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Dialogues between nurses, patients with heart failure and their partners during a dyadic psychoeducational intervention – a qualitative study

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Dialogues between nurses, patients with heart failure and their partners during a dyadic psychoeducational intervention – a qualitative study

Running head;

Patients with heart failure and their partners' dialogues with nurses

Registrerad in ClinicalTrials.gov NCT02398799

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Abstract

Objectives: To describe nurses' documentation of the content in a psycho-educational intervention inspired by Stuijbergen's model addressing cognitive, supportive and behavioural needs of patient-partner dyads affected by heart failure.

Design: A descriptive qualitative design were used analysing nurses' documentation in a dialogue guide based on a health-promotion model.

Settings: The dialogue guide was used during three nurse-led sessions at two heart failure clinics in Sweden with patients and partners with heart failure during the years 2005-2008.

Participants: The dialogue guides from 71 patient-partner dyads were analyzed using direct deductive content analyses. Patients mean age was 69 years and 31% were female, partners mean age was 67 years and 69% were female.

Results. The findings supported the conceptual health-promotion model and identified barriers, recourses and self-efficacy described by the dyads within each category.

Conclusion: The dyads described that during the sessions they had enhanced knowledge and greater confidence to handle their life situation and expressed that they needed psycho-educational support during the whole illness trajectory. The results may guide and help to improve content and quality when caring for patients and partners affected with heart failure and also when designing new interventions.

Trial registration: ClinicalTrials.gov NCT02398799

Keywords; nursing, nurses, heart failure, communication, dyad, family, content analysis, self-care, support, patient education

Strengths and limitations of this study

- A strength of this study is that the patient-nurse discussions were structured on an existing health promotion model.
- This study adds knowledge on how a health promotion model could be used when delivering a psycho-educational intervention to patients with heart failure and their partners.
- Analysis of nurses' documentation did not allow for consideration of broader contextual factors related to patient-partner cognitive, supportive and behavioural needs, and therefore future in-depth qualitative research could give further insights.

Introduction

Heart failure (HF) is a serious condition and the leading cause for hospitalization, and re-admissions for deterioration remains high [1]. Despite most patients receiving education on how to manage the disease, many are not able to adequately engage in self-care activities [2]. HF is characterized by a number of signs and symptoms that influence both the patients' and their partners life situation. Thus, being supported by a partner is important and could improve patients' ability to perform self-care [3, 4]. Partners might need support from healthcare to be able to help the patient handle self-care in everyday life [5-8]. If the partner lack knowledge of HF or do not understand how to support the patient, giving support to the patient may be difficult. Interventions to improve HF self-care should therefore also include involvement of the patients partner and family.

However, more responsibilities laid on partners can lead to increased physical and mental distress, which in turn can cause caregiver burden [9, 10]. Previous studies have found that as much as thirty per cent of the partners perceive a moderate caregiver burden [11, 12].

Guidelines state that education is crucial for patients with HF and it is also advised to include partners in the educational programme [1]. The topics included in the nurse's educational sessions are recommended to cover various aspects of self-care and actions to take should symptoms worsen. Since patient health outcomes are related to the quality of communication with health professionals [13], teaching strategies should be tailored to each patient and reflect the patient's knowledge, motivation and cognitive function [14].

Patients and partners wish for more support from healthcare professionals to be able to handle learn their situation but to date, contemporary HF educational programmes are mainly patient-focused, but recently awareness of partners psycho-educational needs has been increasing [5]. However, there are still few HF interventions addressing both patients' and partners' educational needs. A recent review searched for effective education for HF patients and informal caregivers and found six studies with wide variation in quality [15]. The authors requested further theory-driven interventions to demonstrate what family-based HF interventions are effective for HF patients and informal caregivers.

Background

A few studies have evaluated the effects of family-focused, educational interventions and the results give no clear guidance on how programmes should be designed to give the best effect

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2
3 on patient and partner outcomes [15, 16]. One intervention improved both patients' and
4 partners' knowledge but showed modest improvements in other outcomes [17]. Two studies
5 found that caregiver depression or anxiety did not differ between the educational and control
6 groups over time [18]. Caregiver burden have shown dissimilar results, one supportive
7 intervention study found burden reduced after 3 month for partners in the intervention group
8 [19], whereas another study found no group difference after 24 months [20]. Only one
9 previous study was guided by an educational theory [17] using self-determination theory [21]
10 to guide HF patients and informal caregivers on decreasing sodium intake.

11
12 The lack of conclusive research inspired us to develop a structured dialogue guide based on a
13 conceptual health-promotion model constructed by Stuijbergen, Becker [22] and test it during
14 three nurse-led psycho-educational sessions at the HF outpatient clinic. The model was
15 originally developed and tested for patients with Multiple Sclerosis, a disease with a path
16 similar to HF, with the burden of fatigue and decreased physical ability. The model had not
17 previously included partners or families, but as partners' provides a lot of support to patients'
18 self-care, here the model was used for the patient-partner dyad. The model combined
19 educational and psychosocial support and assumes that development of skills and knowledge
20 reduces barriers and enhances resources and self-efficacy and results in better health-
21 promoting behaviours. Self-efficacy can be defined as a person's belief in their own ability to
22 manage to handle a particular situation [23].

23
24 The dialogue guide was used as a base for the conversations during three sessions and
25 included practical, educational and psychosocial topics that were addressed during the nursing
26 sessions. The result of the interventional study is reported elsewhere [20]. In this study, we set
27 out to analyze the nurses' documentation from the psycho-educational sessions. This was done
28 in order to see how Stuijbergen, Becker [22] model was used during the psycho-educational
29 intervention provided by nurses to the patient-partner dyads. We also wanted to obtain a
30 deeper understanding of what topics the dyads found important to discuss with the nurses, and
31 to what extent all parts of the cognitive, supportive and behavioural components of the model
32 were covered in the dialogues between dyads and nurses.

33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 **Aim**

54 To describe nurses' documentation of the content in a psycho-educational intervention
55 inspired by Stuijbergen's model addressing cognitive, supportive and behavioural needs of
56 patient-partner dyads affected by HF.
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Design

A descriptive, qualitative design was used to analyse nurses' documentation in dialogue guides used during sessions at the outpatient clinic with patients suffering from HF and their partners. The study is part of a project aiming at developing and evaluating psycho-educational support to patient-partner dyads affected by HF, ClinicalTrials.gov Identifier: NCT02398799 [20].

Procedure

The research team started by constructing a dialogue guide whose theoretical framework was based on a conceptual health-promotion model [22, 24], Figure 1. Previous interventions using the model have a cognitive component delivering information, but the major component focused on improving the patient's self-efficacy by identifying barriers, increasing support and developing skills and beliefs in one's capacity to achieve the desired behavioural changes. In the current study, the dialogue guide included a cognitive, a supportive and a behavioural component and focused on helping patients and partners to change thoughts and behaviours and implementing strategies for self-care management. All sessions included practical, educational and psychosocial topics and the dyads were encouraged to speak about all subjects and concerns they felt they needed to discuss.

After construction, the five-page dialogue guide was used during three nursing sessions at the HF outpatient clinic. The sessions took place between years 2005 and 2008 and were scheduled 2, 6 and 12 weeks after patients were discharged from hospital after their being admitted due to worsening HF. Each session was performed as a discussion and focused on both the patients' and the partners' situation and experiences, their individual and mutual needs and expectations. All sessions included HF education to improve the dyads problem-solving skills that would help them to recognize and modify factors contributing to psychological and emotional distress, in order to maintain and strengthen their physical and mental functions and perceived control, Figure 2. During the sessions the patient and partner participated as equals and had the same opportunity to pose questions and speak about their individual concerns.

All four participating HF nurses were experienced in caring for HF patients and had attended three days of theoretical and practical training on how to deliver the intervention and document the dialogues, before the study started. On several occasions, the study team visited

the HF clinics and assessed the nurses' competence and study fidelity through observations and consultations.

Insert Figure 1. The conceptual health promotion model by Stuijbergen et al, and Figure 2. Cognitive, supportive and behavioural goals for each visit.

Participants

The dialogue guides from 71 patients with HF and their co-habiting partners were included in the analyses, Table 1. The mean age for the patients was 69 (± 14) years and partners 67 (± 12) years, 69% of the patients were male and 55% were found to be in the New York Heart Association function-class III. Regarding employment, 14% of the patients and 33% of the partners worked full time, 86% of the patients and 64% of the partners had a pension/were on sick leave, 3% of the partners were homemakers.

