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Nursing Strategies for facilitating family involvement in the care of patients with chronic disease.

A Literature Review

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Abstract

Chronic diseases affect more than 50% of the world’s population, and represent the leading cause of disease burden. Patients and developed professional services cannot meet up with the complex routines and duration of chronic disease care. Involving family in the care process and supporting them has improved outcome for patients, families and nurses. Nurses have acknowledged family support, and have played significant role in involving and supporting them in their patient’s care process. However, there are limited resources to guide them.

The aim of this study was to identify strategies used by nurses to facilitate family involvement in the care of adult patients (≥ 18 years of age) with chronic disease. The purpose was to provide information that nurses and other health care professionals working with families and patients could use.

The study is a literature review of 15 articles, published between 2009 and 2018. Data was searched using Cinahl and Medline databases, and analyzed using content analysis.

Three main categories and eight sub-categories emerged in the data analysis. The three categories were, information sharing, collaborative partnership and support patterns. Better outcome was achieved when each strategy was tailored to patients’ disease pattern, and patient/family individual needs. Based on the results of this study, exploring, acknowledging individuality and therapeutic action, could be considered the logical order of nursing strategies, which can facilitate the integration of family in patients’ care process.

All the strategies identified in this study, may not be applicable to every patient/family. Further research is needed to determine whether these results or strategies are applicable to family members across different cultures.

Keywords/tags (subjects)
Chronic disease, nursing strategies, patient and family.

Miscellaneous (Confidential information)

Contents

Figures

Tables

1 Introduction

Chronic diseases represent one of the greatest global health problems in terms of severity and complexity of care regimes, direct cost to health systems and governments (Lainscak, Blue, Clark, Dahlström, Dickstein, Ekman, McDonagh, McMurray, Ryder, Stewart, Strömberg, & Jaarsma 2011; WHO 2011a; 2018). Cardiovascular diseases, diabetes, chronic respiratory diseases and cancer, considered the most prominent chronic diseases, are the major cause of mortality and disability among affected individuals (WHO 2014), and were the most discussed in this study.

For these diseases, the goals of care are not to cure, but to enhance functional status and prolong life through secondary prevention and management of symptoms, risk factors and complications (NHS 2018a; Whittemore, & Dixon 2008). Patients have to engage in long-term management of complex self and medication regimes, physical, psychological and social demands of the disease as well as with multiple health professionals (Lainscak et al. 2011; Schulman-Green, Jaser, Martin, Alonzo, Grey, McCorkle, Redeker, Reynolds, & Whittemore 2012).

Professional services, including, nurse-led disease education and counselling programs delivered in different health care settings (Poitras, Chouinard, Gallagher, & Fortin 2018), developed to improve care accessibility and management of chronic diseases, cannot meet up with the complex routines and duration of chronic disease care. Involving family in patients' care process, has improved outcome for patients, families and nurses (Gusdal, Josefsson, Adolfsson, & Martin 2018). Nurses have played significant role in involving family (Gusdal et al. 2017; 2018), however, resources to guide them are still limited. Once involved, family, need information, training and support to assist them manage their caregiving burden, while maintaining their responsibility to the patient (Gusdal et al. 2018; Shahriari, Ahmadi, Babaee, Mehrabi, & Sadeghi 2013).

The aim of this study was to identify strategies used by nurses to facilitate family involvement in the care of adults (≥ 18 years) with chronic disease. The purpose is to provide information that could help nurses and other health care professionals meet the needs of these patients and their families.

2 Patient- and Family-centered care

2.1. Defining family

Family refers to two or more persons who are biologically, emotionally or legally related. The patient and family define their “family”, and determine how and to what extend they will participate in the care process and decision making (Institute of Patient- and Family-Centered care 2017.). Family involvement in the care process does not take control from competent patients who can make decisions regarding their own care (ibid.). Family involvement is a choice that should be presented to all patients, and able patients have the right to decide to what extend (if any) they want their family to participate in the care process, and patients desire to involve their families in their care should be respected (Ho 2008; Sedig 2016).

The family member (s), should also be willing and able to take part in the care. Some patients may wish for their family to be involved in the decision-making or even choose to relinquish the decision-making right entirely to them (Micheal, O’Callaghan, & Hiscock 2014). In accordance with patient’s wishes, nurses should explore family’s level of involvement in the care process from the start, create a foundation for mutual collaboration, explain the protocol and resources available (Almborg, Ulander, Thulin, & Berg 2009; Hobbs, Landrum, Arora, Ganz, van Ryn, Weeks, Mack, & Keating 2015; Manias 2015).

The term “family” is used in this study to reflect whomever the patient identified as their caregiver, defined, as someone already involved at some level in patients’ medical care or is willing and able to take on the new role, and patients have consented to their involvement in the care process, at whatever level both parties agree to.

2.2 Defining patient- and family-centered care

Multiple definitions of patient- and family-centered care (PFCC) exist, but, the majority embrace the view of care-client, a collaborative partnership approach to health care decision-making between health care providers, patient and family, however they are defined (Johnson, & Abraham 2012; Institute for Patient- and Family-centered Care 2017; Rahimi, & Gharib 2017). This study builds on the definition of Patient- and family-centered care outlined in the Institute for Patient- and Family-centered Care: “an approach to the planning, provision and evaluation of care at all levels in health care settings that is founded in a mutually beneficial collaborative partnerships among patients, families and health care providers” (2017).

