


# Adaptation of Coping Effectiveness Training for Patients With Heart Failure and Patient-Reported Experience of the Intervention

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## Abstract

Although patients with chronic heart failure (CHF) often experience psychological distress, psychosocial aspects are not an integral part of their treatment and care. The aim is to describe the adaptation of Coping Effectiveness Training for patients with CHF and the participants' reported experiences. The intervention workbook and manual were translated into Swedish and adapted for patients with CHF. Patient-reported experience from 33 of 35 participants, that had completed the psychosocial intervention, was measured with an evaluation form consisting of closed and open-ended questions. Most participants thought they benefited from the intervention, were pleased with the structure and did not want to add anything to the program. The benefits experienced were learning how to cope with the illness and meeting other people to share and discuss experiences. There was a variation concerning the group process of how much direction should be given during the discussions. Overall, unique data from patient-reported experience measure showed that the participants were satisfied with the psychosocial intervention, applied for the first time to patients with CHF.

## Keywords

heart failure, interdisciplinary, intervention design, patient-reported experience measure, psychosocial

## Introduction

Chronic heart failure (CHF) is a serious illness where the poor prognosis and high rehospitalization rates are comparable to those in common forms of cancer (1). Chronic heart failure is the leading cause of hospitalization among people over 65 years and health-care expenditure is very high (2,3). The prevalence of depression and anxiety is also very high in patients with CHF, where research has shown that 1 in 5 patients have depressive symptoms and 32% have anxiety (4,5). Depression has been associated with a doubled risk of mortality and morbidity (5). Anxiety has been associated with higher readmission rates in patients with CHF (6). The European Society of Cardiology (ESC) guidelines states that psychosocial support should be a component of the heart failure management care (7). Despite the ESC guidelines and the known detrimental outcomes of psychological distress in patients with CHF, psychosocial factors are infrequently treated and cared for (8,9).

A meta-analysis of 16 randomized controlled trials (RCTs) showed improved quality of life after psychosocial

interventions for patients with CHF. Interventions based on face-to-face meetings showed greater improvement in the quality of life than did telephone-based interventions (10).

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All the included psychosocial interventions had different intervention designs, for example, relaxation training, cognitive behavioral therapy (CBT), and telephone case management (10). Evidence is lacking and consensus has not been reached regarding the choice of a psychosocial intervention for implementation in clinical practice. Theory-based interventions have shown to be more effective than non-theory-based interventions in a number of somatic conditions (11). One such theory-based intervention is Coping Effectiveness Training (CET), which is based on the seminal cognitive transactional theory of stress and coping (12). Our research group has evaluated CET for the first time for patients with CHF in an RCT. The outcome measures used in the evaluation were mainly patient-reported outcome measures (PROMs) but also included several clinical outcomes (13). Coping Effectiveness Training has been previously applied to, and evaluated for, patients with HIV and spinal cord injuries (SCIs) in controlled trials (14,15) where the CET significantly reduced perceived stress, burnout, and anxiety in patients with HIV (14) and reduced anxiety and depression in patients with SCI (15). Stress components, such as lack of predictability, sense of control, concerns about the physical health and maladaptive coping found in persons with HIV and SCI (14, 15), have close points of similarity to the ones found in CHF (16,17).

Although transparency is crucial when reporting an RCT (18), many reports of RCTs lack a thorough description of the intervention design (11), which this article addresses. Although a very brief description of CET for patients with CHF has been included in our previous evaluation, important details of the intervention design and patients' subjective experiences of participating in CET are not entirely captured and provided due to the limited extent of such a description (13). Consequently, a more detailed description of CET for CHF patients, and additional findings from patient-reported experience measures (PREMs), are needed to provide means of replication, modification and further examination of this intervention in the context of CHF.

The aim of this article is to describe the adaptation of CET for patients with CHF and the participants' reported experiences of the CET intervention.