Table 1. Characteristics of the Participants

	Patients (n=71)	Partners (n=71)
Sociodemographics		
Age, mean \pm SD	69 (± 14)	67 (± 12)
Female, n (%)	31%	69%
NYHA class, n (%)		
II	24 (35)	
III	40 (55)	
IV	7 (10)	
Employment, n (%)		
Full time	10 (14)	22 (33)
Disability pension/sick leave	13 (17)	2 (3)
Homemaker	1 (1)	2 (3)
Pension	47 (68)	45 (61)

Data collection

The data consisted of the nurses hand-written documentation in the five-page dialogue guides used during the intervention. During each of the three sessions, the nurses documented summaries of the discussions regarding the situation, given information and agreements and described difficulties.

Data analysis

A directed content analysis was selected for the analysis [25]. Directed content analysis is by nature deductive and is used to validate or extend an existing theory or a model. The analysis is guided by a structured analytic process using existing research where the researcher begins with predetermined concepts as initial predetermined coding categories [26]. These predetermined categories are then used to code the text [25]. In the current study, we wanted to investigate to what extent Stuijbergen's model [22] had been used and could be validated in the context, using the nurses documentation.

The initial coding categories were based on the areas in the dialogue guide: 1) cognitive components 2) supportive components 3) behavioural components, which were developed from the conceptual health-promotion model [22]. The researchers started by developing operational definitions on the categories, see Table 2.

Table 2. Coding framework based on the conceptual health promotion model

Coding category	Description
Cognitive component	Texts were coded into this category when statements described lifestyle modifications, medications and symptom management.
Supportive components	Texts were coded into this category when statements assess patients or partners need of support, partner's caregiver burden, modifying caregiver behavior, strengthen self-care behaviour.
Behavioural components	Texts were coded into this category when statements described barriers to lifestyle modifications, strategies to improve or maintain self-care behaviour, intentions, abilities and self-efficacy regarding self-care, planning for the future.

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3 Secondly, the first author (ML) typed out the content in the dialogue guides into a clear copy
4 and numbered the transcripts so it was possible to see from which dialogue guide they were
5 derived. To obtain a sense of the whole, transcriptions were read through several times by all
6 authors. In the next step the text was reviewed and text that described cognitive, supportive or
7 behavioural components was sorted into one of the predetermined categories.
8

9
10 The text in the dialogue guide was validated to be part of the predetermined categories or to
11 be findings that were new and unknown [25, 27]. Each category was then reviewed and the
12 content was divided into what were considered to be barriers, resources or self-efficacy,
13 which are the concepts in the model. Finally, we compared the extent to which the data were
14 supported by Stuijbergen's model versus what represented new aspects not described in the
15 model.
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23 The first and the last author conducted the analysis, while the other two authors were involved
24 in the discussions. Throughout the analysis, there was continuous back and forth movement
25 between the whole text and the categories including the concepts of the model, where all
26 authors scrutinized and repeatedly discussed the results to ensure the trustworthiness of the
27 data analysis.
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32 33 **Rigour**

34 In qualitative research, the concepts of credibility, transferability, dependability and
35 confirmability are considered aspects of trustworthiness [28].
36

37 In this study, a directed deductive content analysis was chosen to validate an existing model
38 [22]. Directed content analysis is a structured and systematic analysis process and the method
39 guides the findings towards existing codes and categories [25]. By using directed content
40 analysis, trustworthiness can be achieved, as the text is compared with an existing model,
41 which in turn has gone through a publication process. The systematic way of working with the
42 analysis and the use of an existing model or theory strengthens the trustworthiness [29].
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45 To strengthen the credibility and confirmability different strategies have been used.
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47 The nurses' documentation in the dialogue guides has been used verbatim. The text varied in
48 depth and length. Some nurses wrote summatively and others described the discussions in
49 more words. Nevertheless, all dialogue guides provided important and clear information on
50 the components of dyad functioning as assessed during the sessions. The raw data consisted of
51 handwritten text, but all nurses had clear handwriting so all data were credible.
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58 The results have been discussed and compared to previous research. The authors are all
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3 experienced nurses and for many years have worked with patients with HF and also met their
4 partners. During the analysis, the material has been read many times and the various
5 components in the subcategories and the categories were reflected upon and this result can be
6 seen as a possible interpretation of the data. An analyst triangulation was implied including
7 both individual coding and consensus discussions in the research team allowing for testing
8 negative cases and rival explanations.
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12 To fulfill dependability the authors maintained a decision trail developing the interview guide,
13 during data collection, in analysis and also the research team regularly visited the nurses and
14 assessed their competence to deliver the intervention through observations and consultations.
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16 Transferability of the findings was facilitated as the sample; the context and the analysis
17 process are described in detail. Transferability to similar HF samples is possible since there
18 were dialogue guides available from 71 dyads, which is a fairly large sample.
19

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21 To ensure confidentiality, neither the names of the participants nor hospitals are published.
22
23

24 25 26 **Ethical considerations**

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28 The study was approved by the Regional Ethical Review Board in Linköping, Sweden (Study
29 code 03-568/ M178-04). The nurses at the HF clinic were informed that data would be
30 analyzed for study purposes.
31
32

33 34 35 **Results**

36
37 The findings from the analysis showed that the conceptual health-promotion model by
38 Stuijbergen et al., [22] was used during the psycho-educational sessions. The analysis
39 confirmed the three predetermined categories: 1) cognitive components 2) supportive
40 components 3) behavioural components. The content in the three categories was divided into
41 the concepts barriers, resources and self-efficacy.
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45 46 47 **Cognitive component**

48 49 **Barriers**

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51 The major cognitive barrier for both patients and partners was the described lack of
52 knowledge. Some patients had received information prior to the sessions but several patients
53 had no prior knowledge about the disease. They did not know that self-care could be carried
54 out and affect their well-being although they had lived with the diagnosis for many years.
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56 Others described that they did not really understand that they were sick and the lack of insight
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3 had meant that they had not engaged in self-care activities.
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6 Almost none of the partners expressed that they had prior knowledge and therefore they had
7 not been involved in the patients' self-care activities. A few partners had searched for
8 information about HF on the Internet, but found many websites lacking practical information
9 which became more of a cognitive barrier than a resource in daily living.
10

11 As they discussed their expectations of the sessions, the dyads expressed a broad range of
12 expectations varying from a wish and belief that the patient would be cured, to the other side
13 of the coin; that it does not matter what we do because both body and heart are too old and too
14 sick. Also a few partners did not want to know anything about HF because it made them feel
15 worried and uneasy.
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22 **Resources**

23 Cognitive resources were found when the dyads expressed a wish to learn about HF. At the
24 first session, both patients and partners posed general questions about HF treatment, causes
25 and prognosis after receiving a general knowledge overview by the nurse. However, with
26 increased knowledge, both patients' and partners' questions were more specific regarding
27 how to perform self-care activities on a daily basis.
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34 **Self-efficacy**

35 During the sessions, the dyads described that they enhanced their knowledge and had a greater
36 confidence to handle their situation. The patients felt they have had an opportunity to pose
37 questions and now had in-depth knowledge of the disease, and due to that, the confidence to
38 act had increased.
39

40 Partners felt they had received guidance regarding exercise, for example how much someone
41 who has HF can walk without it becoming harmful. So now they encouraged the patient to
42 exercise. They also learned and felt confident in how to act in case of deterioration and how
43 deterioration could be prevented.
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51 **Supportive component**

52 **Barrier**

53 Supportive barriers could be both emotional and practical, and both patients and partners
54 described they often lacked support. Examples of emotional barriers were that due to anxiety
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3 and consideration, some partners tried to set limits to physical activity so patients do not
4 overstrain themselves. When patients felt overprotected this sometimes leads to tension and
5 conflicts in the relationship. During the discussions the nurses helped and guided dyads to
6 communicate their thoughts and concerns with each other.
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10 Another barrier was loss of friends due to the disease. Patients could no longer socialize like
11 before and therefore the partner had less social support, activities and interactions. The dyads
12 became isolated since the partner did not want to leave patient alone and do things on their
13 own.
14
15

16 Dyads described a lack of good healthcare contacts. Nurses' documentation revealed that
17 many patients were sad and depressed over their situation. Partners described a worry and
18 asked for long-term guidance from healthcare professionals to learn how to offer support.
19 Since several partners had no previous knowledge about the disease, the sessions brought up
20 many thoughts that they needed a nurse's support to process.
21
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23
24 The dyads expressed a wish for further, regular visits at the HF outpatient clinic. The visits
25 had created security for both patient and partner and they expressed anxiety when the possibly
26 to contact the nurses would end. The visits had made them feel secure and they knew they had
27 someone they could contact when questions arose.
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33 A practical, supportive barrier was if the partner also had some illness and therefore was not
34 able to provide support to the patient with HF, and maybe instead needed help and support
35 themselves. Need of formal support from someone outside the family arose primarily if both
36 patient and partner had difficulty carrying out practical tasks, such as driving or managing the
37 household.
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41 Some dyads experienced hopelessness when the future was discussed and patients were
42 perceived as depressed in the nurses' documentation. Some patients expressed a need for
43 contact with a social worker; others were in continuous need of support from home-care.
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47 48 **Resources**

