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Healthcare Practices and Interventions in Europe towards Families of Older Patients with Cardiovascular Disease: A Scoping Review

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Abstract

Introduction: In Europe, cardiovascular disease is one of the predominant causes of mortality and morbidity among older people over 65 years. The occurrence of cardiovascular disease can have a negative impact on the quality of life of older patients and their families and family health overall. Assuming that illness is a family affair shaped by culture and health care systems, we explored European health care practices and interventions toward families of older patients with cardiovascular disease and heart failure. This paper aimed to determine the extent, range, and variety of practices and interventions in Europe directed to families of older patients and to identify knowledge gaps.

Methods: A scoping review was conducted including studies published in Medline, CINHAL, or Cochrane library between 2009 and mid-2020.

Results: A total of 22 articles from 17 studies were included, showing diverse practices and interventions. The interventions targeted the family as a unit (six studies), dyads (five studies), patients alone, but assessed family members’ reactions (five studies) or the family member primarily, but assessed the reaction of the patient (one study). Target outcomes were family caregiver burden; health-related QoL; and perceived control in patients; and family functioning and changes in health behavior or knowledge in both, family members and patients. Most studies did not include an integral view of the family as the unit of care but rather had a disease-centered approach.

Conclusions: This scoping review provides insight into a variety of healthcare practices towards families of older patients with cardiovascular disease in Europe. Clarifying underlying assumptions to involve families is needed. More studies with family-focused approaches as integral models could lead to practices that improve families’ well-being. Exploring integral models for their acceptance in health care and family systems appears pertinent to develop European policy to support and add to family health.
Article type : Review

Word count: 5019 (excluding abstract, declaration and references)

BACKGROUND

Europe’s population will continue to age in the coming decades, as the baby-boom generation retires and people in Europe live longer, according to the 2018 Aging Report by the European Commission (1). The number of persons aged 65 years and above is estimated to increase by 10 percentage points, from 19% in 2016 to 29% in 2070. These projected changes in the structure of the population present serious challenges to health care systems in terms of increases in chronic disease and multimorbidity (2). New strategies are needed to secure the sustainability of health care in Europe over the long term (3).

Cardiovascular disease (CVD), which comprises heart disease, chronic heart failure (HF) and stroke, is the most prevalent health condition in Europe, accounting for 45% of all deaths (4). Despite these high numbers, the mortality rate from CVD has been declining in the Western World since the mid-1990s. It is estimated that in individuals in Europe, aged 55 or older, HF has an annual incidence rate of 1% (5) with an estimated prevalence of 1–2% (6). Consequently, more people today live with chronic conditions, such as HF (7).

As outlined in the clinical practice guidelines from the European Society of Cardiology (ESC), adherence to disease-modifying or life-saving therapies is important to reduce disease burden (8). It has been shown that mortality of patients with chronic HF declines proportionally
with the use of guideline-recommended therapies (9), and also reduces HF hospitalization rates (10). Seventy-five percent of re-hospitalizations for HF are likely preventable (11). In addition to suboptimal adherence by health professionals to guideline-recommended therapies (12), adherence to treatment by patients with HF is low and depends on patient’s knowledge and beliefs (13). Readmission rates are especially high when psychosocial and/or socioeconomic factors interfere with medication adherence, patient self-monitoring, and follow-up (9). An important factor associated with increased adherence to the recommended guidelines is the support from family members or informal carers, which highlights the benefits of involving family members in the care of patients with HF. (14,15).

Chronic diseases such as CVD affect not only the individual patient, but the whole family. The protracted stress experienced by family members of patients with HF and the resultant impact on their quality of life and health status are well documented (16–18). Caregiving often results in chronic stress, contributing to psychological and physical morbidity. Depressive symptoms are described as the most common negative effect of caregiving (18,21,22). As caregiving in the elderly population becomes more intense and complex, caregiving may involve not only the partner/spouse or adult child but the whole family system (21). In the last decades, the focus of research has shifted more towards dyads, meaning patients and their partners as a couple, but not yet to the family unit as a whole (22,23).

The increasing financial constraints in European health care systems increases the pressure on families to take on more informal caregiving responsibilities for their family members. However, literature shows that family caregivers’ preparedness to care depends among other factors on the amount of support they receive from professional health care providers. (24–28). It has been shown that family-focused interventions can be beneficial (29). Recent literature reviews on family involvement in adult chronic disease care, including CVD, showed that interventions focusing on the family as a unit had positive outcomes in decreasing depressive symptoms in patients as well as in family members, as well as helping to maintain supportive relationships within the family (26,30).

The coping patterns of families and the caregiving experiences of family members depend much on the social and cultural context, as well as the larger organizational and financial characteristics of the national or regional health care systems (31,32). Additionally, the occurrence of CVD is
strongly influenced by lifestyle and modifiable risk factors, which are shaped by family patterns and cultural traditions (33). Therefore, risk factor modification education must be adapted to reflect the cultural backgrounds of patients and their families.

Since many countries in Europe have experienced similar demographic patterns with an ageing population and resultant increases in CVD, we decided to examine the healthcare practices and interventions directed at families of patients with CVD in Europe. Additionally, the ESC guidelines stress that families should be involved in preventive measures and treatment throughout the illness trajectory of patients with CVD (33). To date, no reviews are available that explore the healthcare practices and interventions directed at families with an older member suffering from CVD as seen from a European perspective.

The current scoping review focused in particular on healthcare practices and interventions involving families of patients with cardiac heart disease (CHD) and heart failure (HF). We chose to exclude stroke, as the differences in symptomatology between cardiac and cerebrovascular disease may affect the family system differently. By health care practice we refer to the clinical practice in which nurses, doctors, psychologists and/or social workers assess, diagnose and plan interventions for older people with CHD and their families (34).

Therefore, this paper aimed to determine the extent, range and variety of research in Europe describing current health practices and interventions directed at families of older patients with CHD and HF, as well as to identify the targeted outcomes of these practices and interventions. The research question was, “What are the healthcare practices in Europe involving the families of older patients with CHD and HF?”

**METHOD AND MATERIALS**

**Research design**

A scoping review was pursued to determine the body of literature published on healthcare practices and interventions in Europe involving families of older patients with CHD and HF. This type of review was considered most appropriate to investigate the research conducted in this field and to identify knowledge gaps (35). Compared to a systematic review that systematically compares different studies on a certain outcome, a scoping review summarises and synthesises...
the extent, range and nature of the literature to inform research, practice, programs and policy by mapping key concepts, types of evidence and gaps in a defined field (36,37).

We used the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist as provided in Tricco et al, 2018, p.471 to facilitate complete and transparent reporting (38). Our process followed a stepwise approach, which included establishing the research question, identifying and selecting relevant studies, charting and summarising the data, and finally reporting the results. In accordance with the purpose of scoping reviews, we did not appraise the quality of the study extracted before inclusion, but rather provide an overview to map the variety of research studies (35).

**Search strategy**

We used Medline, CINAHL and Cochrane library databases to identify publications with the support of research librarians who helped develop the search protocol (Table 1). The initial search targeted articles published by December 2018 using a combination of the key terms “family”, “health practice”, “older adults”, “Europe”, and “cardiovascular disease”. The search was updated in mid 2020 to include studies published within the last 10 years that might reflect more current clinical practice, with a focus on patient’s loved ones and the influence of individual illness on the whole family (39). Studies comprising qualitative as well as quantitative methodology were included.