## Methods

### *Translation and Adaptation of CET for Patients With CHF*

The design of the CET in this study was developed from the design used by Kennedy et al for patients with SCI (15). In order to apply CET to patients with CHF in a Swedish context, the content of the intervention firstly had to be translated into Swedish. Kennedy published a manual for the group leader and a workbook for the participants (19,20). These written materials were translated and adapted by the first and the last authors. A forward iterative translation approach of the manual and workbook was performed, that

is, the translators translated separate chapters and then jointly discussed all texts to reach agreement on the word choices. Whereas the theoretical content and disposition of the program material were kept, the examples, exercises, scenarios, and home assignments were adapted using an interdisciplinary approach, including both the extensive clinical cardiac nursing experience of the first author and the experience with individual CBT and coping research of the last author. In the adaptation process, the first author reviewed research on how patients with CHF experience and cope with their illness, which provided further foundation for adapted CHF-relevant examples and scenarios. The last author was responsible for keeping the translations and adaptations in line with the general framework of the cognitive transactional theory of stress and coping

For example, regarding the session on problem-solving, CHF-specific problem scenarios and CHF-relevant relation scenarios were generated based on the first author's clinical experience and knowledge about the CHF literature instead of the SCI-specific problem scenarios published by Kennedy (19,20). Concrete examples that would take the participants through the steps of the problem-solving method were developed. For instance, one adapted example describes ways of analyzing and generating potential solutions to a situation where a patient feels worse, has gained weight, and became shorter of breath.

### *Intervention Design of CET Applied for Patients With CHF*

The intervention design of CET consisted of 7, weekly 90-minute sessions with an average of 8 participants per group. The participants received the workbook consisting of a brief summary of the theme for each session, exercises, and home assignments. The group leader was guided by the manual, which explained every theme and exercises and brought out points for discussion, which made the intervention standardized. A typical session was started with a brief repetition of last week's theme and going through the home assignment. After that, the group leader introduced the theme of the current session and this was followed by discussions in the group and intermittent exercises. In the middle of the session, there was a short break. At the end of the session, a new home assignment was given. Table 1 gives an overview of the themes and home assignments and also gives examples of points of discussion.

The group leader (first author) was a cardiac nurse specialized in CHF with more than 10 years of clinical experience, a master's degree, and a PhD candidate in coping and emotional well-being in patients with CHF. The group leader cooperated with a psychologist (last author) with a PhD, which included jointly leading the first group and subsequently receiving supervision after each CET-session.

**Table 1.** Themes, Points of Discussion, and Home Assignments for Each CET-Session.

Session	Theme and Examples of Points of Discussion	Home Assignment
1	Introduce the concepts of and cognitive model of stress and coping. Discuss how stress can be related to CHF and discuss external and internal stressors.	Identify personal signs of stress and record them.
2	Appraise and cope with stress. Appraisal skills training, the introduction of problem and emotion-focused coping strategies and defining adaptive coping. Discussion of how a complex stressor like heart failure can be broken down in small parts in order to make heart failure more manageable to live with.	Identify which stressors, related to CHF, can be changed or not be changed
3	Explain and discuss problem-focused coping and introduce a problem-solving method. Discussion of potential problematic scenarios that patients with heart failure may encounter and how these can be solved with a problem-solving method.	Practice a structured problem-solving method
4	Explain and discuss emotion-focused coping and the cognitive model of emotions. Introduce relaxation training and scheduling pleasant activities to counteract negative thoughts. Discussion of what a pleasant activity can be.	Practice relaxation using a compact disc-recording and engage in pleasant activities
5	Change negative thinking. Discuss negative automatic thinking and common thinking errors. Discuss and practice steps for challenging negative thoughts.	Replace negative thinking with more realistic thoughts
6	Repetition of stress, appraisal, and coping. Discuss adaptive and maladaptive coping. Discuss situations when maladaptive coping is used and replacing it with an adaptive coping strategy.	Continue an adaptive and stop one maladaptive strategy
7	Present different kinds of social support. Explain and discuss assertiveness. Discuss different scenarios a patient with heart failure may encounter and how each scenario could be responded to, with an aggressive reaction, submissive reaction, or an assertive reaction.	Encouragement to practice skills learned during the CET

Abbreviations: CET, Coping Effectiveness Training; CHF, chronic heart failure.

