Mental intervention for chronic fatigue syndrome (CSF/ME) following acute Epstein-Barr virus infection

Treatment manual for the intervention part of the CEBA-project

Children- and youth clinic, Akershus university hospital, June 2015

A. General factors

Introduction

CEBA (Chronic fatigue following acute Epstein-Barr virus infection in adolescents) is a research project investigating correlation between acute EBV-infection and the evolvement of Chronic fatigue syndrome (CSF/ME) in adolescents (12-20 years old) (9,10). An integrated part of this project is a randomized controlled intervention, where youths developing CFS/ME are offered a newly developed treatment program consisting of elements from cognitive behavioral therapy and music therapy.

The treatment program is built on a) theoretical considerations, b) clinical studies of resp. cognitive behavioral therapy and music therapy and c) user experiences from a pilot study carried out by our research group autumn 2014 (17). Here we shortly present background, goal and design, before we elaborate each element in the treatment program. A more comprehensive discussion and arguments are found in a separate research protocol (10).

Background

The "Sustained arousal" – model of CFS/ME is based on principles from cognitive theory and behavioral learning theory (35), primarily "Cognitive Activation Theory of Stress" (CATS) (30). An important premise in this model is that CFS/ME can arise as a result of classical and operant conditioning (25); for example can natural fatigue during long lasting infection gradually be automatically associated with other stimuli, like physical activity. By this the fatigue is sustained even though the infection gradually gets healed.

The validity of this model of understanding is supported by clinical research showing cognitive behavioral therapy as positive for CFS/ME patients (23,34). There is also no risk of serious side effects associated with this way of treatment (14), but at the same time the effect size is rather moderate. Therefore, more effective ways of treatment are needed; at the same time more knowledge about underlying disease mechanisms is also needed, which can be acquired if treatment studies also includes biomarkers and charting of pathophysiological processes. Finally it is important to study a patient cohort with identical actuating cause of fatigue (like EBV-infection), since earlier studies can be criticized for having a heterogeneous patient material (15).

Theoretical reflections indicate that it can be beneficial to combine cognitive behavioral therapy with other mental forms of therapy (24,31). Good effect of such interdisciplinary approach towards youths has been reported (32), but the body of knowledge is sparse, and no randomized controlled trials exist. There also exist corresponding anecdotic reports of the benefit of modified cognitive treatment programs (12).

Music therapy has effect on sensory modulation, cognition, emotions and behavior which seems functional treating CFS/ME; these effects are mediated via central nervous learning processes (18). No studies exist – and consequently no clinical documentation of the benefit of music therapy for treating CFS/ME, but there is shown positive effect in related conditions like

fibromyalgia (6,27). Combinations of music therapy and cognitive behavioral therapy are established in other clinical settings (20).

Aim

In this part of the CEBA-project we want to investigate whether a newly developed mental treatment program encompassing elements from cognitive behavioral therapy and music therapy can have a positive effect on the level of activity, symptoms and markers for disease activity among youths developing CFS/ME six months after debut of EBV-infection.

Design

The inclusion criterion is a fatigue score ≥ 4 (Chalder fatigue questionnaire, dichotomous scoring (11)). Exclusion criteria are intercurrent diseases which can explain the fatigue, and also lasting bedrest (10).

Patients included will be randomized 1:1 to either participation in the mental treatment program or routine follow-up by general practitioner. We calculate 50 participants in total, 25 in each treatment group. The patients undergoes a thorough evaluation before starting treatment (week 0), immediately after the last treatment session (week 12), and twelve months after finished treatment (week 64). Primary endpoint is physical activity (average number of steps per day) by week 12; there are good experiences from earlier research projects using this endpoint on fatigued patients (26). This study has a power of at least 80% (α=0.05) to identify a treatment effect of 2000 more steps per day (10).