(Table 1: Literature search strategy)

Results published in English, German, Spanish, Danish, Norwegian, Swedish or French were included, as these languages were read and understood by the research team. No limitation was used in relation to the study design. Finally, the reference lists of all included papers were manually searched for additional studies.

**Criteria to consider studies for this review**

The following inclusion criteria had to be met:

1) the study was conducted in Europe,
2) patients were diagnosed with CHD or HF, or were included in multi-population studies,
3) patients mean age was 65 years or above,
4) clinical and/or education activities were described in a health or social setting (hospital, community, home etc.) that targeted physical, psychological, social or environmental domains,

5) had to include a healthcare practice or intervention delivered by nurses or teams of healthcare professionals, including nurses, to patients and their families.

6) the practice or intervention focused on family health.

Studies were excluded if they:

1) described specific medical procedures,

2) focused on family members’ needs without reporting an actual practice or intervention by professionals,

3) only consisted of study protocols and conference abstracts

4) reported on results from outside Europe.

Data extraction and management

After deleting duplicates, the publications were imported into the Referencing Software Zotero. In the first round, the articles were assessed by a group of four researchers (RM, BØ, AB, ML) by title, abstract and keywords. The assigned studies were rated by each researcher independently and mutual agreement was sought after the first read. The PICO (Population, Intervention, Context, Outcome) mnemonic was applied to identify the evidentiary material. In combination, the following key terms were used: (P) cardiovascular disease, HF, older adults, family, (I) family nursing, healthcare practice, (C) Europe and (O) targeted outcomes. The four researchers individually determined whether the articles should be in group a) included in the study, b) unsure/to be discussed, or c) excluded. Review articles and articles without abstract or retrievable text were excluded.

The group of four met regularly online and discussed the included papers, as well as that required further discussion. After full-text reading, another group member reread the disputed article, so that a final decision could be reached by group consensus. Titles and abstracts of articles initially excluded were also reread by one of the group members at the end of the selection process, in order to confirm the decision to exclude those publications. Eventually, the findings were presented and discussed with all authors.

Data analysis and synthesis

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A data charting form was developed to extract data from each study. Data were extracted narratively to capture contextual or process-oriented information (40). In an iterative process, data were continually discussed, extracted and updated in the matrix (Table 2). A thematic construction was developed, which included the following: country where the study was conducted, types of participants, description of comparative practice if available, the actual health care intervention, the perceptions of patients and/or family members of the actual intervention, and the targeted outcomes. Eventually, analysing the content led to classify the studies by type of intervention according to the extent of involvement of family members, including a focus on a) the family as a unit; b) the dyad of patients with their partners; c) the patient, but the study reported reactions or outcomes of family members; or d) family members, including reactions or outcomes of patients (Table 3-6). The specific findings were collated and summarized narratively. Additionally, in order to describe the interventions and practices, we screened additional literature in the databases for more detailed information about the interventions/practices of the included studies. The corresponding references were added in the tables.

**RESULTS**

The initial search yielded 903 citations. After removing duplicates, 805 citations remained. After deleting citations due to missing abstracts and text, or non-accessibility, 751 references could be included for the first screening of titles and abstracts. Of those, 708 studies were removed because no connection was made to family, relatives, next of kin or spouses/partners, no clinical practice or intervention was described, or the language was other than English, German, French, Spanish, Danish, Swedish, Finnish or Norwegian. Initially, 19 articles were selected. After the update to include studies published by mid-2020, 22 articles presenting findings from 17 studies (one study reported their findings in three publications and three studies reported findings in two publications) met criteria for inclusion.

The first section of results includes a description of the health care practices, study characteristics by participants, the national setting and the type of study. The second section highlights the extent to which family members were included as part of the healthcare practice or intervention. Both qualitative and quantitative studies are presented. The third section describes the
measures/target outcomes used to capture the reactions of family members and patients toward
the interventions.

**Study characteristics**

**Healthcare Practices**

The practices and interventions in three studies were designed to report reactions and outcomes
about usual care (41–43). Fourteen studies tested new interventions, practices, or services in
comparison with usual care (44–62). The interventions and practices targeted either patients
alone, family members alone or the family as unit or dyad. The interventions and practices are
described in more detail below.

**Study participants**

In total, 1522 patients and 1312 family members were included in the 17 studies, which were
conducted in nine European countries (Belgium, Denmark, Finland, France, Germany, Hungary,
the Netherlands, Sweden and the United Kingdom). The mean age of the patients was 67 years
(range 65 to 83 years) and family members (reported in 12 studies) 65 years (range 59 to 77
years) respectively. The sample sizes ranged from eight to 347 patients and two to 322 family
members. The family members were characterized as caregivers (seven studies), spouses or
partners (six studies), mixed family members (three studies) and significant other (one study).
In 12 out of the 17 studies, patients were diagnosed with HF
(45,44,46,43,41,51,52,55,56,59,62,49); one study included patients after coronary artery bypass
grafting (CABG) (60) and in another the patients had atrial fibrillation (AF) (58). Three studies
included patients with different diagnoses such as angina pectoris (AP) or HF, cancer, and COPD
(42,47,48).

**Type of studies**

Most of the studies (11 studies) had a qualitative, cross-sectional or longitudinal design, five were
randomized controlled trials (RCTs) and one study used a quasi-experimental design (pre-post-
test). Data were collected with questionnaires (44–46,51,53,54,56–58,60,62); interviews
(48,55,61); interviews and questionnaires (42,47,52,59); interviews and focus groups (41,43);
participant observation and interviews (49); and interviews, participant observations and focus
groups (50).

(Table 2: Characteristics of the included studies).

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Healthcare Practices

Practice towards family as a unit of care

Six studies (published in seven articles) reported on interventions directed at both patients and family members simultaneously \((47,48,50,52,60–62)\). The authors reported that the interventions were theoretically guided by family system nursing \((52,61,62)\), theory of social support \((60)\), concepts of integrated palliative care \((47,48)\) or ideas of gameful design \((50)\).

In the study by Gusdal et al. \((52)\), a family system nursing approach was used to train registered nurses how to hold family health conversations. The nurses attended a half-day intensive training course, and then delivered an intervention where they conducted three 45 minute conversations with each family every other week \((52)\). The RCT by Østergaard et al was also based on family system nursing \((62)\). Patients with HF and their family members were randomized to either the family nursing therapeutic conversation group or conventional care. The nurses completed an intensive educational and practical training program; had continuous supervision by the project leader; and attended workshops, lectures and an international family nursing conference. The intervention offered an average of three sessions over six to 12 weeks to the families tailored to their needs \((61,62)\).

Rantanen et al \((60)\) evaluated usual care of social support practices towards patients with CABG and their significant others by nurses or other social service providers on hospital wards. No further description of the usual practice was provided \((60)\).

Two studies were guided by an integrated palliative care framework \((47,48)\). They focused on coordination of care for patients with advanced illness by collaborating with professional as well as unpaid caregivers. The intervention aimed to improve quality of life and a well-supported dying process for the patients and their families.

Another study used gamification as part of a telerehabilitation programme for heart patients and their families \((50)\).

Interventions towards dyads

Six studies (reported in eight articles) delivered interventions to dyads consisting of patients and their caregivers/partners/spouses \((42,44–46,49,53,54,58)\). The interventions were guided by either a conceptual health promotion model \((44–46,53,54)\), a concept of everyday life \((49)\),
theories of hospital discharge (42) or cognitive behavioural therapy (58). In the studies guided by
the conceptual health promotion model, the nurses underwent a three-day education course
followed by individual practical training. The sessions were conducted either in the dyads’ homes
or in the HF clinic (44–46,53,54).