### Patient-Reported Experience Measure

**Participants and procedure.** The methodology of the RCT study evaluating the CET intervention for patients with CHF in a Swedish context is described in detail in an already published manuscript (13). In summary, 103 patients were randomized to either intervention group ( $n = 51$ ) or control group ( $n = 52$ ) and the time points for evaluation with PROMs took place postintervention, 6 weeks, 6 and 12 months after the intervention. In total, there were 5 intervention groups with 7 to 12 people in each group. Thirty-five participants completed the intervention, that is, had participated in at least 5 of the 7 sessions, and 9 did not. There were no significant differences between completers and non-completers.

Directly after the CET intervention, an anonymous written evaluation, PREM, of the CET was given to the participants who had completed the intervention of which 33 of 35 participants responded to. The PREM form consisted of 6 closed questions and 6 open-ended questions, see Table 2. The questions concerned logistics, content, beneficence, and expectations.

The mean age of the participants that had completed the intervention was 72 years, 60% were married or cohabitant, 63% were male, 91% had New York Heart Association (NYHA)-class II, and 9% had NYHA-class III and they have had heart failure for on average duration of 38 months.

The Regional Ethical Review Board in Stockholm, Sweden approved the study, Dnr 2010/1867-31/5. All participants gave written informed consent to participate in the study.

**Analysis.** The closed questions were analyzed with descriptive statistics. The response frequencies were analyzed with Microsoft Office Excel.

The text from the free-text answers consisted of about 2000 words. The free-text answers were analyzed with a conventional qualitative content analysis inspired by Hsieh and Shannon (21). The first author and the last author independently analyzed the text by first reading the text repeatedly to get a sense of the whole. Thereafter, the text was read word-by-word in order to extract codes from the text. Categories were formed from similarities and differences among the codes. Afterward the two authors compared their codes and categories and, through a dialogue, agreed on categories.

## Results

### Patient-Reported Experience From Closed Questions

The reported experiences indicated that most of the participants considered they benefited from the intervention (94%) and that they would recommend it to a friend (97%). The majority were pleased with the number (81%) and length (79%) of the sessions as well as the number of group participants (73%). Table 3 displays the results.

### Patient-Reported Experience From Open-Ended Questions

The results from the two authors were quite similar and, through a dialogue, the authors agreed on four categories that had emerged from the text; *Experienced appraisal and*

**Table 2.** Closed Questions With Response Alternatives and Open-Ended Questions of the PREM.

## Closed questions with multiple response alternatives

If You assess the stress management program as a whole: Do You think You had any benefit from it?

No, no benefit at all—Yes, some benefit—Yes, fairly great benefit—Yes, very great benefit

What expectations did You have of the program before it started?

Very small—Fairly small—Fairly great—Very great

When it comes to the number of group sessions: Do You think it was:

Absolutely too few—A little too few—Just enough—Too many

When it comes to the length of every meeting: Do You think it was:

Absolutely too short—A little too short—Just enough—Too long

Do You think the number of participants in your group was:

Absolutely too few—A little too few—Just enough—Too many

Would You recommend to a good friend with heart failure to participate in the same stress management program that you have attended?

Yes, absolutely—Yes, maybe—No, probably not—No, absolutely not

## Open-ended questions

What benefit do You think You got from the program?

Do You think participating in the program has resulted in any change on Your behalf?

Was there anything You lacked in the program?

Was there anything You thought You especially benefitted from in the program?

Was there anything You didn't think was so good in the program?

Was there anything the facilitators could improve?

Abbreviation: PREM, patient-reported experience measure.

**Table 3.** Response Frequencies of the Closed Questions in the Study PREM.<sup>a</sup>

If you assess the stress management program as a whole: Do you think you had any benefit from it?

No, no benefit at all 6.0%

Yes, some benefit 42.4%

Yes, fairly good benefit 48.5%

Yes, very good benefit 3.0%

What expectations did You have of the program before it started?

