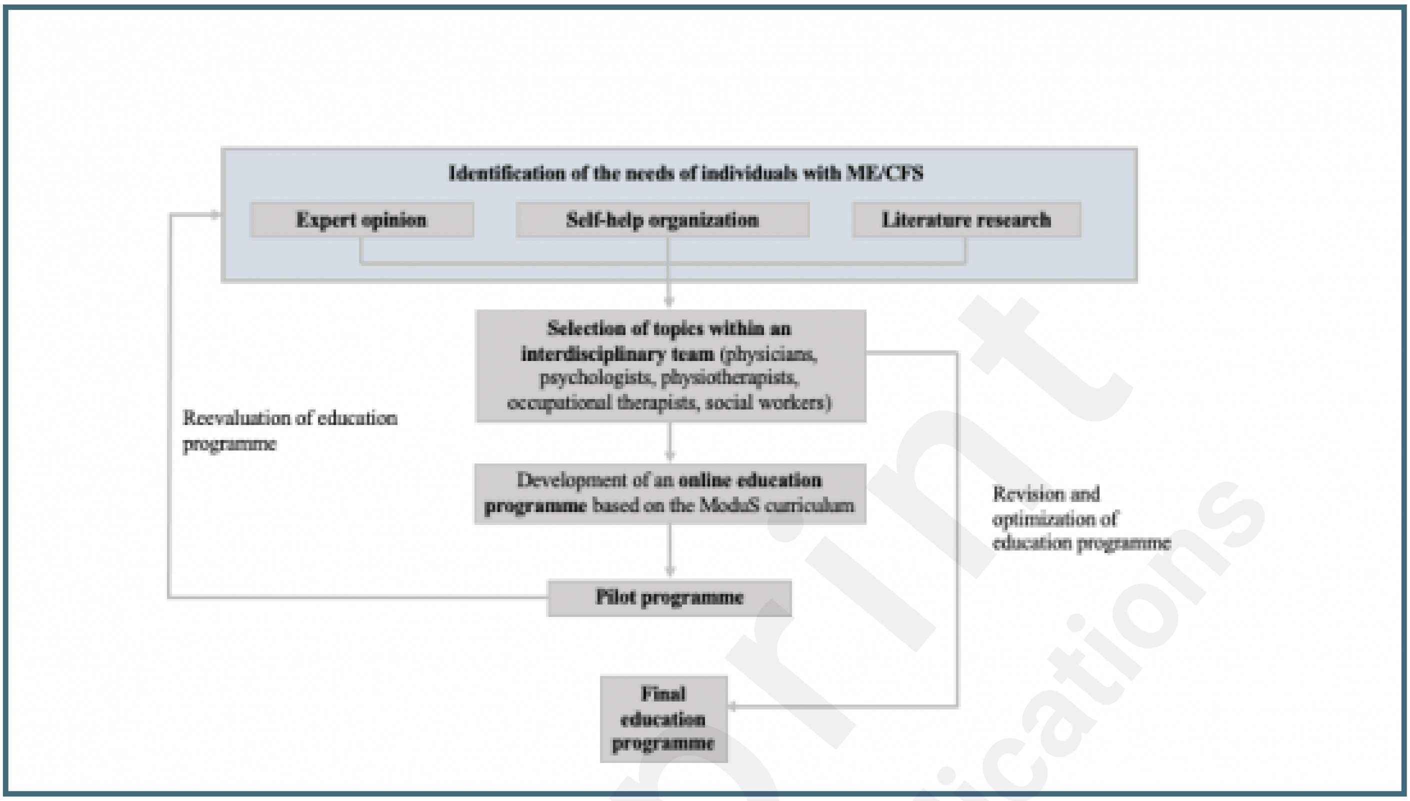
Figures

Process of developing the patient education programme for affected children and adolescents.



Overview of the evaluation of the study.