In Dinesen et al study (49), the interview analysis was guided by the concept of everyday life
regarding patient and partner/spouse experience with a post-discharge tele-homecare technology.
The district nurses transmitted information about the patient’s condition to the hospital via a web
portal. The tele-homecare intervention typically lasted three days per patient.

Doos et al (42) used mixed methods to develop theories about hospital discharge based on patient
and carer perception of hospital discharge practice.

Theories of cognitive behavioural therapy guided a mindfulness-based intervention for patients
with AF and their spouses (58). The intervention was provided by health professionals (a cardiac
nurse, a cardiologist and an educationalist) that had received training in cognitive behavioural
therapy.

(Table 4: Interventions towards the family as a dyad)

Practice towards patients and reaction of family members

Five studies delivered patient-only interventions (41,43,51,55,59), although the outcomes of these
studies were evaluated by responses from caregivers (41,43), patients and their spouses (51,55) or
partners (59).

Two studies evaluated the perception of patients, carers and professionals of the usual palliative
care services for patients with advanced HF (41,43). These studies lack further description of the
specific usual practice. In Garbacz et al study (51), the intervention was theoretically guided by
the concept of therapeutic patient education to facilitate lifestyle change, and was delivered by
cardiologists and other health professionals to patients with HF. The educational tool consisted of
five units, and included knowledge about the diagnosis and the disease, diet control, physical
activity, daily life, and medical treatment (63).

In the study by Lind & Karlsson (55), the intervention relied on telehealth technology providing a
digital pen and a health diary to patients with HF. The diary allowed the patients to send a daily
health status report by text message to their care provider. The device was equipped with an
alarm system to report values below or above predefined limits.
In the study by Näststrom et al (59), patients with HF received structured home care in accordance with the “Heart Failure at Home Model”. The model consists of six components, including a multidisciplinary team approach, staff education, joint care plans, optimized treatment, educational strategies for patients/families/caregivers, and increased accessibility to care (64).

(Table 5: Interventions towards patients and reaction of family members)

Practice towards family members and the reaction of patients

One RCT (reported on in two articles) delivered an intervention to family members of patients with chronic HF (56,57). Family members (spouse, child, close friend and others) participated in a group-based multi-professional programme on topics recommended in the European Society of Cardiology guidelines. Each group had eight participants. In patients, Health care utilization (hospitalisations and readmissions) was assessed in patients(56) and psychological outcomes included depression and anxiety as well as quality of life were evaluated in family members (57).

(Table 6: Intervention towards family members and the reaction of patients)

Patient and family member reactions to healthcare interventions

Studies assessed patient and family member reactions to the healthcare interventions by targeting multiple bio-psychosocial dimensions.

Health-related quality of life (HRQoL), depression or anxiety was measured in five RCTs (45,54,58–60). Only Malm et al study (58) found improvements in HRQoL and reduced psychological distress. Rantanen and colleagues (60) found that HRQoL scores improved more among patients who underwent CABG compared to their significant others.

Perceived control. Three studies aimed to improve perceived control. Ågren et al (44) found that patients improved their perceived control significantly. In two trials with dyads receiving psychoeducational support, the patients’ perceived control increased significantly but disappeared over time (43, 60). No effect was observed in the partners.

Life style changes. Two studies evaluated changes in lifestyle (50,51). Both patients and their relatives reported positive changes in eating habits and physical activity (51). Gamification targeting lifestyle changes was found to be a promising tool to engage heart patients and family members (50).

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Caregiver burden was assessed in seven studies (41,45,46,49,51,52,55). Whereas in three studies caregiver burden could be reduced (47,48), one study could not show any change (46) and in two studies the caregiver burden even increased (49,53).

Family functioning. Two studies focused on family functioning. Therapeutic conversations with patients with HF and their family members showed a potentially positive impact on communication within the family (52) and helped restructure family life in the year following a HF diagnosis (61).

Transitions in care delivery. One study investigated patients and their carer’s perceived challenges around hospital discharge (42). Patients with HF discharged to a hospital at home programme via a web portal felt more secure and better cared for, and showed improved awareness of their symptoms. However, patients expressed irritation that their spouse/partner not only experienced the hospital at home programme as an increased burden but also worried about invasions of privacy (49).

Knowledge. One study reported improved knowledge about the illness among family members (56).

**DISCUSSION**

To our knowledge, this is the first scoping review from a European perspective focusing on healthcare practices and interventions directed at older patients with CHD or HF together with their families. Few studies met the inclusion criteria and we found a limited number of studies that aimed to involve families of older patients with CHD and HF into care services. The majority of the studies were conducted in the Scandinavian countries. The interventions and practices aimed to reach a variety of patients and family members, but often provided little information about patients or family members characteristics, the aim of the intervention or practice, the quality of the program and evaluation methodology. This is in line with a previous review analysing 19 randomised trials, showing that the overall descriptions of education programmes for patients with HF were available, but key elements such as educational methodology, outcomes evaluation, and follow-up strategies were missing in most of the studies (65).

The studies used different methods to collect data. The main outcomes were caregiver burden, HRQoL and perceived control, and family functioning; as well as changes in health behaviour or knowledge among family members and patients. These outcome measures are comparable to outcome measures and findings described in other reviews (66,67), but little information has been...
provided why those outcomes have been chosen. Therefore, there is a strong need for detailed
descriptions of healthcare interventions and their underlying frameworks in order to compare
practices, their fit to the targeted population and their related outcomes.
In this scoping review, the majority of the studies used qualitative or descriptive designs and the
knowledge about the effectiveness of the health interventions towards older patients with CHD
or HF and families was limited. Therefore, there is a need to develop family-focused nursing
interventions in Europe, and to conduct research among patients with CVD and their families
with the goal to provide health services that are effective to meet the needs of both the individual
patients and the family as a unit (62).
Nurses play a central role in the care of patients with CVD and nursing interventions can be
delivered across all stages of the CVD continuum (68,69). Terms such as family navigator nurse,
family-oriented care, family-focused care or family systems nursing have been used to describe a
nursing approach that embraces both the health of the individual and the family, and to build
interventions that serve both (70). A common understanding on the theoretical frameworks of
family nursing interventions is needed. When the relationship between the family members
becomes the focus of the nursing intervention, such interventions are grounded in family system
nursing (71). Surprisingly, only six of the 17 studies tailored the intervention for the family as a
unit aligned with the concept family system nursing.
Especially the interventions and practices directed at dyads used a variety of approaches and
provided little information on the partners’ assumed level of involvement or how the partner
might serve as a resource as part to the patients illness management. We did not find assumptions
about the importance of family and often no rationale on determining whether to provide
interventions only to the patients or to family members. Therefore, this review shows that most of
the interventions lacked a family-focused approach that addresses the health and well-being of
the family as a unit. Assuming that illness is a family affair and has an impact on the health of all
(39), healthcare interventions should aim to improved family health as a whole by addressing the
family as a unit. Including relationship-focused interventions to address changes within the
family structure and to acknowledge the emotional burden can alleviate stress.
In our review, only a few studies had an explicit relationship-focused intervention that looked at
family functioning and the wellbeing of patients and family members (52,61). Findings of meta-
analyses, however, showed that family interventions in this sense had significant effects on
patients’ and family members’ depressive symptoms, marital functioning, and distress among the

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families of patients experiencing illnesses such as cancer, arthritis, cardiovascular disease, chronic pain, HIV, and Type 2 diabetes (26,66,72).