The intervention – outlines of the mental treatment program

The treatment program is delivered through 10 treatment sessions á 90 minutes over a period of 10 weeks. The first session is an introduction and takes place with the patient, his/her parents/guardians and all therapists that are carrying out the treatment (figure 1). Then follow nine treatment sessions, four led by a music therapist (lesson nr. 2, 3, 5 and 9) and five led by a cognitive therapist (lesson nr. 4, 6, 7, 8 and 10). At three of the sessions with cognitive therapists (lesson 4, 7 and 10) parents/guardians participate; also, parents/guardians may attend lesson nr. 5 and 8 if the team of therapists considers it advantageous. Between the sessions each patient gets home work, and will also be called up at least once a week by either music therapist or cognitive therapist for advice and counselling.

In the first part of the treatment program music therapy will be emphasized (figure 1), with a combination of musical improvisation, songwriting, music listening and also developing personal playlists to be used in the daily living (1,2,28). Elements from cognitive therapy will be introduced gradually, and will in the end be the dominating form of treatment.

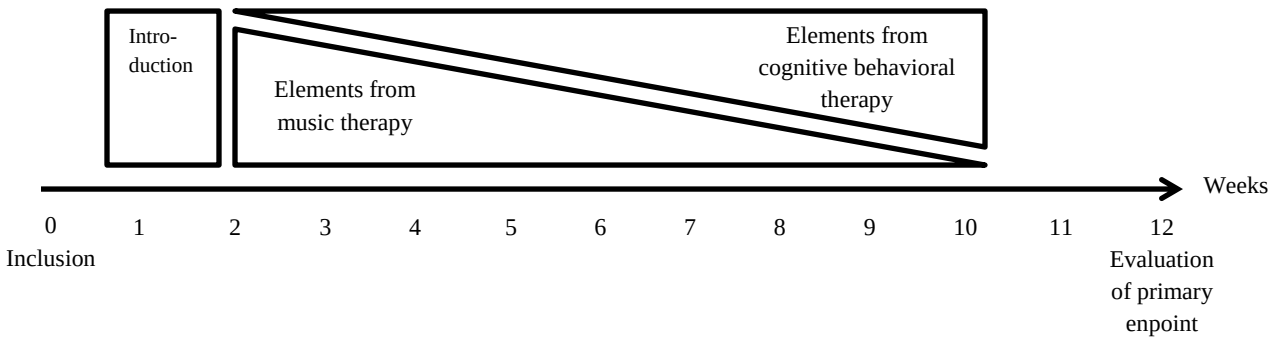

Figure 1. General model of the mental treatment program

Central principles in the mental treatment program

Therapeutic alliance

A good alliance between therapist and patient is of great importance for the effect of cognitive therapy (33). It is important that the alliance is established as soon as possible and is strengthened by positive patient experiences. Elements from music therapy stimulating positive feelings should be emphasized in the beginning of the treatment program (18,29). User experiences indicate that cognitive therapy may be experienced as "duty-oriented" and "school-alike"; therefore it is favorable if elements from this form of treatment are introduced later on (17).

Expectations and hope

One may have expectations both to specific targets and more general to "what will happen in the future". It is important charting the patients expectations, both to the disease/symptoms itself, specific situations in the everyday life, and future circumstances of life. Negative patient expectations, both what is going to happen (stimulus expectation), and how you can deal with it (response outcome expectation) have in themselves impact on the stress responses, and may be included as vicious circles in the patients (8,30,35).

The therapist must attempt to communicate to the patient a realistic hope of improvement, both from disease and life in general. This presupposes that the therapist possesses specialist authority, confidence as a therapist, empathy and a trustful relation to the patient. The patient needs to experience that his/her complaints and symptoms are taken seriously, that they can be explained in a rational way, and that no differential diagnoses are missed. User experiences indicate that histories from other patients (who have become healed) are of great importance for expectation and hope (17).

Control and coping

The feeling of having control/the belief in one's ability to cope is strongly dependent on earlier coping experiences, but is also influenced by observation of others coping, verbal persuasion about one's ability to manage something and a positive emotional/physical activation (4).