49 Many dyads said that they helped each other and shared the chores on the basis of strength
50 and ability. With increased knowledge, they seemed to understand better why it is important
51 to perform self-care activities, and for some patients this led to a need of support from the
52 partner. Partners wished to learn and become more involved in the care and help with
53 decision-making on a daily basis.
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57 The need for support increased when patients were depressed or suffered from multi-
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3 morbidity. Some patients had previously had contact with a social worker and have, due to
4 these visits, been helped to accept their situation.
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7 8 **Self-efficacy**

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10 The documentation described that many partners give plenty of practical support, but also
11 how they encouraged patients to take own responsibility. Also, when the partner had
12 knowledge and the patient was motivated, confidence in their own abilities increased in both
13 patients and partners.
14
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16 17 18 **Behavioural component**

19 20 **Barrier**

21 A behavioural barrier was patients' lack of strength, which led to involuntary inactivity. Both
22 patients and partners felt that partners had to take on more of the workload in the household.
23 The additional burden was described as mentally exhausting for the partners due to a greater
24 responsibility.
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28 Some dyads described that the new roles led to conflicts and fractions in the relationship.
29 Partners thought it was difficult to leave the patient alone and that they had to hurry home
30 from work, leaving no time for own activities.
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33 Some patients found it hard to follow dietary advice, to weigh themselves daily and to
34 monitor and assess HF signs and symptoms. For some dyads, HF had been a barrier for
35 sexuality, where the patient no longer has the energy and the partner no longer dares to have a
36 sexual relation. The documentation did not reveal how the nurse discussed the perceived
37 sexual difficulties with the dyads.
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43 44 **Resources**

45 Most patients wished to take the main responsibility to manage their self-care, but sometimes
46 were lacking confidence in their own ability and doubting the effect of self-care advices.
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48 When seeing effects of their self-care activities, the patients' confidence to manage self-care
49 increased.
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53 For some dyads, the new roles had strengthened the relationship. They collaborated to follow
54 instructions about behavioural changes and provided mutual support to each other. In some
55 relationships, the partner functioned as a resource for the patient, someone to discuss
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3 strategies with. Other partners provided help with self-care on a daily basis.
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6 **Self-efficacy**

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8 During the last visit, the nurses assessed that most of the dyads had a good understanding
9 about HF. They had confidence when following the self-care advice given during the sessions
10 and had gradually adapted to the situation. Adaptations could, for example, be a change of
11 accommodation or partner's employment.
12
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14 **Discussion**

15
16 Our study showed that the model developed by Stuijbergen et al., [22], covering cognitive,
17 supportive and behavioural components of dyad functioning, was fully addressed during the
18 nursing sessions. The findings revealed a wide range of cognitive, supportive and behavioural
19 needs among the dyads. The model highlights the importance of identifying and discussing
20 barriers, resources and self-efficacy to increase the dyads health- promoting behaviours.
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23 For some dyads the new roles had strengthened their relationship and patients and partners
24 collaborated and provided mutual support to each other. It is known that supporting a person
25 with HF involves several salient changes in daily life and includes both benefits and burdens.
26 It represents an opportunity for increased intimacy with the person who is ill. Care-giving is
27 sometimes experienced as rewarding and provides satisfaction and hopes for a positive future
28 [30, 31].
29

30 The nurses' documentation showed that most patients found great support in their partners
31 and partners provided both practical and emotional support. Caregiver support is known to
32 improve self-care and strengthen patients adherence to medical treatment and maintaining a
33 healthy lifestyle [3, 32, 33]. However, one recent study found the contrary. Cocchieri and
34 colleagues [34] found that having a caregiver was associated with poor self-care maintenance.
35 They concluded that their result might be due to the fact that patients having a partner were
36 more cognitive and functionally impaired, had higher co-morbidity and were in need of more
37 care.
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41 Caregiving may sometimes be experienced as burdensome for the partner. Partners in the
42 current study described they have taken over much of the workload in the household and
43 helped the patients with practical tasks regarding the patient's self-care management, and for
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3 some it meant a burden. One third of partners to patients with HF were perceived moderate
4 caregiver burden and could be at higher risk of decreased health [11]. As in previous research,
5 partners sacrificed their own needs in order to support care for the patient. Partners perceived
6 a need for support with daily living as well as easy access to the healthcare providers [35]. To
7 reduce caregiver burden interventions should focus on improving social support and provide
8 knowledge of HF to both patients and caregivers to increase their perceived control over the
9 situation [30].
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16 With the increasing awareness of patient needs, there are a lot of educational moments in
17 most current HF care. However, it still seems important to consider cognitive aspects during
18 nursing sessions. Patients felt that they had never received information about their illness
19 before. One reason could be that they had suffered from HF for many years and only received
20 education at the time of the diagnosis, and now the information has been forgotten. Another
21 reason could be that there is a high occurrence of mild cognitive deficits among patients with
22 HF without known cognitive diseases or disorders [36]. This calls for repeated information
23 and follow-ups and close attention should be paid to the patient's self-care abilities and
24 compliance, as inadequate self-care activities could lead to repeated hospitalizations.
25 Cognitive impairment presents a barrier to the complex medication and self-care management
26 that is required in HF treatment [37]. Due to this, both patients and caregivers perceive a need
27 to have a long-term healthcare contact they can turn to when questions arise [35, 38]. This is
28 supported in the present results where the dyads expressed a need for long-term support from
29 nurses, and for some, also homecare and social workers.
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41 The behavioural component includes self-care abilities, and a prerequisite for self-care
42 adherence is to gain knowledge. Self-care has been defined as a naturalistic decision-making
43 process which influences actions that maintain physiologic stability, facilitates the perception
44 of symptoms and directs the management of symptoms [39]. Patients and partners need to
45 learn about HF to become active participants in the management of the illness but sometimes
46 their own knowledge was not enough and then the dyads wanted easy access to healthcare.
47 Long-term support was highlighted as an important factor to remain being perceived as
48 healthy and well-being. Previous research has also addressed both patients and caregivers
49 need for a regular healthcare contact they can easily contact, as they currently experience
50 difficulties both navigating and assessing support [40]. Today, a lot of different healthcare
51 professionals (primary care physicians and nurses, cardiologists and HF nurses) could be
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3 involved in the care for HF patients. Patients and caregivers have to decide whom to contact
4 based on their previous experiences, which is perceived as confusing and leads to insecurity.
5 To instead have a permanent healthcare contact they can turn to if necessary would facilitate
6 daily life.
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10 **Limitations**

11 In qualitative research, generalizability of the findings may be restricted to a particular setting
12 or context. However, the current study findings are consistent with previous research using
13 the Stuijbergen, Becker [22] model in a different setting and for patients with Multiple
14 Sclerosis.
15

16 The nurses were informed beforehand that their documentation was going to be analysed. The
17 nurses' documentation in the dialogue guides was transcribed verbatim. The text varied in
18 depth and length. Some nurses wrote summatively and others described the discussions in
19 more words. Nevertheless, all dialogue guides provided important and clear information on
20 the components of dyad functioning as assessed during the sessions.
21

22 The raw data consisted of handwritten text which may affect credibility. However, all nurses
23 had clear handwriting so all data were considered accurate.
24
25
26

27 **Conclusion**

28 This study described how cognitive, supportive and behavioural components of dyad
29 functioning were addressed during nursing sessions with dyads affected by HF.
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31 We found the model to be suitable for helping patient-partner dyads with HF gain knowledge
32 and develop skills to handle living with HF, and the model promoted healthy and supportive
33 behaviours.
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35 The findings of the current study may be used to improve content and quality in HF care and
36 can also serve as a guide when designing new psychoeducational dyad interventions. The
37 findings provide practical examples of cognitive, supportive and behavioural needs, which
38 need to be considered when meeting patients and partners affected by HF. This knowledge
39 can be applied in HF units to develop a dyad educational regime.
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8 CONTRIBUTOR SHIP STATEMENT