Patient-and family-centered care recognizes the patient as being the centre of the care, but gaining significant support from their family. It also acknowledges the family as vital to the patient’s health care experience and well-being as well as significant allies for quality and safety within health care settings (Allen, Scarinci, & Hickson 2018; Institute of Patient- and Family-Centered care 2017). In addition, PFCC recognizes that individuals experiencing chronic disease are the most dependent on hospital care and health system services. Therefore, they are the most dependent on their families for support (Johnson, Abraham, Conway, Simmons, Edgman-Levitan, Sodomka, & Ford 2008).

The main goals of PFCC are to promote the quality of life of not only the patients but also that of their families, strengthen, support and maintain patient/family control over their health care (Institute for Patient- and Family-centered Care 2017). The four main concepts of PFCC are listed in Table 1 (ibid.). Applying these concepts have been associated with improved patients’ adherence to therapeutic regimes, including, rehabilitation, medication and dietary regimes and increased patient/family satisfaction (Johnson, et al. 2008; Nayeri, Mohammadi, Razi, & Kazemnejad 2014).

Table 1. Main concepts of Patient- and Family-Centered Care (Institute of Patient- and Family-Centered Care 2017).

Elements	Explanation
Dignity and respect	Families are different. Care providers should respect each Patient and family's uniqueness. Listen to them, recognize their strengths and individual coping methods, and try to incorporate their knowledge, values, beliefs, personal goals and cultural backgrounds into the planning and delivery of care.
Information sharing	Providers should communicate and share complete and unbiased information with patients and their families as need arises in ways that are clear and useful. Provide timely information to patients and families so that they can effectively take part in care process
Participation	Care should be provided in collaboration with the patient and their families, rather than "to" or "for" them. Patients and families should be supported and encouraged to participate in the care and decision-making to the extent that they choose.
Collaboration	Patients, families, health care providers and organizations should work in partnership in policy and program development, implementation and evaluation of facility design and professional education. Care providers should adopt policies and design health care that is flexible and responsive to the needs of the patient and family.

2.3 Family support for patients with chronic disease and caregiving needs

In addition to the complexity in their management, chronic diseases place different sets of demand on the patients and their families. Golics, Basra, Salek, & Finlay (2013) reported that chronic disease affected negatively the quality of life of the patients and that of their families in terms of restricted social life, physical, emotional and financial drainage, increased stress and tension on their family relationship. In particular, chronic diseases can affect patients' level of autonomy and skills needed to perform daily life tasks, their psychological and cognitive state, leading to physical limitations, psychosocial and cognitive disabilities (Golics et al. 2013; Pihl, Fridlund, & Mårtensson 2011). For such patients, family are often the main supportive agents, directly performing health-related tasks, and providing physical and psychosocial support (Clark, Reid, Morrison, Capewell, Murdoch & McMurray 2008; Drageset, Lindstrøm, Giske, & Underlid, 2011; Riley, White, Graham, & Alexandrov, 2014).

Even functionally able patients, who want to be as independent as possible in their disease management, still need family support to deal with the stress of the disease and complex routine (Rosland, Heisler, Choi, Silveira, & Piette 2010). Other family roles include, interpreters, reminding patients to take their medications, communication with care providers and facilitating life-style changes (Drageset et al. 2011; Galinato, Montie, Schuman, Patak, & Titler 2016; Golics et al. 2013; Nayeri et al. 2014).

In addition, in many countries, changes in health care systems, including shorter hospital stays (Caminiti, Meschi, Braglia, Diodati, Lezzi, Marcomini, Nouvenne, Palermo, Prati, Schianchi, & Borghi 2013; NHS 2018b), suggests that many patients may not achieve a secure health status before hospital discharge. Over time, family are the biggest support resources, they are long-term caregivers offering continuity of care, especially after hospital discharge. Nurses come and go, they provide invaluable support with medical management, disease education, guidance and counselling as needed (Poitras et al. 2018; Young, Eley, Patterson, & Turner 2016). However, their services are still limited, and even when available, they cannot meet up with the frequency and duration of chronic disease care.

Family support has been linked to better self-care and medication adherence for patients, improved patient/family quality of life, and increased nurses' satisfaction (Stamp, Dunbar, Clark, Reilly, Gary, Higgins, & Ryan 2016). As well as the benefits and continuing growth, family involvement led to poor disease management and patient dissatisfaction, as a result of family criticism, controlling behavior over their patient and provision of unsolicited information to care providers (Drageset et al. 2011; Rosland et al. 2012). However, family support has great potential to help functionally limited and independent patients to better manage their disease both in hospital and home settings.

Therefore, when providing care to individuals with chronic disease, the need for a move from patient-centered-care to a more encompassing "patient- and Family-Centered care "(PFCC) approach seems logical. The current environment i.e. growing number of patients with chronic disease and associated disability, complexity of care, shorter hospital stays, limited resources and increasing benefits of family involvement in patients care, suggests that this trend is likely to continue.