The majority of interventions focused on psychosocial-education to provide disease-related information and educate patients and family members about behavioural changes, symptom monitoring and disease management. The interventions and practices are disease-centred, as coping with the illness is the main focus. Family members reported increased burden in studies that tested new models of care such as early discharge and hospital at home, where more care duties were brought upon families (47, 50, 54). It can be assumed that in these studies, the family is seen as a context for the patient, either as a resource or a stressor to the individuals’ health and illness (73). This increase in stress might highlight that the role of family caregivers is still poorly understood (45). Therefore, it might be useful to design practices that consider the higher level of support needed by older patients and their families, perhaps with a focus on more family-centred than service-centred support.

Greater awareness of the needs of older adults living with CVD is pivotal, as are the coping strategies adopted by the patients and their family members. A comprehensive geriatric assessment has been recognised as a good way to assess the functioning of older patients (74), but systematic assessment of family functioning requires skills which nurses may not always have been taught or had further developed.

Despite the fact that numerous European countries have developed training programs to educate family health nurses to support families in their homes, only few nursing education institutions have adopted measures on how to assess, plan, implement and evaluate family-focused interventions (75). Additionally, only limited research has been conducted on the practice of teaching family-focused care in Europe (70,76). This might explain a lack of a family systems approach within European healthcare institutions (75). Therefore, it is necessary to both expand the teaching of family nursing intervention knowledge and skills in graduate and postgraduate nursing education, as well as to implement family nursing interventions into clinical practice.

Family structures in Europe have changed over the last decades, such that families may or may not have strong ties with the older person with CVD (32). Assessing the strength and the resources of families is key when planning health care services. It is essential to explore the family structure and understand the family experience with the illness. This process may reveal valuable knowledge which professionals can then use to provide tailored support to families and to enhance their preparedness to care for older family members with CVD. From a European
health care perspective, it would be beneficial to compare family-focused approaches in different European countries, based on their acceptance by the health care system and their impact on family health. Moving forward it would be important to develop a European policy to support integrative models in which care is shifted from a disease-centred to family-focused care approach (78).

**Strength and limitations**

We undertook a broad electronic search of studies covering all main health specialities (i.e., nursing, medicine, psychology, social work), and searched the reference lists of selected articles to identify additional studies. We did not, however, include grey literature as recommended in scoping reviews (35). We did not critically appraise included literature as recommended by the Prisma Guidelines (PRISMA-ScR) (38), as the aim of this scoping review was to synthesize a variety of research evidence and gain an overview.

This review covered the different stages of the CVD trajectory, but excluded patients with stroke and their families. A scoping review on cerebrovascular diseases would be worthwhile to pursue. A strength was the process of review, where the selected articles were appraised first independently and then by consensus of European researchers. Data were then extracted and presented in a structured manner (35). Additionally, this scoping review included studies with different designs and methods, to help map the existing literature on the topic. In spite of this, the studies carried out in European countries had limitations in contextual descriptions as well as in information about types of healthcare intervention.

**CONCLUSION**

This scoping review provides insight into the healthcare practices and interventions in Europe provided to families of older patients with CHD and HF. Most interventions and practices did not include an integral view of the family as the unit of care, but rather had a disease-centered approach and diverse conceptualisation of professional support for families. This shows a need for more extensive development of family interventions with a clear detailed descriptions of the healthcare practices and interventions involving families and their underlying framework. Health professionals and especially nurses need to be trained to involve family in the care process. Family members of patients with CVD have needs as a consequence of caring, but have also specific needs because the overall health and functioning of the family has been altered due to
illness. Therefore, further research on interventions and practices with a family-focused approach is needed. Multiple-site studies with a family-focused approach in different European countries would add knowledge on how to improve families’ well-being. Exploring integrative models for their acceptance in health care and family systems is an important step forward in developing European policy to support and add to family health in Europe.
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<tr>
<th>Medline</th>
<th>Cinahl</th>
<th>Cochrane library</th>
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</thead>
<tbody>
<tr>
<td>1. Family Nursing/ 2. Professional-Family Relations/</td>
<td>S28 TI (((family or families) N2 (center* or focus* or health* or practice*))) OR AB (((family or families) N2 (center* or focus* or health* or practice*))) OR S29 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28</td>
<td>#1 (((&quot;adult child**&quot; or &quot;carer**&quot; or &quot;caregiver**&quot; or &quot;daughter**&quot; or &quot;families&quot; or &quot;family&quot; or &quot;husband**&quot; or &quot;next of kin&quot; or &quot;relatives&quot; or &quot;son&quot; or &quot;sons&quot; or &quot;spouse**&quot; or &quot;wife&quot; or &quot;wifes&quot;) NEAR/5 (&quot;clinical practice&quot; or &quot;community health&quot; or &quot;counsel**&quot; or &quot;educat**&quot; or &quot;general practice**&quot; or &quot;geriatric**&quot; or &quot;health care&quot; or &quot;healthcare&quot; or &quot;health practice**&quot; or &quot;health visit**&quot; or &quot;home care&quot; or &quot;intervention**&quot; or &quot;medicine&quot; or &quot;medical practice**&quot; or &quot;nursing&quot; or &quot;nurse&quot; or &quot;physician**&quot; or &quot;primary care&quot; or &quot;professional practice**&quot; or &quot;program**&quot; or &quot;psychol**&quot; or &quot;psychotherap**&quot; or &quot;rehabilitation&quot; or &quot;social care&quot; or &quot;social practice**&quot; or &quot;social work**&quot; or &quot;support**&quot; or &quot;telenursing&quot; or &quot;telemedicine&quot; or &quot;therap**&quot;)):ti,ab,kw OR (((&quot;family&quot; or &quot;families&quot;) NEAR/2 (&quot;center**&quot; or &quot;focus**&quot; or &quot;health&quot; or &quot;practice**&quot;)):ti,ab,kw</td>
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<tr>
<td>3. exp Social support/ 4. exp Counseling/</td>
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<td>5. Health Education/ 6. Delivery of Health Care/</td>
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<td>7. Practice Patterns, Physicians'/ 8. Practice Patterns, Nurses'/</td>
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<td>9. exp Nursing Care/ 10. exp Nurses/</td>
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<td>11. Nursing/ 12. exp Nursing Process/</td>
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<tr>
<td>13. Community Health Services/</td>
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<td>14. exp Community Health Nursing/</td>
<td>S30 (MH &quot;Caregivers&quot;) OR MH (&quot;Caregiver Burden&quot;)</td>
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<td>15. Community Mental Health Services/</td>
<td>S31 (MH &quot;Family&quot;)</td>
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<td>18. Home Care Services, Hospital-Based/ 19. Home Nursing/</td>
<td>S33 (MH &quot;Spouses&quot;)</td>
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<td>20. Primary Health Care/</td>
<td>S34 (MH &quot;Daughters&quot;)</td>
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<tr>
<td>21. Health Services for the Aged/</td>
<td>S35 (MH &quot;Sons&quot;)</td>
<td></td>
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<tr>
<td>22. Family Practice/</td>
<td>S36 TI (&quot;adult child**&quot; or &quot;carer**&quot; or &quot;caregiver**&quot; or &quot;daughter**&quot; or &quot;husband**&quot; or &quot;family&quot; or &quot;families&quot; or &quot;next of kin&quot; or &quot;relatives&quot; or &quot;son&quot; or &quot;sons&quot; or &quot;spouse**&quot; or &quot;wife&quot; or &quot;wifes&quot;) OR AB (&quot;adult child**&quot; or &quot;carer**&quot; or &quot;caregiver**&quot; or &quot;daughter**&quot; or &quot;husband**&quot; or &quot;family&quot; or &quot;families&quot; or &quot;next of kin&quot; or &quot;relatives&quot; or &quot;son&quot; or &quot;sons&quot; or &quot;spouse**&quot; or &quot;wife&quot; or &quot;wifes&quot;):ti,ab,kw</td>
<td>#2 (&quot;adult child**&quot; or &quot;carer**&quot; or &quot;caregiver**&quot; or &quot;daughter**&quot; or &quot;husband**&quot; or &quot;family&quot; or &quot;families&quot; or &quot;next of kin&quot; or &quot;relatives&quot; or &quot;son&quot; or &quot;sons&quot; or &quot;spouse**&quot; or &quot;wife&quot; or &quot;wifes&quot;):ti,ab,kw</td>
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<td>23. exp Physicians/ 24. exp Telemedicine/</td>
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<td>25. Occupational Therapists/</td>
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<td>26. Cardiac Rehabilitation/</td>
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<tr>
<td>27. Occupational Therapy/</td>
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<tr>
<td>28. exp Rehabilitation/ 29. exp Social Work/</td>
<td>S37 S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36</td>
<td>#3 (&quot;aged&quot; or &quot;aging&quot; or &quot;centenarians&quot; or &quot;elder**&quot; or &quot;medical practice**&quot; or &quot;nursing&quot; or &quot;nurse&quot; or &quot;physician**&quot; or &quot;primary care&quot; or &quot;professional practice**&quot; or &quot;program**&quot; or &quot;psychol**&quot; or &quot;psychotherap**&quot; or &quot;rehabilitation&quot; or &quot;social care&quot; or &quot;social practice**&quot; or &quot;social work**&quot; or &quot;support**&quot; or &quot;telenursing&quot; or &quot;telemedicine&quot; or &quot;therap**&quot;)):ti,ab,kw OR (((&quot;family&quot; or &quot;families&quot;) NEAR/2 (&quot;center**&quot; or &quot;focus**&quot; or &quot;health&quot; or &quot;practice**&quot;)):ti,ab,kw</td>
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<tr>
<td>30. Social workers/</td>
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<tr>
<td>31. exp Psychotherapy/</td>
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</tbody>
</table>
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| 44. exp Cardiovascular Diseases/  
| 45. ((cardiac* or cardiopulmonary or cardiovascular or cerebrovascular or coronary or heart or myocardial) adj2 (arrest* or attack* or condition* or disease* or disorder* or failure or ill or illness* or infarc*)).ti,ab,kf.  
| 46. or/44-45  
| 47. exp Europe/48. including any European country  
| 49. or/47-48  
| 50. 34 and 40 and 43 and 46 and 49  
| 51. limit 50 to (danish or english or french or norwegian or spanish or swedish)  
| 52. limit 51 to yr="2008 -Current" |
### Table 2: Characteristics of the included studies