The therapist must facilitate situations where the patients can have coping experiences, with the patients circumstances of life as a starting point. The feeling of coping with a symptom the patient is struggling with, can be of great importance – then a mental control over the illness is established. Coping experiences are in themselves self-energizing: the belief in control/coping strengthen the actual ability to control/cope, and reduce bodily and mental stress activation (30). Participating actively in the treatment, and to some degree being given choices, can promote the feeling of control in the patient. In a confident therapist relation the therapist may also challenge the patients' view of mental control – together with the patient the therapist are able to identify negative thoughts and feelings, and motivating for mental individual effort/activity to take control over these negative thoughts and feelings. Here, special techniques may be helpful, like visualizing and bodily relaxing techniques. Some may have difficulties to identify negative thought patterns, for example they instead experience negative thoughts as neutral ascertains of facts. It is important to be aware of this to avoid negative thought patterns being automated and chronic, thereby blocking changes.

Experience of meaning

The patient must experience the treatment as meaningful and relevant for his/her own situation (5).The therapist may ask him-/herself: "Does what I say and do give meaning for this particular person?" A key question asking the patient may be: "What do you miss the most of the things you are not able to do because of the fatigue"?

Searching for a cause for the disease are often less expedient, since the patients often tend to misattribute (13,16) – therapist and patient should rather together concentrate on maintaining factors and what here and now may give improvement.

Positive experiences

Troublesome symptoms (like fatigue) may be triggered, not only by physical activities, but also by imagining such activities (36), which in next moment may strengthen the already established "mislearning" that all activity leads to afflictions (5). For the patient to get other experiences, the therapist may facilitate activities which to a minimal degree are an object of conscious planning. This will further make it possible to establish other, unconscious association in the central nervous system and contribute to "unlearning" of the inexpedient responses, according to fundamental principles from learning theory (5,25) and the "sustained arousal"-model of CFS/ME (35).

The therapist may also intentional arrange behavioral experiments with the patient, to test the reasonableness of the patients own understanding of the condition. For some patients it may also be required and appropriate with a plan for activities. Nevertheless it will not be established a fixed frame for graded activity, which is an important element in standard cognitive therapy for CFS/ME (8). User experiences indicate that such a plan may be experienced as a duty that must be obeyed. It may create expectations of worsening of symptoms if the plan is not followed, which in turn may trigger inexpedient anxiety.

Emotions

Negative emotions in a therapeutic situation, as anxiety and anger, may lead to learning of something totally different from what is believed by the patient and the therapist, and may block the learning of what was intended (5). If such emotions still arise, the therapist should clearly signal that these emotions are tolerated. A superior goal is still that the therapist all the time aims for a positive emotional activation in the treatment situation. This implies among others a focus on what the patient *wants* to do, rather than the duty to do something. Further may music therapeutic elements be effective in mobilizing positive emotions, which will be emphasized particularly in the first treatment sessions (18,29). The patients will learn visualization; this has been shown having a positive effect on CFS/ME and related conditions (19,21).

Concerns/rumination can be an important sustaining factor among patients with long lasting fatigue (7); it is therefore required to reduce this to a minimum. User experiences indicate moreover that negative emotions may arise in the patients if they experience that their disease is "psychologized" - one should for example not assume that the patient has a "negative way of thinking" in general, but rather present techniques usable on "bad days" (17).

Individual effort

The treatment program assumes active participation from the patient. For many patients avoidance is a (unconscious) coping strategy, which may work effective in a short perspective, but will contribute to sustain the fatigue on a long-term basis (22). The therapist must communicate the necessity of individual effort, particular towards the end of the treatment program where the intention is that the patient has learned techniques which can be used unaided.

The necessity of individual effort should nevertheless not be presented in such a way that the patient increases his/her worries or feels the treatment program more as a duty rather than pleasurable, cf. paragraphs above. User experiences indicate that instructions and homework should not be at too advanced level or remind too much of school assignments (17). Still it is important to strengthen the patients' belief in that they have the ability to affect their situation through effort. To create motivation in each individual patient must be greatly emphasized. Our experience indicates that the patients not necessarily perceive it as negative to be given tasks between the treatment sessions, but notions associated with school or school-related activities are problematic because often these patients have huge challenges with school attendance. This is the reasons for introducing homework gradually, and that it is presented on a digital platform according to the lifestyle of today's youth.