Furthermore, caregiving is positive and rewarding (Golics et al. 2013), especially if caregivers have access to support (Noonan et al. 2018). However, the negative impacts of chronic disease on family health and well-being, and caregiving abilities should not be minimized. Due to the dynamic nature of chronic diseases and the diverse patient/family populations, family needs vary (Noonan, Wingham, & Taylor 2018; Posma et al. 2009). Common needs include, disease-specific information and training in care provision, inclusion as partners of the care team, and support for family to manage their own physical and mental well-being (Gusdal et al. 2016b; 2018; Wingham , Frost, Britten, Jolly, Greaves, Abraham, Dalal, & REACH HF 2015).

2.4 Nurses' role and attitudes toward family importance in chronic diseases management

Nurses are the first point of contact, meeting diverse patients and families in different health care settings, as such, have the key role to meet their needs. Nurses already play vital roles in chronic disease management at family, group and community level (Gusdal et al. 2017; Voltelen, Kondradsen, & Østergaard 2016). Their role in chronic disease management has increased over the years, to involve home visits, telephone follow-up, nurse-led clinics, case management, discharge planning, education and health promotion (Poitras et al. 2018; Voltelen et al. 2016; Young et al. 2016)

Studies have revealed that, nurses in general view family as important source of support for patients with chronic disease, however, attitudes towards actively inviting families to participate in patients' care have been less supportive (Gusdal et al. 2017; Laryionava, Pfeil, Dietrich, Reiter-Theil, Hiddemann, & Winkler 2018; Luttik, Goossens, Ågren, Jaarsma, Mårtensson, Thompson, & Strömberg 2017). Family members have also expressed a need to be seen and acknowledged by care providers, and for involvement together with care providers in patient's care (Gusdal et al. 2016b; 2018).

Nurses with postgraduate specialization, disease-specific education, the most years family nursing experience, and working in environments with supportive approach towards families, viewed family as resource, involved and supported them in heart failure patients' care process. Nurses with the least years of experience, without disease-specific education or competence in working with families, and working in care settings with less family nursing coaching, viewed family as a burden, minimized family involvement and perspective in the care process (Gusdal et al. 2017).

Despite the important role of family in chronic disease management, and the role nurses play in involving and supporting families, little is still known how best to integrate and support family in patients' care process. For optimal care, during hospitalization and transition from hospital to home, nurses need strategies how to partner and collaborate with patients, families and other care providers.

3 Barriers to family participation in patients care process

3.1 Individual barriers

Individual barriers limiting family participation in patients' care process include, individual care providers' attitudes, experiences with families and perceptions toward family importance in the care process, patient/family attitudes and personal life circumstances. Nurses who held positive and supportive attitudes toward families' involvement, invited and involved them in the care process, while those with negative attitudes minimized family involvement (Gudsal et al. 2017.). Nurses previously attacked by angry family members during traumatic event were hesitant to involve family members in the care process (Riley et al. 2014). Some nurses have focus only on the patient, due to lack of time to explain all information to the family (ibid.). As stated by one nurse "*…if I'm gonna spend an hour talking to [the patient's] family, that is an hour of patient care that I'm not giving*." (ibid.). Kiwanuka, Shayan, & Tolulope (2019) found other care providers fear of compromising patient privacy and language differences, as factors limiting family involvement in the care process.

Vrontaras (2018), findings revealed that some patients did not want their family to be involved, because they did not want to frighten them, be a burden or be treated as if they are dying. They just wanted to be left alone as they deal with the disease. "*On the day I had my surgery and when he [husband] said he wanted to visit, I said: "no, I don't want you to come". I tried to stand on my own two feet. […] I didn't want to be a burden… I said to myself that I will be strong and I will manage on my own"*

(Vrontaras et al. 2018.). Others perceived family support to be a nuisance, when family members provided unsolicited or too much to care providers (Drageset et al. 2011).

Some families do not want to participate because they worry what would happen, if patients' condition will get worse (Vrontaras 2018). Some family members have reported that, they did not participate in the care because care providers did not provide enough information about patient's condition (Bélanger, Desmartis, & Coulombe 2018).

3.2 Interdisciplinary barriers

Different interdisciplinary barriers limited family involvement in patients' care. Lack of cooperation between nurses due to differences in attitude and perception on the importance and extend of family involvement in the care process, was a barrier to inviting and involving family in the care process (Chan, Jones, & Wong 2013). Disagreements between patient and family, when family held views that contradicted patient's preference and professional guidelines, interfered with family involvement (Micheal et al. 2014). Conflict between patients, families and doctors, when families and doctors have shared more information than patient should have, and when families contradicted patient's story led to patients not wanting their family to be present during health visits (Rosland, Piette, Choi, & Heisler 2011). Poor communication between nurses and doctor, and nurses sometimes are discouraged by the physician not to discuss certain issues with patients' family for fear of intrusion of patients' privacy (Kiwanuka et al. 2019).