<table>
<thead>
<tr>
<th>Author(s), year, (# in review), country</th>
<th>Title</th>
<th>Aim</th>
<th>Design</th>
<th>Participants</th>
<th>Outcome measurements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Agren et al 2012 (43) Sweden</td>
<td>Dyads Affected by Chronic Heart Failure: A Randomized Study Evaluating Effects of Education and Psychosocial Support to Patients with Heart Failure and Their Partners</td>
<td>To evaluate the effects of an integrated dyad care program with education and psychosocial support to patients with HF and their partners during a post discharge period after acute deterioration of CHF</td>
<td>RCT</td>
<td>155 patients with HF mean age 71 years 155 partners mean age 68,5 years</td>
<td>Patients and partners: Measured at baseline and after 3- and 12-months SF- 36 BDI-II CAS Partners: EHFScB CBS</td>
</tr>
<tr>
<td>2 Agren et al 2015 (44) Sweden</td>
<td>Psychoeducational support to post cardiac surgery heart failure patients and their partners— A randomised pilot study</td>
<td>To evaluate the effects of an intervention in postoperative heart failure patient—partner dyads regarding health, symptoms of depression and perceived control</td>
<td>RCT pilot study</td>
<td>42 postoperative cardiac patients mean age 69,5 years 42 partners mean age 66,5 years</td>
<td>Patients and partners: Measured at baseline and after 3- and 12-months SF- 36 BDI-II CAS</td>
</tr>
<tr>
<td>3 Agren et al</td>
<td>Caregiving tasks and</td>
<td>To evaluate the effects of</td>
<td>RCT</td>
<td>42 Partners of patients</td>
<td>Partners:</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Country</td>
<td>Study Title</td>
<td>Methodology</td>
<td>Participants</td>
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<tr>
<td>2015</td>
<td>(45)</td>
<td>Sweden</td>
<td>Caregiver burden: effects of a psycho-educational intervention in partners of patients with post-operative heart failure</td>
<td>Pilot study</td>
<td>Diagnosed with post-operative HF</td>
</tr>
<tr>
<td>2018</td>
<td>Ates et al.</td>
<td>Belgium, Denmark, United Kingdom, Hungary and the Netherlands</td>
<td>“Never at ease”– family carers within integrated palliative care: a multinational, mixed method study</td>
<td>Mixed-methods</td>
<td>87 patients with Cancer, COPD or HF mean age 69 years 87 caregivers mean age 60 years</td>
</tr>
<tr>
<td>2009</td>
<td>Boyd et al</td>
<td>United Kingdom</td>
<td>Making sure services deliver for people with advanced heart failure: a longitudinal qualitative study of</td>
<td>Qualitative</td>
<td>36 patients with HF mean age 76 years 30 carers age not given</td>
</tr>
<tr>
<td>No.</td>
<td>Authors</td>
<td>Title</td>
<td>Methodology</td>
<td>Participants</td>
<td>Follow-up</td>
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<tr>
<td>6</td>
<td>Browne et al 2014 (47)</td>
<td>Patient, Carer and Professional Perspectives on Barriers and Facilitators to Quality Care in Advanced Heart Failure</td>
<td>Qualitative Content analysis</td>
<td>30 patients with HF mean age 72 years, 20 carers (age not given)</td>
<td>months later.</td>
</tr>
<tr>
<td>7</td>
<td>den Herder-van der Eerden et al. 2017 (58)</td>
<td>How continuity of care is experienced within the context of integrated palliative care: a qualitative study with patients and family caregivers</td>
<td>Qualitative Content analysis</td>
<td>152 patients with cancer, COPD or HF mean age 68 years, 92 caregivers mean age 61 years</td>
<td>Patients and family caregivers: two semi-structured interviews with an interval of 3 months</td>
</tr>
<tr>
<td>8</td>
<td>Dinesen et al.</td>
<td>Under surveillance, yet</td>
<td>Qualitative</td>
<td>8 patients with HF age 71,5</td>
<td>Patients:</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Country</td>
<td>Study Title</td>
<td>Method</td>
<td>Participants</td>
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<tr>
<td>2008</td>
<td>(54)</td>
<td>Denmark</td>
<td>looked after: Tele-home-care as viewed by patients and their spouse/partners</td>
<td>experiences and attitudes of patients and their spouses/partners to the application of tele-home-care technology as an option within home hospitalisation</td>
<td>Phenomenological hermeneutic approach</td>
</tr>
<tr>
<td>2016</td>
<td>Dithmer et al.</td>
<td>Denmark</td>
<td>“The Heart Game”: Using Gamification as Part of a Tele-Rehabilitation Program for Heart Patients</td>
<td>To describe the development and testing of a prototype application (&quot;The Heart Game&quot;) using gamification principles to assist heart patients in their tele-rehabilitation process in the Teledialog project</td>
<td>Qualitative Content analysis</td>
</tr>
<tr>
<td>2015</td>
<td>Doos et al.</td>
<td>United Kingdom</td>
<td>Heart failure and chronic obstructive pulmonary disease multi-morbidty at hospital discharge transition: a study of patient and carer</td>
<td>To explore the experiences of HF and COPD multi-morbid patients and their carers on hospital discharge</td>
<td>Mixed-methods</td>
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<table>
<thead>
<tr>
<th>Reference</th>
<th>Author(s)</th>
<th>Country</th>
<th>Study Title</th>
<th>Research Question</th>
<th>Study Type</th>
<th>Sample Characteristics</th>
<th>Data Collection Details</th>
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<tbody>
<tr>
<td>11</td>
<td>Garbacz et al, 2015 (48)</td>
<td>France</td>
<td>Impact of therapeutic education on lifestyles: perception of patient and their relatives</td>
<td>To describe the perception of HF patients and their families concerning the impact of TPE on their lifestyles.</td>
<td>Cross-sectional descriptive</td>
<td>257 patients diagnosed with HF mean age 67 years 149 Relatives age 59 years</td>
<td>Patients and relatives: An instrument developed for the study consisting of 12 questions measuring the impact of therapeutic education on lifestyle.</td>
</tr>
<tr>
<td>12</td>
<td>Gusdal et al., 2018 (49)</td>
<td>Sweden</td>
<td>Family Health Conversations Conducted by Telephone in Heart Failure Nursing Care: A Feasibility Study</td>
<td>To explore the experiences and feasibility of nurse-led FamHCs conducted by telephone with patients and their family caregivers</td>
<td>Mixed-methods</td>
<td>8 Patients diagnosed with HF mean age 72,5 years 8 family caregivers mean age 62,5 years</td>
<td>Patients, caregivers and nurses: Interviews 4 to 6 weeks after their last FamHC Patients: ICE-FPSQ Communication questionnaire 2 to 3 weeks before the first FamHC Caregivers: ICE-FPSQ Communication</td>
</tr>
<tr>
<td>Study ID</td>
<td>Authors</td>
<td>Title</td>
<td>Design</td>
<td>Participants</td>
<td>Methods</td>
<td>Measures</td>
<td>Follow-Up</td>
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<tr>
<td>13</td>
<td>Liljeroos et al., 2015 (60)</td>
<td>Long Term Follow-Up after a Randomized Integrated Educational and Psychosocial Intervention in Patient-Partner Dyads Affected by Heart Failure</td>
<td>RCT</td>
<td>155 patients with HF mean age 71 years, 155 partners mean age 68,5 years</td>
<td>Patients and partners: Measured at baseline and after 24 months follow-up</td>
<td>SF-36, BDI-II, CAS</td>
<td>2 to 3 weeks before the first FamHC</td>
</tr>
<tr>
<td>14</td>
<td>Liljeroos et al., 2017 (61)</td>
<td>Long-term effects of a dyadic psycho-educational intervention on caregiver burden and morbidity in partners of patients with heart failure: a randomized controlled trial</td>
<td>RCT</td>
<td>155 partners mean age 68,5 years</td>
<td>Partners: Measured at baseline and after 24 months follow-up</td>
<td>CBS, SF-36, BDI-II, CAS</td>
<td>2 to 3 weeks before the first FamHC</td>
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<tr>
<td>15</td>
<td>Lind &amp; Karlsson 2014 (50)</td>
<td>Telehealth for “the Digital Illiterate” elderly Heart Failure Patients’ Experiences</td>
<td>Qualitative</td>
<td>7 patients with HF mean age 83 years, 2 spouses (age not stated)</td>
<td>Patients and spouses: Interviews (time not stated)</td>
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<td>16</td>
<td>Lofvenmark et al.</td>
<td>A group-based multi-</td>
<td>RCT</td>
<td>128 patients with HF mean age</td>
<td>Family members:</td>
<td></td>
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<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Design</th>
<th>Participants</th>
<th>Outcomes</th>
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</thead>
<tbody>
<tr>
<td>Lofvenmark et al 2013 (62)</td>
<td>Sweden</td>
<td>Evaluation of an educational programme for family members of patients living with heart failure: a randomised controlled trial</td>
<td>Evaluation of the effect of a group-based multi-professional educational programme for family members of patients with chronic heart failure with regard to quality of life, depression and anxiety.</td>
<td>RCT</td>
</tr>
<tr>
<td>Malm et al., 2018 (56)</td>
<td>Sweden</td>
<td>Effects of brief mindfulness-based cognitive behavioural therapy on health-related quality of life</td>
<td>To evaluate the effects of a brief dyadic cognitive behavioural therapy (CBT) programme on the health-related quality of life</td>
<td>RCT</td>
</tr>
<tr>
<td>Study Number</td>
<td>Authors (Year)</td>
<td>Country</td>
<td>Objective</td>
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<td>19</td>
<td>Näsström et al. 2017 (52)</td>
<td>Sweden</td>
<td>Exploring partners’ perspectives on participation in heart failure home care: a mixed-method design</td>
<td>Mixed-methods</td>
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<td>20</td>
<td>Rantanen et al., 2009 (63)</td>
<td>Finland</td>
<td>Health-related quality of life after coronary artery bypass grafting</td>
<td>Longitudinal descriptive</td>
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<td></td>
<td>Study Authors and Year</td>
<td>Title and Context</td>
<td>Methodology</td>
<td>Key Findings</td>
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<tr>
<td>21</td>
<td>Voltelen et al 2018 (64)</td>
<td>Family Nursing Therapeutic Conversations: Family Reorganization Processes After Diagnosis.</td>
<td>Qualitative Grounded theory</td>
<td>To explore and explain the readjustment processes of families living with a family member suffering from heart failure 1 year after having attended a heart failure clinic where family nursing therapeutic conversations were conducted</td>
</tr>
<tr>
<td>22</td>
<td>Østergaard et al 2018 (53)</td>
<td>Effect of family nursing therapeutic conversations on health-related quality of life, self-care and depression among outpatients with heart failure: A randomized multi-centre trial</td>
<td>RCT</td>
<td>To evaluate the short-term (3 months) effects of family nursing therapeutic conversations (FNTC) on health-related quality of life, self-care and depression in outpatients with Heart failure (HF)</td>
</tr>
</tbody>
</table>