9 SÅ and ML collected the data. ML analysed the data and wrote the manuscript. SÅ, TJ and
10 AS contributed to data analysis and to the writing of the manuscript. AS and TJ
11 conceptualised and developed the idea for the study as part of the broader research
12 programme, contributed to data analysis and to the writing of the manuscript. All authors
13 critically edited the manuscript and read and approved the final version.
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26 Competing interests

27 None declared.
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29

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31 Ethics approval

32 The study was approved by the Regional Ethical Review Board in Linköping, Sweden (Study
33 code 03-568/ M178-04).
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38 Data sharing statement

39 No additional data are available.
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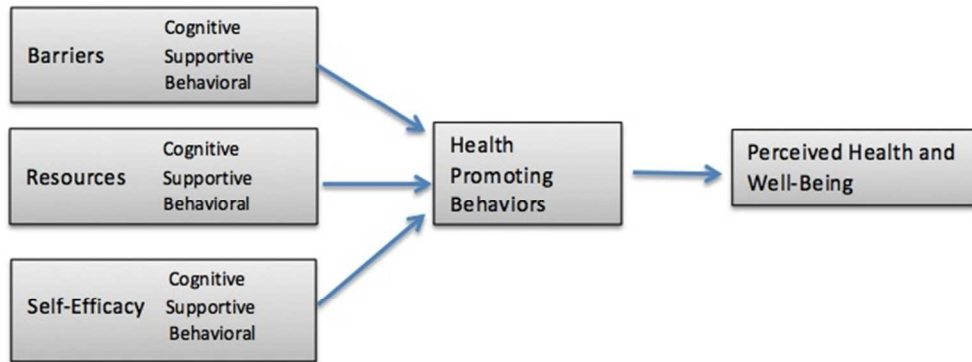


Figure 1. The conceptual health promotion model by Stuijbergen et al.

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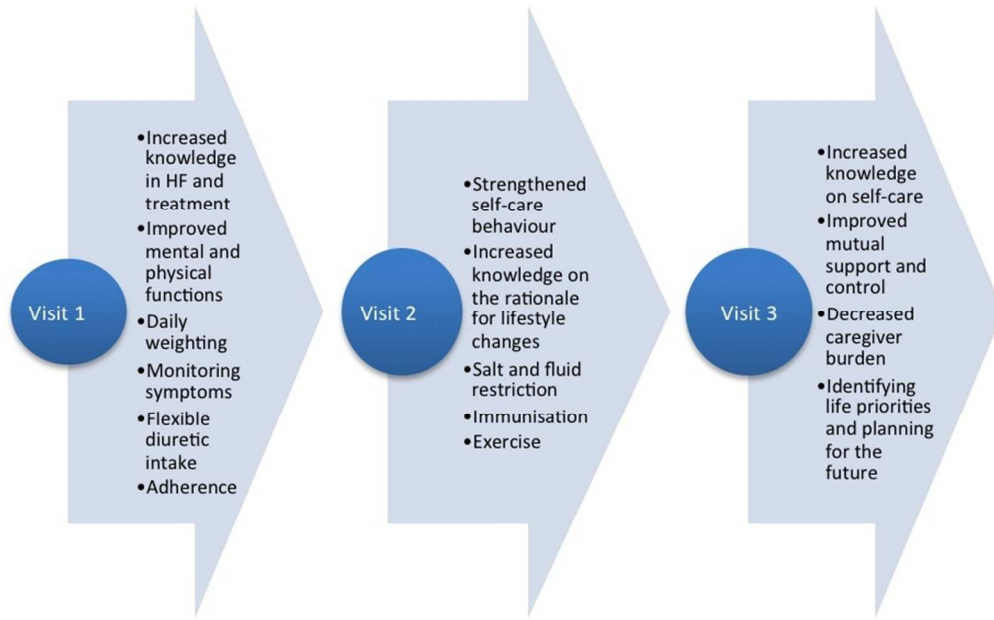


Figure 2. Cognitive, supportive and behavioural goals for each visit.

322x197mm (72 x 72 DPI)

Review only

**Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)
September 15, 2015**

Text Section and Item Name	Section or Item Description	
<p style="text-align: center;">Notes to authors</p>	<ul style="list-style-type: none"> • The SQUIRE guidelines provide a framework for reporting new knowledge about how to improve healthcare • The SQUIRE guidelines are intended for reports that describe system level work to improve the quality, safety, and value of healthcare, and used methods to establish that observed outcomes were due to the intervention(s). • A range of approaches exists for improving healthcare. SQUIRE may be adapted for reporting any of these. • Authors should consider every SQUIRE item, but it may be inappropriate or unnecessary to include every SQUIRE element in a particular manuscript. • The SQUIRE Glossary contains definitions of many of the key words in SQUIRE. • The Explanation and Elaboration document provides specific examples of well-written SQUIRE items, and an in-depth explanation of each item. • Please cite SQUIRE when it is used to write a manuscript. 	<p style="text-align: center; color: purple;">As you review the manuscript, place a checkmark in this column for each SQUIRE item that is appropriately addressed in the manuscript. Remember that not every item is necessary in every manuscript.</p>
<p style="text-align: center;">Title and Abstract</p>		
<p style="text-align: center;">1. Title</p>	<p>Indicate that the manuscript concerns an initiative to improve healthcare (broadly defined to include the quality, safety, effectiveness, patient-centeredness, timeliness, cost, efficiency, and equity of healthcare)</p>	<p style="text-align: center;">Title page 1</p>
<p style="text-align: center;">2. Abstract</p>	<ol style="list-style-type: none"> a. Provide adequate information to aid in searching and indexing b. Summarize all key information from various sections of the text using the abstract format of the intended publication or a structured summary such as: background, local problem, methods, interventions, results, conclusions 	<p style="text-align: center;">page 2</p>

Introduction	<i>Why did you start?</i>	
3. Problem Description	Nature and significance of the local problem	4
4. Available knowledge	Summary of what is currently known about the problem, including relevant previous studies	4-5
5. Rationale	Informal or formal frameworks, models, concepts, and/or theories used to explain the problem, any reasons or assumptions that were used to develop the intervention(s), and reasons why the intervention(s) was expected to work	4-5
6. Specific aims	Purpose of the project and of this report	5
Methods	<i>What did you do?</i>	
7. Context	Contextual elements considered important at the outset of introducing the intervention(s)	6
8. Intervention(s)	a. Description of the intervention(s) in sufficient detail that others could reproduce it b. Specifics of the team involved in the work	procedure, page 6
9. Study of the Intervention(s)	a. Approach chosen for assessing the impact of the intervention(s) b. Approach used to establish whether the observed outcomes were due to the intervention(s)	Design p 6 Rigour p 9
10. Measures	a. Measures chosen for studying processes and outcomes of the intervention(s), including rationale for choosing them, their operational definitions, and their validity and reliability b. Description of the approach to the ongoing assessment of contextual elements that contributed to the success, failure, efficiency, and cost c. Methods employed for assessing completeness and accuracy of data	Method p 6-10
11. Analysis	a. Qualitative and quantitative methods used to draw inferences from the data b. Methods for understanding variation within the data, including the effects of time as a variable	8
12. Ethical Considerations	Ethical aspects of implementing and studying the intervention(s) and how they were addressed, including, but not limited to, formal ethics review and potential conflict(s) of interest	10

Results	<i>What did you find?</i>	
13. Results	<ul style="list-style-type: none"> a. Initial steps of the intervention(s) and their evolution over time (<i>e.g.</i>, time-line diagram, flow chart, or table), including modifications made to the intervention during the project b. Details of the process measures and outcome c. Contextual elements that interacted with the intervention(s) d. Observed associations between outcomes, interventions, and relevant contextual elements e. Unintended consequences such as unexpected benefits, problems, failures, or costs associated with the intervention(s). f. Details about missing data 	10-14
Discussion	<i>What does it mean?</i>	
14. Summary	<ul style="list-style-type: none"> a. Key findings, including relevance to the rationale and specific aims b. Particular strengths of the project 	14-15
15. Interpretation	<ul style="list-style-type: none"> a. Nature of the association between the intervention(s) and the outcomes b. Comparison of results with findings from other publications c. Impact of the project on people and systems d. Reasons for any differences between observed and anticipated outcomes, including the influence of context e. Costs and strategic trade-offs, including opportunity costs 	14-15
16. Limitations	<ul style="list-style-type: none"> a. Limits to the generalizability of the work b. Factors that might have limited internal validity such as confounding, bias, or imprecision in the design, methods, measurement, or analysis c. Efforts made to minimize and adjust for limitations 	16
17. Conclusions	<ul style="list-style-type: none"> a. Usefulness of the work b. Sustainability c. Potential for spread to other contexts d. Implications for practice and for further study in the field e. Suggested next steps 	16
Other information		
18. Funding	Sources of funding that supported this work. Role, if any, of the funding organization in the design, implementation, interpretation, and reporting	19

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Dialogues between nurses, patients with heart failure and their partners during a dyadic psychoeducational intervention – a qualitative study

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Dialogues between nurses, patients with heart failure and their partners during a dyadic psychoeducational intervention – a qualitative study

Running head:

Patients with heart failure and their partners' dialogues with nurses

Registered in ClinicalTrials.gov NCT02398799

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Abstract

Objectives: To describe nurses' documentation of the content in a psychoeducational intervention inspired by Stuijbergen's model addressing cognitive, supportive and behavioural needs of patient-partner dyads affected by heart failure.