Individual adaption

As a main principle the treatment must be individually adapted (cf. the paragraph about meaning above), but still within certain frames as outlined under point B below. Individual adaption must also be done considering age and the level of maturity (in particular this happens to be the case with the cognitive techniques), and considering specific problematic areas in the patient group

that are already mapped out (trough questionnaires and cognitive tests) (10). Primarily these problematic areas are: anxiety, depression, sleeping disorders, trouble with executive functions (attention, working memory), perfectionism and worries.

Involvement of parents/guardians

Parents/guardians are the most essential caregivers for the patient, and can in a positive way motivate the patient and help guiding through the principles and specific techniques which will be introduced in the treatment program. At the same time parents/guardians may also strengthen a negative illness behavior and disease attribution, which in turn may have a negative impact on the prognosis (3). Therefore it is of great importance to involve the parents/guardians in the treatment program, and they are expected to participate in four out of ten sessions. The therapist is not intended to establish an extensive family therapy, but must be prepared for straightforward dialogue with parents/guardians which are perceived to have a clearly negative influence on the treatment plan.

Principal differences between this mental treatment program and traditional cognitive behavior therapy for CFS/ME

This treatment program is built on several of the same principles as traditional cognitive therapy for CFS/ME, but deviate on certain important points:

- It is built on a model of CFS/ME which postulates *sustained arousal* maintained through *classical and operant conditioning* (30,35). In traditional cognitive therapy one has rather emphasized factors like sickness belief, reduced and inconsistent activity, sleeping disturbances, medical uncertainty and lack of counselling as maintaining factors in CFS/ME (8).
- *Music therapy* is being integrated together with traditional cognitive techniques to an overall mental treatment program.
- *Emotions* are to a greater degree paid attention to compared to what is normal in traditional cognitive therapy, and specific techniques (like mindfulness and visualization) will be introduced to increase the access of positive feelings.
- *Unconscious/automatic experiences* are given more attention, whereas conscious processing of thoughts and planning of behavior is less emphasized. Therefore a fixed plan for graded activity is not an integrated part in the program, such as in traditional cognitive therapy; rather emphasized is spontaneous experiences not involving conscious planning.
- There will be an *individual adaption* regarding specific psychological issues, and *parents/guardians* are included in the treatment.

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B: Treatment sessions

1st meeting (week 1): Introduction with parents/guardians

Frames:

- Participants: The patient, parents/guardians, music therapist, cognitive therapist, responsible researcher, "speaker"
- Time: 90 minutes
- Place: Akershus University Hospital (AHUS)

Aim/focus

This is the first session in the treatment program, and is set as a psycho-educative introduction where understanding of the disease, treatment rationale and so on are being presented. Important keywords are:

- Give information about the treatment program and underlying grounds
- Clarify expectations to the treatment program
- Create motivation, hope and enthusiasm both in patients and parents/guardians
- Present the music therapist and cognitive therapist. Establish alliances.

Implementation

The first 15 min is reserved for mingling, light refreshments will be served (drinks and fruit e.g.). In this part it is important that all participating therapists actively are focused on greeting the patient and his/her parents/guardians. There will be played background music (intentionally chosen). This part finishes off with a music performance, before the chairman takes over. This one gives 2-3 min of information, before the responsible researcher is being presented. The researcher further gives a presentation on our understanding of CSF/ME. Here it is important to use the patients' own histories as a starting point. This further leads to how one is able to deal with it. Explain the concept of music changing the brain. Before a 15 min break there will be an opportunity to ask questions.

After the break a "success history" is presented. A patient who has recovered first tells his/her history, before this one is interviewed by the chairman, focusing on hope and opportunities. Open up for conversation with the patient and his/her parents/guardians, detect whether the patient recognizes some aspects in the "success history", with the aim of connecting the patients thinking and behavior pattern to the rationale earlier presented.