HF = heart failure; CABG = coronary bypass grafting; HF-CQ = Heart Failure Caregiver Questionnaire; ICE-FPSQ = Iceland-Family Perceived Support Questionnaire; HRQoL = health related-quality of life; TPE = Therapeutic Education; RCT = randomised clinical trial; FNTC = Family nursing therapeutic conversations; KCCQ: Kansas City Cardiomyopathy Questionnaire; EHFScB = The European Heart Failure Self-care Behaviour Scale; MDI = Major Depression Inventory; COPD = Chronic Obstructive pulmonary Disease; POS = Palliative Care Outcome Scale; CRA = Caregiver Reaction Assessment; CANHELP Lite = Canadian Health Care Evaluation Project Questionnaire; This article is protected by copyright. All rights reserved
SF-36 = The 36-Item Short-Form Health Survey; BDI-II = Beck Depression Inventory; CAS = Control Attitude Scale; CBS = Caregiver Burden Scale; DOBI = Dutch Objective Burden Inventory; EQ-5D = EuroQol questionnaire; HADS = Hospital Anxiety and Depression Scale; SOC-13 = Sense of Coherence Scale; AF = atrial fibrillation; HCAHPS = American Hospital Consumer Assessment of Healthcare Providers and Systems; PHQ-9 = Patient Health Questionnaire; ISSI = Interview Schedule for Social Interaction
<table>
<thead>
<tr>
<th>Author(s), year, country</th>
<th>Participants</th>
<th>Conventional health practice</th>
<th>Actual health practice</th>
<th>Perceptions of patients and family members</th>
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<tr>
<td>Ates et al., 2018 Germany Belgium, Denmark, United Kingdom, Hungary and Netherlands</td>
<td>87 patients with Cancer, COPD or HF mean and 87 caregivers</td>
<td>Not described</td>
<td>Integrated palliative care involves bringing together administrative, organisational, clinical and service aspects between all actors involved in the care network of patients receiving palliative care. The aim is to maintain the best possible well-being of patients and their family caregivers</td>
<td>Quantitative data showed moderate burden, but the qualitative findings indicated that this burden might be underrated. Needs of family carers were similar in all participating countries Qualitative findings indicate a need for proactive care for family carers, e.g. provision of respite care, training, and access to resources</td>
</tr>
<tr>
<td>den Herder-van der Eerden et al., 2017 Netherlands, United Kingdom, Belgium, Germany, Hungary</td>
<td>152 patients with cancer, COPD or HF and 92 caregivers</td>
<td>Not described</td>
<td>Integrated palliative care with ongoing therapeutic relationships, using information about past events and personal circumstances to make current care appropriate for each individual and consistent and coherent approach to the management of a health condition that is responsive to a patient’s changing needs</td>
<td>Patients and family caregivers most likely experienced continuity of care by having a small number of trusted health care professionals who were available, provided multidisciplinary care and regularly transferred information to all health care professionals involved.</td>
</tr>
<tr>
<td>Dithmer et al., 2016 Denmark</td>
<td>10 patients with HF, MI or AP and 10 family members</td>
<td>Not described</td>
<td>“The Heart Game” was designed to be played by a two-person team: a patient and someone close to the patient. Every day for 2 weeks, the two “players” were presented with two challenges e.g.</td>
<td>Gamification seems to be a promising platform for use in the rehabilitation process of heart patients. Inclusion of the patient’s spouse in the</td>
</tr>
<tr>
<td>Study</td>
<td>Patients</td>
<td>Caregivers</td>
<td>Intervention Details</td>
<td>Outcome</td>
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<td>-----------------------------</td>
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<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Gusdal et al., 2018</td>
<td>8 Patients diagnosed with HF and 8 family caregivers</td>
<td>Not described</td>
<td>Family Health Conversations Conducted by Telephone. Nurses conducted three conversations with each family, with an average duration of 45 minutes. Focus was on family’s strengths, narratives and reflections through asking reflective questions.</td>
<td>The intervention facilitated communication within the family and initiated and strengthened the nurse–family relationships.</td>
</tr>
<tr>
<td>Rantanen et al., 2009</td>
<td>163 post CABG patients and 163 significant others</td>
<td>Social support received from support network and from nurses on the hospital ward</td>
<td>Not relevant</td>
<td>HRQoL was lowest one month after the operation but improved during follow-up. HRQoL scores improvement more among patients compared to the significant others. Social support was not associated with change in HRQoL</td>
</tr>
<tr>
<td>Voltelen et al., 2018</td>
<td>15 families in which a member suffered from HF</td>
<td>See Østergaard et al., 2018</td>
<td>See Østergaard et al., 2018</td>
<td>Reorganizing family life was characterized by a process of balancing needs while maintaining personal integrity and maintaining family bonds.</td>
</tr>
<tr>
<td>Østergaard et al., 2018</td>
<td>347 patients with HF and 322 family members</td>
<td>All patients received standard treatment consisting of a preliminary clinical assessment of the patient by consulting</td>
<td>FNTC based on the Calgary family assessment and implementation models that aims to improve or maintain family functioning in the cognitive, affective, and behavioural domains. A genogram was drawn reflecting a picture of family</td>
<td>No statistically significant difference in HRQoL, self-care and depression between the groups. HRQoL scores of patients in the FNTC group changed clinically significant in seven domains, compared to one domain in the control group.</td>
</tr>
</tbody>
</table>
cardiologists, followed by continued treatment in the nurse-led HF clinics for up-titration and adjustment of the pharmacological medication, telephone consultations and patient education. Structure and social relationships. Each family member was encouraged to tell their illness narrative and to reflect upon their beliefs about the HF diagnosis. They were also asked about which issues and problems they considered as being the most important and their expectations regarding the meeting. Future goals were identified, and the impact of the illness on the family unit as well as on the individual member’s daily life was discussed. With the highest improvement in self-efficacy, social limitation and symptom burden.