Design: A descriptive qualitative design was used analysing nurses' documentation in a dialogue guide based on a health-promotion model.

Settings: The dialogue guide was used during three nurse-led sessions at two heart failure clinics in Sweden with patients affected with heart failure and their partners-during the years 2005-2008.

Participants: The dialogue guides from 71 patient-partner dyads were analysed using direct deductive content analyses. Patients' mean age was 69 years and 31% were female, partners' mean age was 67 years and 69% were female.

Results. The findings supported the conceptual health-promotion model and identified barriers, recourses and self-efficacy described by the dyads within each category.

Conclusion: The dyads described that during the sessions they had gained enhanced knowledge and greater confidence to handle their life situation and expressed that they needed psycho-educational support during the whole illness trajectory. The results may guide and help to improve content and quality when caring for patients affected with heart failure and their partners and also when designing new interventions.

Trial registration: ClinicalTrials.gov NCT02398799

Keywords; nursing, nurses, heart failure, communication, dyad, family, content analysis, self-care, support, patient education

Strengths and limitations of this study

- A strength of this study is that the patient-nurse discussions were structured on an existing health promotion model.
- This study adds knowledge on how a health promotion model could be used when delivering a psycho-educational intervention to patients with heart failure and their partners.
- Analysis of nurses' documentation did not allow for consideration of broader contextual factors related to patient-partner cognitive, supportive and behavioural needs, and therefore future in-depth qualitative research could give further insights.

Introduction

Heart failure (HF) is a serious condition and the leading cause for hospitalization, and re-admissions for deterioration remain high [1]. Despite most patients receiving education on how to manage the disease, many are not able to adequately engage in self-care activities [2]. HF is characterized by a number of signs and symptoms that influence both the patients' and their partners' life situation. Thus, being supported by a partner is important and could improve patients' ability to perform self-care [3, 4]. Partners might need support from healthcare to be able to help the patient handle self-care in everyday life [5-8]. If the partner lacks knowledge of HF or does not understand how to support the patient, then giving support to the patient may be difficult. Interventions to improve HF self-care should therefore also include involvement of the patient's partner and family.

However, more responsibilities laid on partners can lead to increased physical and mental distress, which in turn can cause caregiver burden [9, 10]. Previous studies have found that as much as thirty per cent of the partners perceive a moderate caregiver burden [11, 12].

Guidelines state that education is crucial for patients with HF and it is also advised to include partners in the educational programme [1]. The topics included in the nurse's educational sessions are recommended to cover various aspects of self-care and actions to take should symptoms worsen. Since patient health outcomes are related to the quality of communication with health professionals [13], teaching strategies should be tailored to suit each patient and reflect the patient's knowledge, motivation and cognitive function [14].

Patients and partners wish for more support from healthcare professionals to be able to handle their situation. To date, contemporary HF educational programmes are mainly patient-focused, but recently awareness of partners' psycho-educational needs has been increasing [5]. However, there are still few HF interventions addressing both patients' and partners' educational needs. A recent review searched for effective education for HF patients and informal caregivers and found six studies with wide variation in quality [15]. The authors requested further theory-driven interventions to demonstrate which family-based HF interventions are effective for HF patients and informal caregivers.

Background

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3 A few studies have evaluated the effects of family-focused, educational interventions and the
4 results give no clear guidance on how programmes should be designed to give the best effect
5 on patient and partner outcomes [15, 16]. One intervention improved both patients' and
6 partners' knowledge but showed modest improvements in other outcomes [17]. Two studies
7 found that caregiver depression or anxiety did not differ between the educational and control
8 groups over time [18]. Caregiver burden has shown dissimilar results, one supportive
9 intervention study found burden reduced after 3 months for partners in the intervention group
10 [19], whereas another study found no group difference after 24 months [20]. Only one
11 previous study was guided by an educational theory, [17] using self-determination theory [21]
12 to guide HF patients and informal caregivers on decreasing sodium intake.

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14 The lack of conclusive research inspired us to develop a structured dialogue guide based on a
15 conceptual health-promotion model constructed by Stuifbergen et al., [22] delivered during
16 three nurse-led psycho-educational sessions at the HF outpatient clinic. When the study was
17 designed there were no previous theory-based studies in the HF population; the model used
18 was originally developed and tested for patients with Multiple Sclerosis (MS). Multiple
19 Sclerosis is a disease with a path similar to HF, with the burden of fatigue and decreased
20 physical ability. The model focuses on promoting health and not solely helping individuals to
21 manage a disease, and propose that health promoting behaviours are influenced by a person's
22 perceived barriers, resources and self-efficacy for health behaviours. The concepts in the
23 model are developed from Pender's model of health promotion [23] and Bandura's self-
24 efficacy theory [24]. The assumption is that development of knowledge and skills reduces
25 barriers and enhances resources and self-efficacy. This will result in better health promoting
26 behaviours, such as self-care. Self-efficacy can be defined as an individual's belief in his or
27 her ability to succeed in a particular situation [24]. Individuals with high self-efficacy have
28 been found to be more likely to view perceived difficulties, such as self-care activities, as
29 something to be mastered rather than something to avoid [25]. Gaining knowledge about
30 disease management is viewed as the basis for the choice of behaviours to sustain and
31 enhance quality of life [24].

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33 A previous intervention programme designed within this model had a cognitive component
34 delivering information, but the major component focused on improving patient's self-efficacy
35 by identifying barriers, enhancing resources, increasing support and helping to develop skills
36 and beliefs in one's own capacity to achieve desired behaviour changes. The programme
37 included lifestyle-change classes for 8 weeks and telephone follow-up for 3 months. The
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3 results showed positive effects regarding health behaviours, health-promoting behaviours,
4 mental health and pain [22, 26].

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6 The model had not previously included partners or families, but as partners provide a lot of
7 support to patients' self-care, here the model was used for the patient-partner dyad. The
8 caregiving situation may be considered as a stressor that poses demands and is often
9 perceived as a stressful or challenging situation for both the partner providing care and the
10 patient receiving care [27]. Caregiving can be conceptualized as a dyadic interpersonal
11 interaction that involves both the caregiver's and the patient's perspectives [27].

12
13 The current intervention focused on problem-solving, information acquisition, self-care
14 management, and emotional and social support to dyads. The nurses delivering the
15 intervention assisted the dyads in recognising and modifying factors that contributed to
16 physical and emotional distress, by supporting them in changing their thoughts and rooted
17 behaviours and implementing strategies for self-care management and maintenance.

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19 The dialogue guide was used as a base for the conversations during three sessions and
20 included practical, educational and psychosocial topics that were addressed during the nursing
21 sessions. The result of the interventional study is reported elsewhere [20]. In this study, we set
22 out to analyse the nurses' documentation from the psycho-educational sessions. This was done
23 in order to see how the Stuijbergen, Becker [22] model was used during the psycho-
24 educational intervention provided by nurses to the patient-partner dyads. We also wanted to
25 obtain a deeper understanding of what topics the dyads found important to discuss with the
26 nurses and to what extent all parts of the cognitive, supportive and behavioural components of
27 the model were covered in the dialogues between dyads and nurses.
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43 **Aim**

44 To describe nurses' documentation of the content in a psycho-educational intervention
45 inspired by Stuijbergen's model addressing cognitive, supportive and behavioural needs of
46 patient-partner dyads affected by HF.
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50 **Design**

51 A descriptive, qualitative design was used to analyse nurses' documentation in dialogue
52 guides used during sessions at the outpatient clinic with patients affected by HF and their
53 partners. The study is part of a project aiming at developing and evaluating psycho-
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3 educational support to patient-partner dyads affected by HF, ClinicalTrials.gov Identifier:
4 NCT02398799 [20].
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8 **Procedure**