Further the therapists are presented, each having a short presentation of his/her treatment form. Then a new opportunity for open questions is given, before another music performance ends the session.

2nd meeting (week 2): Individual session

Frames:

- Participants: Patient, music therapist
- Time: 90 minutes
- Place: Ahus

Aim and implementation

This is the first lesson with music therapy. It is important to continue the work with building alliances, common understanding e.g., and that the patient is feeling confident in the situation. It is the patient's wish for the music therapeutic action that guides the here-and-now-meeting. The music therapist focuses on the client's resources. At the same time more specific actions are introduced, primarily:

- Mapping out the patients' music interests: music preferences and music listening in the daily living.
- Open up for an improvisatory approach to songwriting and music composition. This means a) put music to some of the patients' personal feelings and experiences, through focus on subjects from the daily life, or subjects of a more existential character, or b) have a starting point in music spontaneously referred by the patient – and put the patients' personal sayings in such a musical frame. If the patient brings a text, a poem or own music it is important to follow up this and put the texts in a positive musical frame.
- Music listening in a relaxed state. This means focus on mindfulness, focus on visualization of a "safe place", and relaxing/easing of tension/stress reduction. Visualization makes use of positive and pleasurable expressions. The music listening spend over a short time span. The patient chooses whether he/she want to sit or lay down.

Home tasks

- Choose music and listen actively to it for 5-10 minutes every day. *Pay attention to* what you think about different kinds of music. Pay attention to how different kinds of music affect you.

3rd meeting (week 3): Individual session

Frames:

- Participants: Patient, music therapist
- Time: 90 minutes
- Plave: Ahus

Aim and implementation

This is the second lesson with music therapy. There will be repetition of techniques from the previous lesson, and eventually work more on these depending on the patient's wishes and skills. Following up the patients tasks in music listening is of particular importance. In addition a goal for this lesson is to facilitate activities which to a minimal degree involve conscious planning, but focus on what is happening here and now. The intention is to create new automatic associations: Instead of the association "activity leads to fatigue" one shall facilitate associations like "activity gives energy" and "activity is fun". Here the patient's own wishes will guide the coming music activity; improvisation, songwriting and/or music listening. What kind of activity and what type of music usable for this are individual adapted. If one does not succeed, and the patient actually gets tired of the activity started, it is important to play down and rather try to use this experience for something useful – for example using a technique for resting or a technique for visualization used to chase away the feeling of fatigue and to focus on something else. Keywords are:

- Open up for an improvisatory approach to songwriting and music composition. This means a) put music to some of the patients' personal feelings and experiences, through focus on subjects from the daily life, or subjects of a more existential character, or b) have a starting point in music spontaneously referred by the patient – and put the patients' personal sayings in such a musical frame. If the patient brings a text, a poem or own music it is important to follow up this and put the texts in a positive musical frame.
- Music listening in a relaxed state. This means focus on mindfulness, focus on visualization of a "safe place", and relaxing/easing of tension/stress reduction. Visualization makes use of positive and pleasurable expressions. The music listening spends over a short time span. The patient chooses whether he/she wants to sit or lay down.
- Activities which are not consciously planned: music therapy will have a starting point in what is pleasurable, and will follow the patient's wish for musical approach.

Home tasks

- Tasks for 5th meeting (i.e. next time with music therapy) are further built on the task given in the 2nd meeting: Listen to music 5-10 min every day. *Choose* (at least) one piece of music/tune in each of the categories: a) I really like this piece of music/tune b) this piece of music/tune makes me feel calm and relaxed, and c) this piece of music/tune may give me new strength and energy. This means to choose (at least) three pieces of music/tunes. *Bring*

along these pieces of music/these tunes to the next meeting with the music therapist, i.e. 5th meeting.