Very small 12.1%

Fairly small 42.4%

Fairly good 42.4%

Very good 3.0%

<sup>b</sup>When it comes to the number of group sessions: Do You think it was:

Absolutely too few 3.1%

A little too few 3.1%

Just enough 81.3%

Too many 12.5%

When it comes to the length of every meeting: Do You think it was:

Absolutely too short 0.0%

A little too short 18.2%

Just enough 78.8%

Too long 3.0%

Do You think the number of participants in your group was:

Absolutely too few 3.0%

A little too few 24.2%

Just enough 72.7%

Too many 0.0%

Would You recommend to a good friend with heart failure to participate in the same stress management program that you have attended?

Yes, absolutely 69.7%

Yes, maybe 27.3%

No, probably not 3.0%

No, absolutely not 0.0%

Abbreviations: CET, Coping Effectiveness Training; PREM, patient-reported experience measure.

<sup>a</sup>n = 33.

<sup>b</sup>The frequency does not equal 33 due to missing response (n = 32).

*copied, Supportive meetings with others, Met expectations of content, and finally Freedom and direction.*

**Experienced appraisal and coping.** Benefits from the intervention were learning about means to cope with the illness, such as acceptance, thinking positively, and planning. Specific exercises and/or content in the CET, that were experienced as particularly useful by the participants, were different coping strategies discussed in the program. A broad repertoire of useful coping strategies was mentioned by the participants where problem-solving and relaxation were salient. Also mentioned was how to best apply the coping strategies in different situations, that is, adaptive coping.

To reason and use available resources to cope with a stressful situation.

Acquiring knowledge about stress was also seen as beneficial, which was experienced as positive changes after the CET. The participants came to realize the situation and acquired increased self-knowledge. There was also some indication that participants experienced other possibilities to appraise their situation and that the coping strategies led to increased self-reliance, they felt an inner calmness and more courageous.

Has made me think differently. Acquired tools to think things through and solve things.

In contrast, a few of the participants thought they did not benefit from the intervention and that it did not bring any changes for them. One participant explained it as:

That the course didn't give me so much, is because I don't feel stressed at all.

**Supportive meetings with others.** A common feature concerning the benefits of the CET was meeting other people in the same situation. It was seen as positive to be able to share and discuss experiences with the other group members and gave a sense of not being alone with the problem. These interactions were experienced as supportive of their ability to cope in an adaptive manner.

To meet other people with the same problems. That has been positive for me.

Variations of the experienced support were, however, found where there were some tendencies of wanting more individual support and more discussions.

**Met expectations of content.** Answers about the content of the CET, and if anything was missing, revealed that most of the participants did not want to add anything to the program. They were pleased with the content. However, there was a

tendency that more information about stress and heart failure should have been included, as well as underlining the importance of physical exercise.

A run-through of heart failure and symptoms. Show the heart on a picture and explanations.

The majority did not have any negative comments on either the program itself or the facilitation of the program.

**Freedom and direction.** This category concerns the group process and, in particular, how much guidance was to be given during the participants' discussions. There was a variation between appreciating openness in the discussions, where the group members could talk freely, in contrast to wanting more steering of the group discussions. For instance, some participants could express annoyance if one individual took a lot of space in the group discussions.

## Discussion

This study elucidates how a psychosocial education program, CET, was adapted for the first time for patients with CHF. In addition, the participants' experiences of the CET were examined, which showed an overall positive satisfaction with the program. The intervention was provided in 7 weekly sessions for patients with CHF. In the original CET intervention designed by Chesney et al, for patients with HIV, the CET was provided in an extended manner with 10 sessions and thereafter maintenance sessions over a 9-month period, including a day-long retreat, with the aim of reengaging participants and addressing relapses in stress reactions (14). This additional supportive phase of the intervention could be argued to contribute to a more sustainable effect, as was indicated in the study by Chesney et al. (14) However, a maintenance phase implemented for CET for patients with CHF requires evaluation, not only for sustainable effect but also for feasibility and cost-effectiveness. Another consideration would be how the intervention should be delivered, whether it should be face-to-face or by some other means, such as by telephone or online. While psychosocial interventions for patients with CHF, with meetings face-to-face and by telephone have been evaluated (10), there are few studies with online interventions for this patient group. Some studies have found web-based interventions feasible for patients with CHF focused on physical self-care (22,23) and on depression (24). Online interventions have the advantage of being independent of physical location and make it possible for more severely ill patients to participate, who would otherwise decline participation. More studies evaluating online psychosocial interventions are required.