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10 The research team started by constructing a dialogue guide whose theoretical framework was
11 based on a conceptual health-promotion model [22, 26], Figure 1. Previous interventions
12 using the model have a cognitive component delivering information, but the major component
13 focused on improving the patient's self-efficacy by identifying barriers, increasing support
14 and developing skills and beliefs in one's capacity to achieve the desired behavioural changes.
15 In the current study, the dialogue guide included a cognitive, a supportive and a behavioural
16 component and focused on helping patients and partners to change thoughts and behaviours
17 and implement strategies for self-care management. All sessions included practical,
18 educational and psychosocial topics and the dyads were encouraged to speak about all
19 subjects and concerns they felt they needed to discuss.
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28 After construction, the five-page dialogue guide was used during three nursing sessions at the
29 HF outpatient clinic. The sessions took place between years 2005 and 2008 and were
30 scheduled 2, 6 and 12 weeks after patients were discharged from hospital after their admission
31 due to worsening HF. Each session was performed as a discussion and focused on both the
32 patients' and the partners' situation and experiences, their individual and mutual needs and
33 expectations. All sessions included HF education to improve the dyads' problem- solving
34 skills that would help them to recognize and modify factors contributing to psychological and
35 emotional distress, in order to maintain and strengthen their physical and mental functions and
36 perceived control, Figure 2. During the sessions, the patient and partner participated as equals
37 and had the same opportunity to pose questions and speak about their individual concerns.
38 All four participating HF nurses were experienced in caring for HF patients and had attended
39 three days of theoretical and practical training on how to deliver the intervention and
40 document the dialogues, before the study started. On several occasions, the study team visited
41 the HF clinics and assessed the nurses' competence and study fidelity through observations
42 and consultations. The study was designed in accordance with the World Medical Association
43 Declaration of Helsinki and the Code of Ethics for Nurses [28]. Permission was granted by
44 the Regional Ethical Review Board in Linköping. The nurses and the dyads were informed
45 that the documentation was planned to be used for research. The nurses all consented verbally
46 that the material could be analyzed. The dyads of patients and caregivers gave their informed
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consent to participating in the study and were aware of that the dialogues were documented and planned to be analysed.

Insert Figure 1. The conceptual health promotion model by Stuijbergen et al., and Figure 2. Cognitive, supportive and behavioural goals for each visit.

Participants

The dialogue guides from 71 patients with HF and their co-habiting partners were included in the analyses, Table 1. The mean age for the patients was 69 (± 14) years and partners 67 (± 12) years, 69% of the patients were male and 55% were found to be in the New York Heart Association function-class III. Regarding employment, 14% of the patients and 33% of the partners worked full time, 86% of the patients and 64% of the partners had a pension/were on sick leave, 3% of the partners were homemakers.

Table 1. Characteristics of the Participants

	Patients (n=71)	Partners (n=71)
Sociodemographics		
Age, mean \pm SD	69 (± 14)	67 (± 12)
Female, n (%)	31%	69%
NYHA class, n (%)		
II	24 (35)	
III	40 (55)	
IV	7 (10)	
Employment, n (%)		
Full time	10 (14)	22 (33)
Disability pension/sick leave	13 (17)	2 (3)
Homemaker	1 (1)	2 (3)
Pension	47 (68)	45 (61)

Data collection

The data consisted of the nurses hand-written documentation in the five-page dialogue guides used during the intervention. During each of the three sessions, the nurses documented summaries of the discussions regarding the situation, given information and agreements and described difficulties.

Data analysis

A directed content analysis was selected for the analysis [29]. Directed content analysis is by nature deductive and is used to validate or extend an existing theory or a model. The analysis is guided by a structured analytic process using existing research where the researcher begins with predetermined concepts as initial predetermined coding categories [30]. These predetermined categories are then used to code the text [29]. In the current study, we wanted to investigate to what extent Stuijbergen's model [22] had been used and could be validated in the context, using the nurses' documentation.

The initial coding categories were based on the areas in the dialogue guide: 1) cognitive components 2) supportive components 3) behavioural components, which were developed from the conceptual health-promotion model [22]. The researchers started by developing operational definitions of the categories, see Table 2.

Table 2. Coding framework based on the conceptual health promotion model

Coding category	Description
Cognitive component	Texts were coded into this category when statements described lifestyle modifications, medications and symptom management.
Supportive components	Texts were coded into this category when statements assessed the patient's or partner's need of support, partner's caregiver burden, modifying caregiver behaviour, strengthening self-care behaviour.
Behavioural components	Texts were coded into this category when statements described barriers to lifestyle modifications, strategies to improve or maintain self-care behaviour, intentions, abilities and self-efficacy regarding self-care, planning for the future.

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3 Secondly, the first author (ML) typed out the content in the dialogue guides into a clear copy
4 and numbered the transcripts so it was possible to see from which dialogue guide they were
5 derived. To obtain a sense of the whole, transcriptions were read through several times by all
6 authors. In the next step the text was reviewed and text that described cognitive, supportive or
7 behavioural components was sorted into one of the predetermined categories.
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10 The text in the dialogue guide was validated to be part of the predetermined categories or to
11 be findings that were new and unknown [29, 31]. Each category was then reviewed and the
12 content was divided into what were considered to be barriers, resources or self-efficacy, i.e.
13 the concepts in the model. Finally, we compared the extent to which the data were supported
14 by Stuijbergen's model versus what represented new aspects not described in the model.
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21 The first and the last author conducted the analysis, while the other two authors were involved
22 in the discussions. Throughout the analysis, there was continuous back and forth movement
23 between the whole text and the categories, including the concepts of the model, where all
24 authors scrutinized and repeatedly discussed the results to ensure the trustworthiness of the
25 data analysis.
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30 31 **Rigour**

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33 In qualitative research, the concepts of credibility, transferability, dependability and
34 confirmability are considered aspects of trustworthiness [32].
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36 In this study, a directed deductive content analysis was chosen to validate an existing model
37 [22]. Directed content analysis is a structured and systematic analysis process and the method
38 guides the findings towards existing codes and categories [29]. By using directed content
39 analysis, trustworthiness can be achieved, as the text is compared with an existing model,
40 which in turn has gone through a publication process. The systematic way of working with the
41 analysis and the use of an existing model or theory strengthens the trustworthiness [33].
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46 To strengthen the credibility and confirmability different strategies have been used.

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48 The nurses' documentation in the dialogue guides has been used verbatim. The texts varied in
49 depth and length. Some nurses wrote summatively and others described the discussions in
50 more words. Nevertheless, all dialogue guides provided important and clear information on
51 the components of dyad functioning as assessed during the sessions. The raw data consisted of
52 handwritten text, but all nurses had clear handwriting so all data were credible.
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56 The results have been discussed and compared to previous research. The authors are all
57 experienced nurses, and have worked with patients with HF for many years and also met their
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3 partners. During the analysis, the material has been read many times and the various
4 components in the subcategories and the categories were reflected upon and this result can be
5 seen as a possible interpretation of the data. An analyst triangulation was implied including
6 both individual coding and consensus discussions in the research team allowing for testing
7 negative cases and rival explanations.
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11 To fulfill dependability the authors maintained a decision trail developing the interview guide,
12 during data collection, in analysis and also the research team regularly visited the nurses and
13 assessed their competence to deliver the intervention through observations and consultations.
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16 Transferability of the findings was facilitated as the sample; the context and the analysis
17 process are described in detail. Transferability to similar HF samples is possible since there
18 were dialogue guides available from 71 dyads, which is a fairly large sample.
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21 To ensure confidentiality, neither the names of the participants nor hospitals are published.
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24 25 **Ethical considerations**

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27 The study was approved by the Regional Ethical Review Board in Linköping, Sweden (Study
28 code 03-568/ M178-04). The nurses at the HF clinic were informed that data would be
29 analysed for study purposes.
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32 33 **Results**

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35 The findings from the analysis showed that the conceptual health-promotion model by
36 Stuijbergen et al., [22] was used during the psycho-educational sessions. The analysis
37 confirmed the three predetermined categories: 1) cognitive components 2) supportive
38 components 3) behavioural components. The content in the three categories was divided into
39 the concepts barriers, resources and self-efficacy.
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45 46 **Cognitive component**

47 **Barriers**

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49 The major cognitive barrier for both patients and partners was the described lack of
50 knowledge. Some patients had received information prior to the sessions but several patients
51 had no prior knowledge about the disease. They did not know that self-care could be carried
52 out and affect their well-being although they had lived with the diagnosis for many years.
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54 Others described that they did not really understand that they were sick and the lack of insight
55 had meant that they had not engaged in self-care activities.
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Almost none of the partners expressed that they had prior knowledge and therefore they had not been involved in the patients' self-care activities. A few partners had searched for information about HF on the Internet, but found many websites were lacking practical information which became more of a cognitive barrier than a resource in daily living. As they discussed their expectations of the sessions, the dyads expressed a broad range of expectations varying from a wish and belief that the patient would be cured, to the other side of the coin; that it does not matter what we do because both body and heart are too old and too sick. Also a few partners did not want to know anything about HF because it made them feel worried and uneasy.