4th meeting (week 4): Session with patient and parents/guardians

Frames:

- Participants: patient, parents/guardians, cognitive therapist, music therapist (teammate and observer)
- Time: 90 minutes
- Place: Ahus

Aim and implementation

This is the first individual meeting with the cognitive therapist, and also the first meeting where parents/guardians are attending after the first group session in the beginning of the treatment period. The lesson opens with the music therapist going through what have been subjects the two previous sessions, and how this may be evolved in the rest of the treatment period. The rest of the session is lead by a cognitive therapist and the structure is much like a traditional startup lesson in cognitive therapy. Keywords are:

- The patient and the family's history. Explore the patient and parents/guardians points of view, thoughts, ideas, explanation models, expectations and so on.
- Mapping out the patient and the family. Before the conversation much information regarding the patient is already known from the questionnaires (particularily anxiety, depression, sleeping problems, problems with executive functions (attention, working memory), perfectionism and worries). Use this and anamnestic information to make a fundament for individual adapted treatment in the rest of the treatment program.
- Go over the rationale once again and try to establish a common understanding. In particular it is important to draw in the music therapy, and actively use the patients experiences from the previous two sessions with music therapy, including how the music may activate different kinds of feelings. One may for example explain how techniques for relaxation, mindfulness and visualization may be used in different situations. But one shall not verbalize the principle of doing spontaneous activities – it is important that this is an unconscious experience, not an object for much mental work.
- Focus on building alliances – create good frames for learning.

Homework

Towards the end of this session more comprehensive homework than the patient has had earlier is introduced. It is important to motivate both parents/guardians and patient to do these tasks – underline the positive aspects in the possibility of being able do something with his/her own situation, and at the same time give some demands regarding individual effort. The motivation may also be strengthened by underlining that tasks are presented on a digital platform, adapted to the youths everyday life. I may be expedient to use some of the lesson working through the tasks together with the youths, so they are getting familiar with them and experience coping.
Keywords for home tasks after meeting nr 4:

- Practice techniques in mindfulness, relaxation and visualization (simple instructions are given on the digital platform).
- View a presentation of disease models for fatigue and argument for treatment (preferable together with parents/guardians).
- Keep a sleeping and activity diary.
- Listen to music for 5-10 minutes every day.

These home tasks are in the first phase meant to go on for two weeks, to session nr. 6.

5th meeting (week 5): Individual session

Frames:

- Participants: Patient, music therapist, eventually parents/guardians
- Time: 90 minutes
- Place: Ahus

Aim and implementation

This is the third meeting between the patient and the music therapist. Parents/guardians may be included if the treatment team consider it favorable. A central point in this session will be to continue and repeat already learnt techniques regarding attention, relaxation and visualization, which the patient now has received on a digital platform. It is important to integrate music therapeutic instruments with the cognitive approaches presented in the 4th session (where the music therapist participated as an observer). One should demonstrate the relevance of such techniques for the patients, and also help them to see how they can use them in everyday challenges.

The most important point in this session is still to try to experience activities which are not a result of conscious planning. The patient's homework finding at least three pieces of music/notes giving the patient positive associations can be used as a starting point. Create consciousness about elements/music so the patients are able to look for additional music giving the same feelings. The patients have brought music communicating positive emotions and which gives energy. If these attempts fail to succeed – try to turn this experience into something positive, as mentioned above.

- Open up for an improvisatory approach to songwriting and music composition. This means a) put music to some of the patient's personal feelings and experiences, through focusing on subjects from the daily life, or subjects of a more existential character, or b) have a starting point in music spontaneously referred by the patient – and put the patients' personal sayings in such a musical frame. If the patient brings a text, a poem or own music it is important to follow up this and put the texts in a positive musical frame. This may mean that the main focus is now on songwriting. Here the music therapist must "tune in" to clarify which part of the music therapy patient itself experiences as most meaningful.
- Music listening in a relaxed state. This means focus on mindfulness, focus on visualization of a "safe place", and relaxing/easing of tension/stress reduction. Visualization makes use of positive and pleasurable expressions. The music listening spend over a short time span. The patient chooses whether he/she wants to sit or lay down.