3.3 Organizational-related barriers

Many studies have cited organizational-related barriers, which interfered with family involvement in the care process. Inappropriate working environment, including, lack of time and private space for patient and family, and defined guidelines and tools care providers need to facilitate family involvement (Kiwanuka, et al. 2019; Lloyd, Elkins, & Innes 2018; Nkrumah et al. 2019; Rosland, et al. 2011). Patient- and family-centered care concepts are not fully included in the organization's vision and the leaders are not committed to facilitating family involvement (Herrin, Harris, Kenward, Hines, Joshi, & Frosh 2016). In addition, historical accepted physicians' dominance over health care systems limits family involvement in patients care process, especially in some developing countries. For example, in Iran, physicians believe that they have full authority over the health care system including the right to make all the decisions about the patients care (Mirlashari, Brown, Fomani, de Salaberry, Zadeh, & Khoshkhou 2020).

4 Aim, purpose and research questions

The aim of this study was to identify strategies used by nurses to facilitate family involvement in the care of patients (≥ 18 years) with chronic disease. The purpose is to provide information that could help nurses and other health care professionals meet the needs of these patients and their families.

Research questions:
What strategies have nurses used to facilitate family involvement in the care process of patients with chronic disease? How was the strategy implemented and what patient/family and nurse outcomes were achieved?

5. Research methodology

5.1 Literature review

According to Conner (2014), a literature review is a clearly structured document that summarizes in a logically argued manner current knowledge on a given topic leading to comprehensive understanding of a given topic. It involves searching, selection, synthesis and interpretation of different but relevant published and unpublished studies that aims at answering clearly targeted research question(s) and provides a sound foundation for new research ideas (Fink 2009).

This study used literature review to explore different approaches used by nurses to facilitate family involvement in the care process of patients with chronic disease. This study reviewed research materials relating to the research topic from different countries and health care settings. As such, the results can be applied in different health care settings as it provides a summary of a large body of analyzed research.

Literature review should be done in a systematic manner, using explicit and reproducible method to identify analyze and synthesis the existing body of completed and recorded work that meet pre-specified inclusion criteria set to answer defined research questions (Fink 2009). While, traditional or narrative literature review critiques and summarizes results of different studies, systematic review aims to provide as complete list as possible of all published and unpublished studies relating to the research topic (Aveyard 2014; Cronin, Ryan, & Coughlan 2008). The systematic rigorous step-by-step approach delimit bias inherent in other methods, improves the reliability and accuracy of conclusion (Cronin et al. 2008).

The six steps for conducting a literature review outlined by Machi and McEvoy (2009), which were followed in this study are present in Table 2. These steps include, selecting a topic, searching the literature, developing an argument, surveying the literature, critiquing the literature and writing the literature.

Table 2. The literature review process (Machi, & McEvoy 2009).

Steps	Tasks
1. Selecting a topic	Identifying the topic of interest, by focusing on what is important and why. Identifying individuals who are most dependent on hospital care and different health care services, hence, the most dependent on family support, helped defined the research topic of this study.
2. Searching the literature	Data for this study was previewed, selected and organized by skimming, scanning and mapping literature. Relevant materials for the study were listed and documented.
3. Develop an argument	Logical arguments were developed from claims logically arranged, evidence and justifications that explain what is known about the topic. Evidence was connected with claim.
4. Survey the literature	Data was assembled, synthesized and analyzed to form an argument about the current knowledge on the selected topic.
5. Critiquing the literature	Consisted of interpreting the current understanding of the selected topic and analyzing how previous knowledge answers the research questions
6. Writing the literature	Concise summary of findings that described current knowledge. Final document should be understood by intended audience.

5.2 Literature search

After defining the research topic, questions, terms and inclusion criteria, literature search was performed. Literature was reviewed by one person. Selecting studies that answered the research question involved two processes (Cronin et al. 2008). First, selecting studies relevant to the research topic and questions based on the title and abstract/summary. Secondly, full texts of studies that passed the initial process were read to determine if they meet the inclusion criteria. Studies included in this study met the inclusion criteria listed in Table 3, and those that did not meet the criteria were automatically excluded.

Table 3. Inclusion criteria

Inclusion criteria
Full text access for JAMK students
Articles in English
Scientific publications
Peer reviewed
Published between 2008-2020
Responds to the research question

The inclusion criteria were selected in order to find relevant up-to-date and evidence-based information related to the research topic. Data was retrieved from Cinahl and Medline databases. These databases provide reliable and up-to-date evidence-based publications in medical research, including nursing (Smith, & Dixon 2009). Using different databases minimizes the possibility of missing some studies (ibid.).

Search terms used were, nursing attitudes OR perceptions OR opinions AND family support, nursing strategy OR Interventions AND family AND chronic disease and Family support OR role AND chronic disease. To gain more results, Boolean operators, “AND” and “OR” were used to combine keywords. With “AND”, all words appeared in the same article and with “OR”, one, a combination or all words appeared in same article. A total of 15 articles from seven countries, namely, Australia (n=1), Germany (n=1), Iran (n=1), Netherlands (n=2), Sweden (n=3), USA (n=6), and UK (n=1), were selected to be reviewed. These articles were published between 2009 and 2018.