Resources

Cognitive resources were found when the dyads expressed a wish to learn about HF. During the first session, both patients and partners posed general questions about HF treatment, causes and prognosis after receiving a general knowledge overview from the nurse. However, with increased knowledge, both patients' and partners' questions were more specific regarding how to perform self-care activities on a daily basis.

Self-efficacy

During the sessions, the dyads described that they had enhanced their knowledge and had greater confidence to handle their situation. The patients felt they have had an opportunity to pose questions and now had in-depth knowledge of the disease and, due to that, the confidence to act had increased.

Partners felt they had received guidance regarding exercise, for example how much someone who has HF can walk without it becoming harmful. So now they encouraged the patient to exercise. They also learned about and felt confident in how to act in case of deterioration and how deterioration could be prevented.

Supportive component

Barrier

Supportive barriers could be both emotional and practical, and both patients and partners described that they often lacked support. Examples of emotional barriers were that due to anxiety and consideration, some partners tried to set limits to physical activity so patients did

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3 not overstrain themselves. When patients felt overprotected this sometimes led to tension and
4 conflicts in the relationship. During the discussions, the nurses helped and guided dyads to
5 communicate their thoughts and concerns with each other.
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8 Another barrier was loss of friends' due to the disease. Patients could no longer socialize as
9 before and therefore the partner had less social support, activities and interactions. The dyads
10 became isolated since the partner did not want to leave patient alone and do things on their
11 own.
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14 Dyads described a lack of good healthcare contacts. Nurses' documentation revealed that
15 many patients were sad and depressed over their situation. Partners described a worry and
16 asked for long-term guidance from healthcare professionals to learn how to offer support.
17 Since several partners had no previous knowledge about the disease, the sessions brought up
18 many thoughts for example that they needed the nurse's support to process.
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23 The dyads expressed a wish for further, regular visits at the HF outpatient clinic. The visits
24 had created security for both patient and partner and they expressed anxiety when the possibly
25 to contact the nurses would end. The visits had made them feel secure and they knew they had
26 someone they could contact when questions arose.
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31 A practical, supportive barrier was if the partner also had some illness and therefore was not
32 able to provide support to the patient with HF, and maybe instead needed help and support
33 themselves. Need of formal support from someone outside the family arose primarily if both
34 patient and partner had difficulty carrying out practical tasks, such as driving or managing the
35 household.
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39 Some dyads experienced hopelessness when the future was discussed and patients were
40 perceived as depressed in the nurses' documentation. Some patients expressed a need for
41 contact with a social worker; others were in continuous need of support from homecare.
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46 **Resources**

47 Many dyads said that they helped each other and shared the chores on the basis of strength
48 and ability. With increased knowledge, they seemed to understand better why it is important
49 to perform self-care activities, and for some patients this led to a need of support from the
50 partner. Partners wished to learn and become more involved in the care and help with
51 decision-making on a daily basis.
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3 The need for support increased when patients were depressed or suffered from multi-
4 morbidity. Some patients had previously had contact with a social worker and have, due to
5 these visits, been helped to accept their situation.
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9 10 **Self-efficacy**

11 The documentation described that many partners give plenty of practical support, but also
12 how they encouraged patients to take own responsibility. Also, when the partner had
13 knowledge and the patient was motivated, confidence in their own abilities increased in both
14 patients and partners.
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18 19 20 **Behavioural component**

21 **Barrier**

22 A behavioural barrier was patients' lack of strength, which led to involuntary inactivity. Both
23 patients and partners felt that partners had to take on more of the workload in the household.
24 The additional burden was described as mentally exhausting for the partners due to a greater
25 responsibility.
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28 Some dyads described that the new roles led to conflicts and fractions in the relationship.
29 Partners thought it was difficult to leave the patient alone and that they had to hurry home
30 from work, leaving no time for own activities.
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32 Some patients found it hard to follow dietary advice, to weigh themselves daily and to
33 monitor and assess HF signs and symptoms. For some dyads, HF had been a barrier for
34 sexuality, where the patient no longer has the energy and the partner no longer dares to have a
35 sexual relation. The documentation did not reveal how the nurse discussed the perceived
36 sexual difficulties with the dyads.
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45 **Resources**

46 Most patients wished to take the main responsibility to manage their self-care, but sometimes
47 were lacking confidence in their own ability and doubting the effect of self-care advices.
48 When seeing the effects of their self-care activities, the patients' confidence to manage self-
49 care increased.
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55 For some dyads, the new roles had strengthened the relationship. They collaborated to follow
56 instructions about behavioural changes and provided mutual support to each other. In some
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3 relationships, the partner functioned as a resource for the patient, someone to discuss
4 strategies with. Other partners provided help with self-care on a daily basis.
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7 8 **Self-efficacy**

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10 During the last visit, the nurses assessed that most of the dyads had a good understanding
11 about HF. They had confidence when following the self-care advice given during the sessions
12 and had gradually adapted to the situation. Adaptations could, for example, be a change of
13 accommodation or partner's employment.
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20 **Discussion**

21 Our study showed that the model developed by Stuifbergen et al., [22], covering cognitive,
22 supportive and behavioural components of dyad functioning, was fully addressed during the
23 nursing sessions. The findings revealed a wide range of cognitive, supportive and behavioural
24 needs among the dyads. The model highlights the importance of identifying and discussing
25 barriers, resources and self-efficacy to increase the dyads health-promoting behaviours.
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29 For some dyads, the new roles had strengthened their relationship; patients and partners
30 collaborated and provided mutual support to each other. It is known that supporting a person
31 with HF involves several salient changes in daily life and includes both benefits and burdens.
32 It represents an opportunity for increased intimacy with the person who is ill. Care-giving is
33 sometimes experienced as rewarding and provides satisfaction and hopes for a positive future
34 [34, 35].
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40 The nurses' documentation showed that most patients found great support in their partners
41 and partners provided both practical and emotional support. Caregiver support is known to
42 improve self-care and strengthen patients' adherence to medical treatment and maintaining a
43 healthy lifestyle [3, 36, 37]. However, one recent study found the contrary. Cocchieri and
44 colleagues [38] found that having a caregiver was associated with poor self-care maintenance.
45 They concluded that their result might be due to the fact that patients having a partner were
46 more cognitive and functionally impaired, had higher co-morbidity and were in need of more
47 care.
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54 Caregiving may sometimes be experienced as burdensome for the partner. Partners in the
55 current study described their having taken over much of the household workload and helped
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3 the patients with practical tasks regarding the patient's self-care management and for some it
4 meant a burden. One third of partners of patients with HF perceive moderate caregiver burden
5 and could be at higher risk of worsened health [11]. As in previous research, partners
6 sacrificed their own needs in order to support care for the patient. Partners perceived a need
7 for support with daily living as well as easy access to the healthcare providers [39]. To reduce
8 caregiver burden, interventions should focus on improving social support and provide
9 knowledge of HF to both patients and caregivers to increase their perceived control over the
10 situation [34].
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18 With the increasing awareness of patient needs, there are a lot of educational moments in
19 most current HF care. However, it still seems important to consider cognitive aspects during
20 nursing sessions. Patients felt that they had never received information about their illness
21 previously. One reason could be that they had suffered from HF for many years and only
22 received education at the time of the diagnosis, and now the information has been forgotten.
23 Another reason could be that there is a high occurrence of mild cognitive deficits among
24 patients with HF without known cognitive diseases or disorders [40]. This calls for repeated
25 information and follow-ups and close attention should be paid to the patient's self-care
26 abilities and compliance, as inadequate self-care activities could lead to repeated
27 hospitalisations. Cognitive impairment presents a barrier to the complex medication and self-
28 care management that is required in HF treatment [41]. Due to this, both patients and
29 caregivers perceive a need to have a long-term healthcare contact they can turn to when
30 questions arise [39, 42]. This is supported in the present results where the dyads expressed a
31 need for long-term support from nurses, and for some, also homecare and social workers.
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43 The behavioural component includes self-care abilities, and a prerequisite for self-care
44 adherence is to gain knowledge. Self-care has been defined as a naturalistic decision-making
45 process which influences actions that maintain physiologic stability, facilitates the perception
46 of symptoms and directs the management of symptoms [43]. Patients and partners need to
47 learn about HF to become active participants in the management of the illness but sometimes
48 their own knowledge was not enough and then the dyads wanted easy access to healthcare.
49 Long-term support was highlighted as an important factor to remain being perceived as
50 healthy and experiencing well-being. Previous research has also addressed both patients' and
51 caregivers' need for a regular healthcare contact they can easily contact, as they currently
52 experience difficulties both navigating for and assessing support [44]. Today, a lot of different
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3 healthcare professionals (primary care physicians and nurses, cardiologists and HF nurses)
4 could be involved in the care for HF patients. Patients and caregivers have to decide who to
5 contact based on their previous experiences, which is perceived as confusing and leads to
6 insecurity. Instead, to have a permanent healthcare contact they can turn to if necessary would
7 facilitate daily life.
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11 **Limitations**