Home tasks:

Tasks for next session with music therapy are built further on the task given in session nr. 5. Task: Listen to music at least 5-10 min every day. Choose 3-5 music pieces/tunes in each of the following categories: a) I really like this piece of music/tune b) this piece of music/tune makes

me feel calm and relaxed, and c) this piece of music/tune may give me new strength and energy. *Bring with you* these music pieces/tunes to the next meeting with music therapy, i.e. session nr. 9. Maybe you want to make your own playlist at home? If the patient is not able/doesn't want to, the music therapist may support make such a list during session nr. 9.

6th meeting (week 6): Individual session

Frames:

- Participants: Patient, cognitive therapist
- Time: 90 min
- Place: Ahus

Aim and implementation

This is the second meeting with cognitive therapist, and the first where the patient is alone with the therapist. At this point the patients' main challenges are thoroughly mapped out through

- Questionnaires from earlier registrations in the CEBA-project
- Last meeting with cognitive therapist and parents/guardians (meeting nr. 4), and
- Sleeping and activity diary (homework from meeting nr. 4).

Based on this the therapist discusses with the patient which challenges are most important to handle. A goal is to make the patient an active participant in the treatment – a key question may be "what is the most important for you to do something with right away?" But the starting point must always be what one really *want* to try do something with, rather than what are dominated by duty and worries. The therapist should steer away from discussions concerning underlying causes of fatigue – the focus should be on what gives improvement. At this point it will be natural to introduce more specific elements from cognitive theory, particularly how *expectations* regarding what will happen (stimuli expectation) and *expectations* related to their own coping, and which techniques that are useful to help stopping such thoughts.

This discussion should end up with a plan for the patients' tasks until next meeting. Have as a starting point the registration already done by the patient. Have a positive focus on what one actually have been able to do. Elements in this plan may be:

- Integrate techniques which the patient already has learned in the music therapy (visualization, attention, relaxation) to stop unappropriated thought patterns.
- Introduce simple behavioral experiments to test the validity of the patients' understanding of connections between fatigue and activity – it may be based on unconscious planned behavior done earlier by the patient during the music therapy sessions. The behavioral experiments may also be related to other troublesome areas, like sleeping difficulties where provable techniques exist (stimuli control and sleeping restrictions).
- Explain to the patient the necessity of practice. Require own effort, but be convincing that the patient actually is able to cope.

Home tasks

Hometasks after this meeting are:

- Listen to music 5-10 minutes every day.

- Practice techniques in mindfulness, relaxation and visualization (simple instructions on the digital platform).
- Review the presentation of sickness models and grounds for treatment (favorable together with parents/guardians)
- Keep a diary of inexpedient/negative thoughts
- Keep a “behavioral experiments” diary

The last two elements are new, but the first three are the same as after session nr. 4. These home tasks are going to last for additional two weeks, until session nr. 8.

7th meeting (week 7); Session with patient and parents/guardians

Frames:

- Participants: Patient, parents/guardians, cognitive therapist
- Time: 90 minutes
- Place: Ahus

Aim and interpretation

This is the third meeting with cognitive therapist, and the second where the parents/guardians are participating. During meeting nr. 4 there was, in addition to mapping out the patient, done a mapping of family functions, parents/guardians understanding of the disease etc. The intention with this lesson is to:

- Further investigate the families' disease understanding, worries, explanations etc.
- Converse about how the family may be a support for a sick patient. What kind of family behavior promotes and prevents disease, viewed in the light of our understanding of underlying mechanisms for long lasting fatigue.
- Make specific plans on how the parents/guardians in a best way may help the patient in the everyday life. It is important that the parents/guardians a) strengthen the patients coping belief (worries regarding school etc should be put aside), b) motivate and supervise the patient, c) require own effort regarding practicing different mental techniques ("do the homework"), d) do not transmit own worries to the patients

Home tasks

After this lesson the parents/guardians are getting home tasks:

- Motivate and supervise the patient in techniques regarding mindfulness, relaxation and visualization
- Review the presentation of disease models and grounds for treatment. The tasks last until meeting nr 10.