The adaptation of CET for patients with CHF was performed by an interdisciplinary team. This approach had not previously been incorporated when CET was developed and adapted for other patient groups. The interdisciplinary

research group in this study is a strength, as several perspectives were accounted for when the CET was adapted. Another perspective that could be considered, if the CET would be further developed, is the patient perspective. Involving the target group for the intervention with, for example, intervention mapping (25) to promote a person-centered intervention is a technique that has been applied in other studies such as when developing an online support program for patients with cancer (26). Specific patient-focused PROMs for heart failure are now developed within the International Consortium for Health Outcomes Measurement (ICHOM) Program, to improve person-centered care of heart failure internationally (27).

When evaluating an intervention, it is not only outcome measures that are important but also evaluation of structure and process. While PROMs provide measures of outcome, PREM can also, besides outcomes such as experience and satisfaction, contribute to the evaluation of structure and process (28), which this study addresses. In the current study, unique data from PREM evaluated the CET, while the previously published studies mainly focused on PROMs (13–15). However, Kennedy et al did present some patient feedback in the study where the CET was evaluated for patients with SCI (15). The results from the current study showed that the participants seemed to be satisfied with the structure of the CET and the vast majority thought they had benefited from the intervention. The free-text answers gave insights into what they explicitly thought had been beneficial. The results found that it was valuable to discuss different coping strategies and, specifically, problem-solving and relaxation were much appreciated. Although the former study evaluating the CET for patients with CHF did not show any statistically significant effect of the CET with regard to the outcome measures of emotional well-being and health-related quality of life, as well as any change in coping strategies (13), the results of the PREM in the current study imply that there could have been an effect of the intervention in the outcome measures that were not detected in the previous study due to poor statistical power. Another finding showed that meeting other people to share and discuss experiences was experienced as very positive. This aspect has also been confirmed in feedback from patients with SCI (15). Although the discussions were appreciated, there were some participants who wanted more discussions, and some wanted more individual support. Similar findings were shown in the feedback from patients with SCI who had participated in the CET, where there were some who wanted more discussions whereas some wanted less (15). Results concerning the group process showed a variation in the preferable amount of steering of discussions being held during the sessions. Some wanted more and some wanted less steering. Feedback from the participants after each session regarding this issue could be performed to adjust the amount of direction in the group discussions according to their needs, if there is a consensus in the group.

## Limitations

There are some limitations to this study. Firstly, the PREM was used on patients who had completed the intervention, hence there is a selection bias. Experiences from participants who did not complete the intervention could have provided important information, with potentially a more critical view of the intervention. The number of participants was limited, which also could have affected the results. Also, 91% were in NYHA-class II and might not be the group who would benefit most from the intervention, such as patients with a greater symptom burden. Secondly, although the data provide some insight to the participants' experiences, the data from the free-texts answers did not provide in-depth information. The credibility of the findings was, however, increased by having two researchers analyzing the data independently. The transferability of the results is limited to patients with CHF. Finally, the PREM was used directly after the intervention, hence longer term experience of benefits was not explored.

## Conclusion and Future Direction

The CET intervention, applied for the first time to patients with CHF, seems to be feasible. Overall, the participants were satisfied with the psychosocial support program concerning the structure as well as the benefits of the intervention.

Today, there is no standard psychosocial intervention for patients with CHF implemented in clinical practice despite the high prevalence of psychological distress in this patient group. The patient satisfaction and benefits of the CET is encouraging. To build an evidence base for CET, a modified intervention design incorporating maintenance sessions could be explored and possibly the CET could be administered online. It would also be interesting to explore which groups, for example, functional class would benefit the most from the intervention. Furthermore, interviews would provide an in-depth knowledge of the participants' experience.

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