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14 In qualitative research, generalisability of the findings may be restricted to a particular setting
15 or context. However, the current study findings are consistent with previous research using
16 the model [22] in a different setting and for patients with Multiple Sclerosis.
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19 The nurses were informed beforehand that their documentation was going to be analysed. The
20 nurses' documentation in the dialogue guides was transcribed verbatim. The text varied in
21 depth and length. Some nurses wrote summatively and others described the discussions in
22 more words. Nevertheless, all dialogue guides were found to provide important and clear
23 information on the components of dyad functioning as assessed during the sessions.
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26 The raw data consisted of handwritten text which may affect credibility. However, all nurses
27 had clear handwriting so all data were considered accurate.
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30 The data were collected between the years 2005 and 2008. There have been some changes in
31 HF treatment since then, however the importance of self-care and family support has been
32 increasingly acknowledged in guidelines, [1] thus making this study even more relevant today
33 than when the data were collected. Further, since the aim of the study was to describe nurses'
34 documentation regarding a psycho-educational intervention inspired by a health promotion
35 model, the data are still valid and of interest. To date, there are still very few models or
36 theory-based interventions for patients and partners living with HF [17, 45], and our results
37 can hopefully serve as an example and inspiration for further research in this area.
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48 **Conclusion**

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50 This study described how cognitive, supportive and behavioural components of dyad
51 functioning were addressed during nursing sessions with dyads affected by HF.
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53 We found the model to be suitable for helping patient-partner HF dyads to gain knowledge
54 and develop skills to handle living with HF. The model promoted healthy and supportive
55 behaviours i.e. to improve self-care. The results show the importance of providing continuous
56 healthcare contacts throughout the illness trajectory. The findings emphasise that gaining
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3 knowledge of HF is not enough. It also seems clear that one type of intervention does not fits
4 all dyads, as a variety of equal and diverse needs emerged during the analysis and when the
5 needs were met the dyads developed self-efficacy. It is important that healthcare providers
6 take time to discuss all aspects related to the disease that are of importance for the dyad to
7 support improved self-efficacy and reduce insecurity. Furthermore, the model was applicable
8 for dyads consisting of a patient with HF and their partner, not only for patients alone as
9 shown in previous studies implementing the model.

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11 The result can inspire others when using this model or designing new psychoeducational dyad
12 interventions. The findings provide practical examples of cognitive, supportive and
13 behavioural needs, which need to be considered when meeting patients and partners affected
14 by HF. This knowledge can be applied in HF units to develop a dyad educational regime.
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11 CONTRIBUTORSHIP STATEMENT

12 SÅ and ML collected the data. ML was mainly responsible for analysing data and drafting the
13 manuscript and SÅ, TJ and AS contributed to the data analysis and writing the manuscript.
14 AS and TJ conceptualised and developed the idea for the study as part of the broader research
15 programme. All authors critically edited the manuscript and read and approved the final
16 version.
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23 This research received no specific grant from any funding agency in the public, commercial or
24 not-for-profit sectors.
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29 Competing interests

30 None declared.
31
32
33

34 Ethics approval

35 The study was approved by the Regional Ethical Review Board in Linköping, Sweden (Study
36 code 03-568/ M178-04).
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40 Data-sharing statement

41 No additional data are available.
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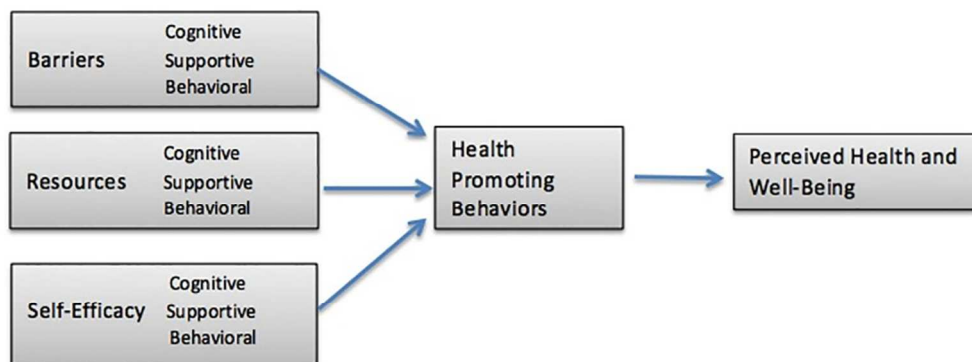


Figure 1. The conceptual health promotion model by Stuijbergen et al.

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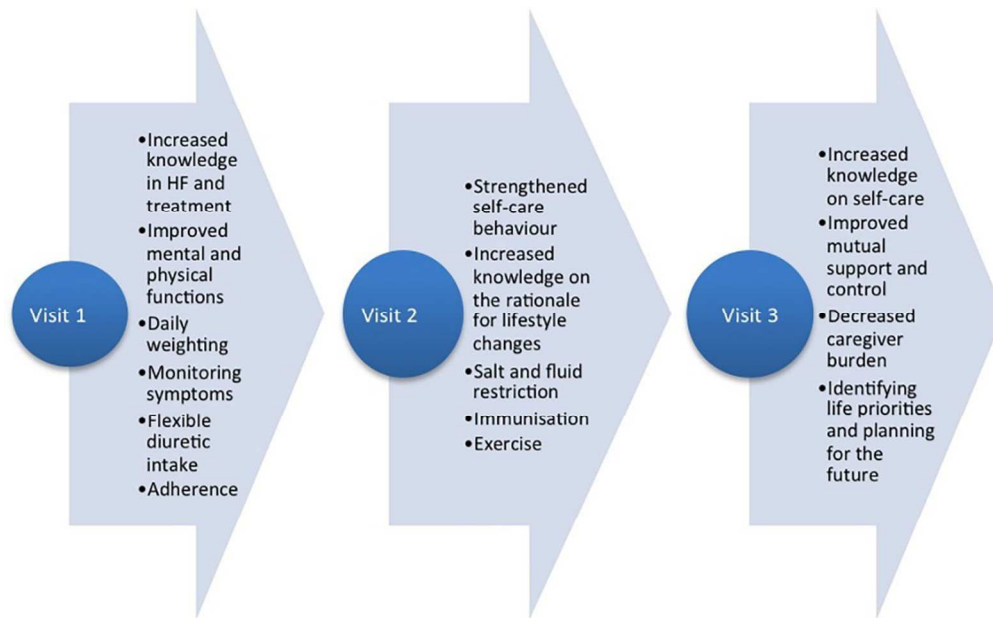


Figure 2. Cognitive, supportive and behavioural goals for each visit.

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	7, Title page
3. Occupation	What was their occupation at the time of the study?	7, Title page
4. Gender	Was the researcher male or female?	Title page
5. Experience and training	What experience or training did the researcher have?	7
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	NA
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	8
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	NA
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	NA
12. Sample size	How many participants were in the study?	7

13. Non-participation	How many people refused to participate or dropped out? Reasons?	NA
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	6-7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	6-7
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	7-8
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	NA
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	8
20. Field notes	Were field notes made during and/or after the inter view or focus group?	8
21. Duration	What was the duration of the inter views or focus group?	NA
22. Data saturation	Was data saturation discussed?	NA
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	NA
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	19
25. Description of the coding tree	Did authors provide a description of the coding tree?	8
26. Derivation of themes	Were themes identified in advance or derived from the data?	8
27. Software	What software, if applicable, was used to manage the data?	NA
28. Participant checking	Did participants provide feedback on the findings?	NA
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	NA
30. Data and findings consistent	Was there consistency between the data presented and the findings?	11-14
31. Clarity of major themes	Were major themes clearly presented in the findings?	11-14
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	11-14

Once you have completed this checklist, please save a copy and upload it as part of your submission. When requested to do so as part of the upload process, please select the file type: *Checklist*. You will NOT be able to proceed with

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