8th meeting (week 8): Individual session

Frames:

- Participants: Patient, cognitive therapist, parents/guardians if suitable.
- Time: 90 minutes
- Place: Ahus

Aim and interpretation

This is the second meeting alone with the cognitive therapist. If the therapist experiences that the family dynamics to an extended degree participate in sustaining the patients' problems, parents/guardians may participate. One has as a starting point the home tasks regarding a. inexpedient thinking patterns and b. behavioral experiments, and uses this for a further discussion along the same lines as meeting nr. 6. What has been achieved so far? Is it natural to expand the perspectives and work with more of the challenges the therapist and patient together have defined as important. It may be relevant to discuss worries the patient may have, and eventually elements blocking further progression.

Cognitive theories and techniques are being introduced to a degree that seems appropriate. There should always be a positive and optimistic focus. The patient must be motivated to continue the work of learning to identify negative thought patterns, practicing techniques to stop such thoughts and experiments regarding behavior requiring increasing own effort. If the patient does "too much", and gets an increasing feeling of fatigue, it is important not to view this as a sign of failure or worsening of sickness, but a normal response everyone would experience after long lasting disease.

Home tasks

- Keep a diary over "behavioral experiments"
- Make a draft of a plan for how what is learned in the treatment program may be used further when the program is finished. How to continue the progress? How to deal with relapses if they come?
- Listen to music 5-10 minutes every day.

The tasks last until meeting nr. 10.

9th meeting (week 9): Individual session

Frames:
Participants: Patient, music therapist
Time: 90 minutes
Place: Ahus

Aim and interpretation
This is the last session with music therapist. It may be natural to repeat exercises and techniques the patient has learned and practiced through the treatment period. Main focus is although to be future-oriented:

- How to continue the progress?
- How to deal with relapses?

The goal is that the patient to a largest possible extend will be self-reliant regarding using techniques and principles acquired through the treatment period. It is important to motivate for further own effort – it may happen through pleasurable activities giving energy/joy/energy, and which give the feeling of coping. This meeting too should contain:

- Open up for an improvisatory approach to songwriting and music composition. This means a) put music to some of the patients' personal feelings and experiences, through focus on subjects from the daily life, or subjects of a more existential character, or b) have a starting point in music spontaneously referred by the patient – and put the patients' personal sayings in such a musical frame. If the patient brings a text, a poem or own music it is important to follow up this and put the texts in a positive musical frame. This may mean that the main focus is now on songwriting. Here the music therapist must "tune in" to clarify which part of the music therapy patient itself experience as most meaningful.
- Music listening in a relaxed state. This means focus on mindfulness, focus on visualization of a "safe place", and relaxing/easing of tension/stress reduction. Visualization makes use of positive and pleasurable expressions. The music listening spend over a short time span. The patient chooses whether he/she want to sit or lay down.

Home tasks:

- Task until next session: Use actively the music/notes you have chosen: 9(15) pieces of music/notes. Actively listen to these every day. Use your own playlist, which was made during the last session with music therapist.

10th meeting (week 10): Session with patient and parents/guardians

Frames:

- Participants: Patient, parents/guardians, cognitive therapist
- Time: 90 minutes
- Place: Ahus

Aim and interpretation

This is the last meeting in the treatment program. It will be natural to have as a starting point the home tasks both parents/guardians (7^{th} meeting) and the patients (8^{th} meeting) have received, and in particular the task regarding make a drawing on how to continue using what is learned in the treatment program when the treatment is finished. One should also discuss with the parents/guardians how they may continue to in a best way support the patients' progress. It may be appropriate to repeat a part of what has been gone through earlier, like the model of disease mechanisms and rationale for treatment, cognitive theories, techniques to distract negative thoughts, the importance of behavioral experiments and so on. The main focus should still be future-oriented:

- How to continue the progress?
- How to deal with relapses?

The goal is that the patient to a largest possible extend shall be self-reliant regarding using techniques and principles acquired through the treatment period. It is important to motivate for further own effort – it may happen through pleasurable activities giving energy/joy/energy, and which give the feeling of coping. One technique may be to listen actively to the music chosen by the patient, eventually encourage the patient to express itself through text and music, i.e. song/music/songwriting.