Table 4 demonstrates the data search. Duplicates were excluded from the final result. A table of all the articles reviewed can be found in Appendix 1.

Table 4. Data search

Database	Search items	Number of studies	Chosen based on titles, abstract/summary	Relevant articles
Cinahl	Nursing attitudes OR perceptions OR opinions AND family support	59	30	4
Cinahl	Nursing strategy OR Interventions AND family AND chronic diseases,	87	36	5
Cinahl	Family support OR role AND chronic disease	49	38	1
Medline	Nursing attitudes OR perceptions OR opinions AND family support	26	11	2
Medline	Nursing strategy OR Interventions AND Family support AND chronic diseases,	34	15	4
Medline	Family support OR role AND chronic disease	33	9	1

5.3 Data analysis

The purpose of data analysis is to bring together findings from the different articles reviewed that respond to the research questions comprehensively and objectively (Webb & Roe 2008). Content analysis is one of the approaches that has been used increasingly in data analysis in social and health research, including nursing research (Elo, & Kyngäs 2008; Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs 2014; Vaismoradi, Turunen, & Bondas 2013). It is a research method that can be used with either quantitative or qualitative data, as well as in a deductive or inductive way. It offers the possibility to analyze different types of data, and at the same time describe them, and a means of synthesizing studies by categorization and code counting themes (Elo at al. 2008; 2014; Vaismoradi et al. 2013).

Deciding on the content analytical method to use is determined by the purpose of the study. If the study begins with a hypothesis and aims at testing previous theories in different situations, the deductive approach is recommended. Inductive content analysis can be used when the study uses a research questions in order to narrow the scope of the study and, when previous knowledge about a phenomenon is not sufficient or fragmented (Elo et al. 2008). Therefore, for this study, inductive content analysis was chosen and followed. In addition, content analysis is a suitable method that can be used to analyze multifaceted and sensitive phenomena characteristic of nursing research (Elo et al. 2008; Vaismoradi et al. 2013).

The three main phases followed included, preparation, organizing and reporting (Elo et al. 2008). Before the analysis, collected studies were read several times, looking for keywords, trends, or themes, which helped outline the analysis. The preparation phase involved, selecting the unit or theme of the analysis and then making sense of the data. In this study, the units selected were answers to the research questions.

The organization phase, included, open coding, creating categories and abstraction. Open coding entailed reading and highlighting the main findings within selected studies, and then coding them based on the content (Elo et al. 2008). Codes were words that summarized the main aspects of each study. In the next step, similar codes were grouped together as sub-categories, and sub-categories with similar incidents and events were grouped as categories (ibid.). Abstraction, involved formulating a general description of the research topic by generating categories using content-characteristic words. In the final stage, results were analyzed and reported (Elo et al. 2008). The data analysis process for this study is presented in Table 5.

Table 5: Data analysis phases (Elo et al. 2008).

Categories	Sub-categories	Codes	Main findings
Facilitating Information sharing	Linguistic diversity	- Use of interpreter services	- Interpretation services facilitated communication between care recipients and providers
	Supportive communication	- Talking widely and openly about personal sensitive and emotional issues - Reflective discussion - Information provided orally and written documentation	Learning patient/family unique story, allowed for collaborative designing of communication and clinical strategies responsive to their individual needs.
Involving family in care	Family structure	- Elicit patients' opinion for family involvement - Stimulate and encourage joint health visits	Family involvement created a win-win situation for nurses, patients and families
	Family role	- Identifying specific roles, set goals to achieve them - Identify needs - Provision of support as needed	Family members needs were met, they felt supported and were satisfied in their role
	Partnering in decision-making	- Passive, shared and active involvement in decision-making by family members	Family members involved in shared decision-making identified and rectified problems related to patients' medication
Facilitating family involvement	Knowledge and understanding	- Education - Psychosocial support	Family supportive intervention improved self-care behaviors in heart failure, family gained more confidence in supporting patient
	Managing caregiving burden	- Psychoeducation - Supportive counselling - Information	Family-focused interventions decreased caregiving burden, improved quality of life and mental health
	Disagreement	- Involving family members in ways that support healthy family relationships and patient autonomy	Able patients' preference was priority, family opinion came second

6 Results

Three categories, namely, information sharing, collaborative partnership and support patterns, and eight sub-categories that emerged in the analysis process are depicted in Figure 1.