HF = heart failure; COPD = chronic obstructive pulmonary disease; CABG = coronary artery bypass grafting; HRQoL = health related quality of life; FNCTC = family nursing therapeutic conversations
<table>
<thead>
<tr>
<th>Author (s), year, country</th>
<th>Participants</th>
<th>Conventional health practice</th>
<th>New health practice</th>
<th>Perceptions of patients, family members or health professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agren et al 2012, Sweden</td>
<td>155 dyads consisting of a patient diagnosed with HF and a partner</td>
<td>The control group received traditional in hospital and outpatient education and support mainly focusing on the patient’s needs on education and psychosocial support. The partner was not systematically involved in the follow-up</td>
<td>Psychoeducational intervention in addition to conventional care including a computer-based CD-ROM program, and other written teaching materials was delivered in 3 sessions by a nurse. Cognitive-behavioural strategies assisted dyads in recognizing and modifying factors that contribute to physical and emotional distress and in solving problems related to implementing strategies for self-care. The first session was conducted two weeks after discharge and the remaining sessions occurred 6 and 12 weeks after discharge</td>
<td>Patients in the intervention group improved perceived control significantly more than control patients after 3 months, but not after 12 months. No differences in partners perceived control. No differences in HRQoL and depression in dyads, self-care behaviour in patients, and caregiver burden in the partners between the groups after 3 and 12 months.</td>
</tr>
<tr>
<td>Agren et al 2015, Sweden</td>
<td>42 dyads consisting of a patient diagnosed with postoperative HF, and a partner living in the same household as the patient</td>
<td>Preoperatively, all patients received information from the thoracic surgeon, thoracic anaesthetist and a nurse. After 1 week, the same nurse contacted the patients</td>
<td>Psychoeducational support in addition to conventional care from an interdisciplinary team consisting of a physician, nurse and physiotherapist. The first session involved the entire multidisciplinary team and the last two involved telephone consultation by the team nurse. If the patient—partner dyad</td>
<td>No significant differences between groups in quality of life and depression. Patients in the intervention group improved their perceived control significantly at three months and 12 months compared to baseline. No effect on partners.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Description</td>
<td>Intervention</td>
<td>Findings</td>
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<tr>
<td>Agren et al. 2015</td>
<td>Sweden</td>
<td>42 Partners of patients diagnosed with post-operative HF</td>
<td>Care as usual included optimized treatment according to international guidelines. Verbal and written patient education focused on the patient’s needs. Partners were able to join in, but were not systematically invited to participate in the care.</td>
<td>No significant differences in caregiver burden between the groups were found at 3- and 12-months follow-up.</td>
</tr>
<tr>
<td>Liljeroos et al., 2015</td>
<td>Sweden</td>
<td>155 dyads consisting of a patient diagnosed with HF and a partner acting as informal caregiver</td>
<td>Based on a conceptual health promotion model focusing on enhancing self-efficacy to improve self-care. The intervention was delivered in three modules by a nurse including a computer-based program and written materials. The sessions took place two, six and twelve weeks after discharge from hospital. Each module contained cognitive, supportive and behavioural components and outcomes. The partner’s need for support and perceived caregiver burden, were assessed in order to find strategies to improve control and self-care behaviour, and plan for the future.</td>
<td>No effect on health, depressive symptoms or perceived control among the patient-partner dyads after 24 months.</td>
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See Liljeroos et al., 2015