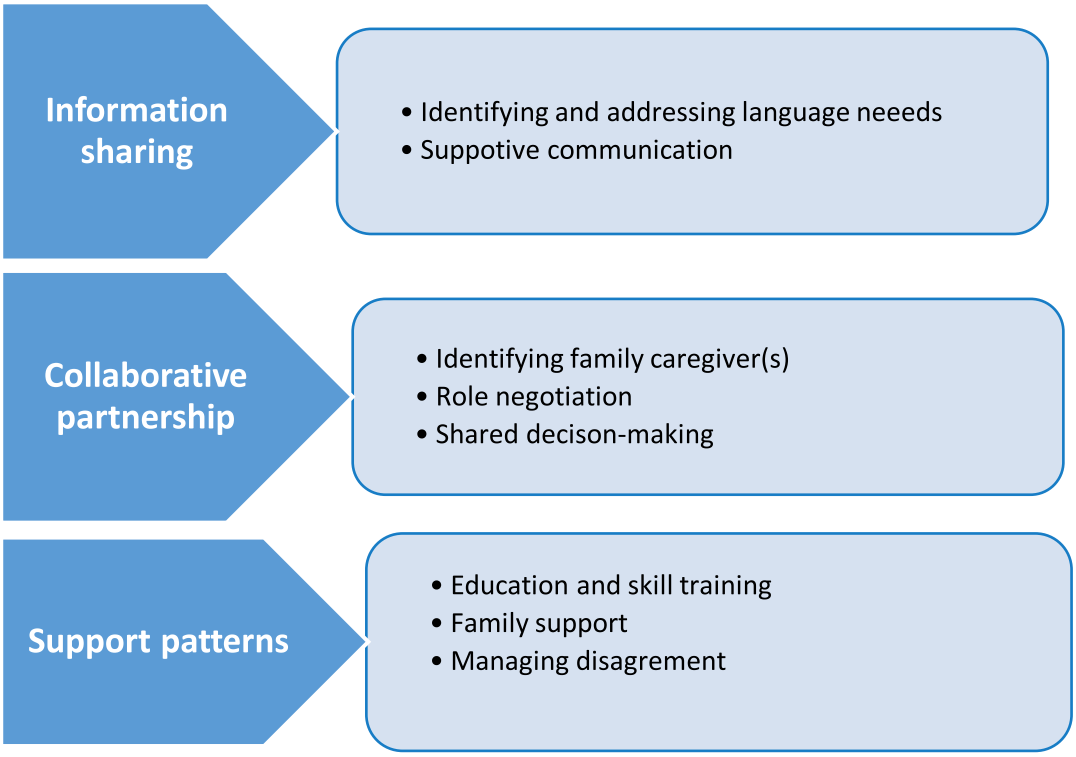

Figure 1. Categories and sub-categories

6.1 Information sharing

Identifying and addressing language needs

Nurses have reported caring for patients with limited language proficiency at least monthly (Galinato, Montie, Schuman, Patak, & Titler 2016). To facilitate communication and information sharing with patients/families with limited proficiency in the host country's official/majority language, nurses have used different interpreter services, at admission, during patient education and at discharge. These included, professional interpreters in-person or via telephone/video technology, interpreter phones, Eloquence™, ad-hoc interpreters (family and bilingual nurses) and non-verbal or visual aids such as, flashcards, gestures and charades (Galinato et al. 2016; van Rosse, Suurmond, Wagner, de Bruijne, & Essink-Bot 2016b).

At admission, nurses have used non-verbal aids where they used hand gestures to mouth with glass to mean drinking, and visual aids, such as, flash cards containing pictures with words of the picture in the patients' and nurses' primary language. In addition, nurses have used Eloquence™, language proficient family members and google translate for simple request (Galinato et al. 2016; van Rosse, et al. 2016b). Although, these interpreter services were mainly designed to be used for transitional or transactional conversations, in situations where a professional interpreter cannot be available in time, they were the most used as they were readily available and easily accessible (Galinato et al. 2016). In this review, nurses rarely used in-person professional interpreters and interpreter phones to access a specific language interpreter, at admission and during in-depth conversation (ibid.).

Positive outcome was demonstrated with the use of Eloquence™, an analogue call light system that uses a touch screen bedside digital user interface with > 30 icons of specific phrases/requests (Galinato et al. 2016). When the patient wanted anything, they will press the corresponding icon and the nurse will receive the message in their own language through their own digital handheld device, and then respond accordingly. Eloquence™ facilitated nurses' communication with language limited patients much better than ad-hoc interpreters (ibid.). Having language proficient family members at patients' bedside provided a convenient means for nurses to communicate with patients with limited language proficiency, however, nurses also admitted that interpretation provided by family may not be reliable or accurate (Galinato et al. 2016.).

Supportive communication

In chronic disease care, nurses have used different verbal and non-verbal techniques to communicate and share information with patients and families (dyad), at admission, during counselling and education sessions, and after hospital discharge. Verbal techniques involved, nurse-led family health telephone conversations (Gusdal et al. 2018), counselling and computer-based education sessions (Ågren, Evangelista, Hjelm, & Strömberg 2012), face- to-face interviews (Posma, van Weert, Jansen, & Bensing 2009), telephone coaching and tech-back (Piamjariyakul, Smith, Russell, Werkowitch, & Elyachar 2013). Non-verbal techniques used were flash cards, questionnaires and written materials, often provided to supplement verbal information (Gusdal et al. 2018; Posma et al. 2009).

Nurses used different supportive communication mechanisms by inviting narratives and reflections through open-ended questions, encouraging dyad to talk openly about sensitive and emotional issues, and subjects of joy surrounding heart failure, disease experience and impact on individual and family life, expectations and preferences (Gusdal et al. 2018; Ågren et al. 2012). Speaking slowly and using simple words, prioritizing information, listening attentively and taking patient/family perspective into account, and together with them, nurses designed communication and clinical strategies responsive to their personal needs (Gusdal et al. 2018).

For patients diagnosed with advanced-disease stage, palliative and end-of-life (hospice) communication is very crucial but difficult for patients, families and nurses. Nurses have used the seven basic nursing communication strategies, namely, communication, orientation and options, mindful communication, family, opening, relation and team (COMFORT), to communicate with dyad around difficult topics in chronic heart failure (Gusdal et al. 2018) and cancer care (Wittenberg, Reb & Kanter 2018). Nurses have used three modules of the curriculum (“O”, “F” and “R”)

Using the COMFORT principle of R-Relating, nurses have asked open-ended reflective questions, and encouraged dyad to discuss about their concerns and feelings (Gusdal et al. 2018; Wittenberg et al. 2018). By learning their unique life story, nurses captured an awareness of their lived-experiences, recognized their feelings and in-corporates them into communication about the disease. Giving them the opportunity to reflect on each other’s narrative, loss and changes the disease has brought (Family) (Gusdal et al. 2018). By learning their unique life story, nurses provided education regarding disease stages and symptoms within the context of their daily living, discussed treatment options and seek patient/family preference for possible available support services (Orientation and Option) (Gusdal et al. 2018; Wittenberg et al. 2018).

Patients and families reported that giving them the permission to talk and reflect about their own experiences beyond self-care and monitoring of disease symptoms, in the presence of a nurse was relieving and liberating. It provided an opportunity for them to become aware of own beliefs, clarify potential misunderstanding between family members, gain new understanding of themselves as individuals and as a family. Nurses gained novel and better understanding of the family picture and their needs, especially family caregivers' burden (Gusdal et al. 2018.).

6.2 Collaborative partnership

Identifying family caregiver (s)

Nurses have asked patients to nominate their family care giver, invited family to actively take part in the patient's care, to have a conversation at the end-of-care period, and encouraged joint health visits for patients who preferred to come to health visits on their own, and supported them (Bakitas, Dionne-Odom, Pamboukian, Tallaj, Kvale, Swetz, Frost, Wells, Azuero, Keebler, Akyar, Ejem, Steinhauser, Smith, Durant & Kono 2017; Dionne-Odom, Azuero, Lyos, Hull, Tosteson, Li, Li, Frost, Dragnev, Akyar, Hegel, & Bakitas 2015; Gusdal et al. 2016a; 2017).

Nurses have encouraged heart failure patients who rarely came with their family to health visits or leave them in the waiting room, to bring the family member with them (Gusdal et al. 2016a). Nurses stimulated patients by emphasizing the advantage of bringing a family to the consultation. Some patients changed their mind and invited their family to health visits, and nurses supported their involvement at different levels in the care process (ibid.). Involving and supporting family members created a win-win situation for patients, family and nurses. Family gained important knowledge on heart failure and self-care. Family had expert knowledge about patient's health status and helped nurses understand reasons for deterioration, which nurses used and it eased their workload. Patients adherence to self-care was higher when both parties heard and understood the rationale behind self-care regime, and family motivated patient to sought health care earlier (Gusdal et al. 2016a.).

During early palliative education and support sessions, nurses have asked patients newly diagnosed with advanced-stage cancer (Dionne-Odom et al. 2015), and those diagnosed with heart failure class III/IV (Bakitas, et al. 2017) to identify their family caregiver, defined as a person in their life who knows them well, has some knowledge and is already involved at some level in their medical care, or is willing and able to take on the new role, and supported them as needed. With patients' permission, nurses invited approved and willing family members to the ENABLE intervention session that involved patients' in-person outpatient palliative care consultation and subsequent palliative consultations (Bakitas et al. 2017; Dionne-Odom et al. 2015). During the sessions, nurses encouraged patient/families and assisted them in developing skills needed to make value-decisions regarding medical and life-sustaining treatment options as patients disease worsened over time (Bakitas et al. 2017). Positive outcome was demonstrated for patients and family involvement in the early palliative care. Moderate improvement in patient and family quality of life and mental health, family caregiving burden and depression, and reduced patient hospital stay and emergency visits (ibid.).

The ENABLE (Education, Nurture, Advice, Before Life Ends) intervention, is a telehealth approach that has been used by nurse to provide early palliative education and support to families and patients diagnosed with advanced-stage cancer and heart failure (Bakitas et al. 2017; Dionne-Edom et al. 2015). It involves an in-person outpatient palliative care consultation with family invited to attend, semi-structured follow-up telephone sessions using a guidebook that covers the following topics, problem solving, symptom management, care coordination, self-care, decision-making and advanced care planning (Bakitas yet al. 2017, Dionne-Edom 2015).