No significant differences between the groups in

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<table>
<thead>
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<tbody>
<tr>
<td>2017</td>
<td>Sweden</td>
<td>201 patients diagnosed with HF</td>
<td>2015</td>
<td>Caregiver burden after 24 months. No difference in number of hospital admissions or hospital days among partners during the 24 months. Compared to baseline, the total mean scores of caregiver burden increased significantly.</td>
</tr>
<tr>
<td></td>
<td>Malm et al., 2018</td>
<td>111 patients diagnosed with AF</td>
<td>Conventional care included prescription of anticoagulants. After discharge, patients were encouraged to reduce the risk of new AF episodes by exercising regularly, refraining from smoking or using snuff, not exceeding a moderate intake of alcohol and coffee, and avoiding psychological distress, in accordance with provided guideline.</td>
<td>Cognitive behavioural therapy in addition to conventional care consisting of three 2.5-hour group sessions over a period of 9 weeks, with four to six AF patients, including spouses. Participants were trained to be aware of their breathing. Moreover, heart rate variability biofeedback was demonstrated during these training sessions. Significant differences between the groups in HRQoL, depression and SOC in favour of the intervention at 12 months follow-up.</td>
</tr>
<tr>
<td>2015</td>
<td>United Kingdom</td>
<td>14 patients with HF and COPD and 5 carers</td>
<td>Not described</td>
<td>Patient and carers’ views on hospital discharge – no further description</td>
</tr>
<tr>
<td>Dinesen et al., 2008</td>
<td>Denmark</td>
<td>8 patients with HF, 6 spouses/partners</td>
<td>Patients were transferred from traditional hospital admissions to home hospitalisation in joint responsibility between the district nurses and the hospital for typically 3 days. Via a joint web-portal, the healthcare professionals could enter data on blood pressure, pulse, weight, and blood sample for anticoagulation therapy. When the district nurse was taking an ECG recording, she could write a brief commentary about the patient’s symptoms and transmit this information to the hospital. The staff at the hospital received the ECG recording in an e-mailbox.</td>
<td>Patients experienced security, freedom, increased awareness of own symptoms, being ‘looked after’ but annoyed with their spouse/partner. Spouses experienced increased responsibility, nervous tension, and invasion of privacy.</td>
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HF = heart failure; COPD = chronic obstructive pulmonary disease; HRQoL = health related quality of life; SOC = sense of coherence
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<tr>
<td>Boyd et al., 2009, United Kingdom</td>
<td>36 patients with HF, 30 carers and professionals</td>
<td>A charitably funded user forum and a multi-professional heart failure steering group that included primary care, medicine of the elderly and palliative care. The heart failure nursing service was available exclusively to patients with left ventricular systolic dysfunction following a hospital admission. Professionals could access specialist palliative care services for any patients with complex palliative care needs using agreed referral criteria</td>
<td>Not relevant</td>
<td>The interviews revealed four themes regarding: 1) Key components of effective heart failure services 2) Specialist services versus primary care 3) Barriers to delivery of effective heart failure services 4) Prognostic uncertainty and talking about dying</td>
</tr>
<tr>
<td>Browne et al., 2014, United Kingdom</td>
<td>30 patients with HF, 20 carers and professionals</td>
<td>Provision of palliative care service. No further description</td>
<td>Not relevant</td>
<td>The interviews revealed four key problems: 1) Knowledge and understanding deficits 2) Difficulties navigating and accessing health and social care support</td>
</tr>
<tr>
<td>Garbacz et al 2015 &amp; Juillière et al., 2006 France</td>
<td>257 patients diagnosed with HF mean and 149 relatives</td>
<td>Not described</td>
<td>TPE consists of educational tools in a briefcase including a joined compact disc containing the basic parts of the tools which is supposed to be individualised according to the patient’s needs. Five units concerning: 1) educational diagnosis (clinical, biological, socio-professional and psychological dimensions of the disease), 2) knowledge of the disease (explanation of physiology of the heart and pathophysiology of CHF), 3) diet control (low-salt recipe book, different menus of restaurants, and a set of 1-g salt spoons), 4) physical activity and daily life (recommendations for practice of physical exercises, trips and holidays, vaccinations and sexual activity) and 5) medical treatment (drugs explicitly devoted treatment of HF and mostly used drugs in cardiovascular diseases)</td>
<td>Patients and their relatives reported positive changes in their lifestyle due to therapeutic education. The relatives complied with the recommendations of health professionals, initially designed for the patient.</td>
</tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Lind &amp; Karlsson, 2014</td>
<td>7 patients with HF and 2 spouses</td>
<td>Not described</td>
<td>Digital pen technology compromising pen and ordinary paper with a close-to-invisible pattern read by a camera inside the digital pen. The strokes made by the pen are recorded and transferred via mobile internet to a server. The health diary system supported daily reports on shortness of breath, intake of p.n. medicine weight etc. free text messages to the care provider and alarms if patient reported values were below/above certain limits</td>
<td>The interviews revealed two categories regarding: 1) Difficult seeing one's own change 2) Multimorbid, but with a sense of security and trust</td>
</tr>
<tr>
<td>Näsström et al., 2017 &amp; Näsström et al., 2014</td>
<td>15 partners of patients with HF</td>
<td>Not described</td>
<td>The partners were cohabiting with patients who received structured home care from one of four home-care units in Sweden. Three of the units were organized from hospitals and one was organized in a primary care setting. The patient or their partner could contact the home-care team at all hours.</td>
<td>Partners were satisfied with most aspects of participation, information and contact. Qualitative findings revealed four different aspects of participation 1) Adapting to the caring needs and illness trajectory 2) Coping with caregiving demands 3) Interacting with healthcare providers 4) Need for knowledge to comprehend the health situation</td>
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HF = heart failure  TPE = therapeutic patient education
Table 6: Intervention towards family members and reaction of patients

<table>
<thead>
<tr>
<th>Author (s), year, country</th>
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<tr>
<td>Lofvenmark et al., 2011</td>
<td>128 patients with HF and 128 family members</td>
<td>Information was usually provided by a physician or a nurse following a request from a family member, or if the health care providers considered it important</td>
<td>A multi-professional patient education programme based on ESC guidelines including six sessions for six months. The sessions started with information about one separate theme by one of the professions, and time was always available for questions, reflections and discussions. At the final session, there were follow-up discussions, and a possibility to invite someone of the earlier speakers</td>
<td>Significant differences in family members’ knowledge about HF in favour of the education programme after 2 weeks and 6-month follow-up. No significance difference in readmission of patients due to HF</td>
</tr>
<tr>
<td>Lofvenmark et al., 2013</td>
<td>128 family members</td>
<td>See Lofvenmark et al., 2011</td>
<td>Lofvenmark et al., 2011</td>
<td>No significant differences in anxiety, depression or quality of life between the intervention group and the control group</td>
</tr>
</tbody>
</table>

HF = heart failure; ESC = European Society of Cardiology