Role negotiation

Nurses have conducted individual and focus group (patient and family) interviews to enquire about family caregivers' role in heart failure management at home, and how the role is negotiated with the patient, caregiving needs and how families take care of themselves (Wingham, Frost, Britten, Jolly, Greaves, Abraham, Dalal, & REACH HF 2015). Family members identified their role to include facilitating patients' self-care, management of disease symptoms and emergencies, and their needs to include, transition to becoming a caregiver, provision of support and help from available sources (ibid.). Nurses together with patients/families set goals how this can be achieved, and supported them to their desired level. Nurses also provided information about available support resources. Some family members reported that their caregiving needs were met, and as a result they felt supported, valued and were satisfied with their role, while others felt that their needs were not met (Wingham et al. 2015).

Through semi-structured interviews with families of hospitalized diabetic patients, nurses have asked about specific roles of the family caregiver in patients' care, the quality of hospital care and the safety of care (van Rosse at al. 2016b). Different roles were identified, interpreters, visitors providing emotional and informational support, washing and mobilizing patients (ibid.). Nurses explained patient's dietary and fluid restriction to the families on several occasion as they continued to bring food and drinks and did not adhere to set fluid and dietary restrictions. Role clarification, training and empowering of families can decrease patient safety risks. Family members were always involved in interpretation for patients with limited language proficiency, took over some tasks thereby reducing nurses' workload (van Rosse et al. 2016b.).

Shared decision-making

Shared decision-making is a collaborative process that allows patients, families and care providers to make care-decisions together, taking into account patients and families goals and preferences (Manias 2015). In accordance with patients' wishes, nurses have involved family members who demonstrated shared-decision making abilities as partners in decision-making regarding medication management in hospitals, treatment limitation in advanced-disease stage and continuation of treatment after hospital discharged (Dionne-Edom et al. 2015, Laryionava et al. 2018; Manias 2015).

Nurses asked family opinion regarding the suitability of patients' new medication and if patient will be able to use the patient controlled analgesia (PCA) pump. Family members negotiated how patients' medications were managed in terms of changing their administration by suggesting the dose, frequency and day of administration, maximizing effectiveness of treatment and managing side-effects, on behalf of the patient put in compromised position because of the disease, or in collaboration with able patients, nurses and doctors (Manias et al. 2015). Medication management strategies nominated by family included the use of interpreters and written lists of all medications that could be updated periodically. Nurses provided information to families about the uses of the medications and the side-effects (ibid.). Decision regarding patients’ medication was jointly made by nurses, patients, families and doctors (Manias et al. 2015).

Family members who contributed extensively in medication activities at home, and were involved in the decision-making regarding patients’ medication, presented valuable, unique information about patient’s medications that promoted patient safety. They addressed problems related to continuity of care, identified and rectified problems related to medications that should have been prescribed, administered or withheld (Manias et al. 2015).

Through a step-by-step approach, nurses have used the ENABLE randomized clinical trial intervention to involve families early on and latter (three months after diagnosis) in effective partnering regarding symptom evaluation and management, advanced care-planning and decision-making regarding treatment limitation of patients newly diagnosed with advanced-stage cancer (Dionne-Odom et al. 2015). Families involved early on in patients care process had lower depression and stress scores (ibid.).

6.3 Support patterns

Education and skill training

Nurses have used different educational programs and psychosocial support interventions designed to meet the preferred learning method and needs of individual patients/families (Bakitas et al. 2017; Dionne-Odom et al. 2015; Gusdal et al. 2018; Piamjariyakul et al. 2013; Posma et al. 2009; Shahriari et al. 2013; Ågren, et al. 2012). These interventions focused on supporting and strengthening patient/family resources, both within and outside in order to enable and empower them to engage in care collaboratively (Posma et al. 2009.).

Nurse-led educational programs for families and/or patients with heart failure and cancer, to prepare them for disease management at home, were conducted through face-to-face counseling, computer-based education CD-ROM program, educative booklets and telephone coaching (Bakitas et al. 2017; Dionne-Edom et al. 2015; Piamjariyakul et al. 2013; Posma et al. 2019; Shahriari et al 2013; Ågren et al. 2012). The content of the sessions included, exploration of patient/family personal situation and needs, education about the disease, symptoms, treatment options and management of side-effects, reinforcement of health action plan, importance and manner of self-care behaviors (Bakitas et al. 2017; Posma et al. 2009; Shahriari et al 2013). At the end of each telephone session, nurses engaged family in teach-back techniques, aimed at determining understanding and identifying areas that need reinforcement, by asking families to reiterate what they had learned in each session (Piamjariyakul et al. 2013).

Psychosocial support interventions were also nurse-administered. These were administered through the use of cognitive-behavioral strategies to assist dyad develop post-discharge problem-solving skills they will need to implement self-care, identify and modify behaviors that contribute to caregiving burnout and stress, and supporting partnership with patients' care team members and provision of information about available support resources (Piamjariyakul et al. 2013; Posma et al. 2009). For families of patients diagnosed with advanced-disease stage, psychosocial support involved the activation of problem-solving coping and self-care skills using the COPE (Creative, Optimism, Planning, Expert Information) framework (Bakitas et al. 2017; Dionne et al. 2015).

Combining these intervention strategies, improved dyad perceived control over heart failure and self-care behavior after three, but not after 12 months (Ågren et al. 2012), improved dyad self-care behaviors (Shahriari et al 2013). Telephone coaching improved family confidence and preparedness to support patient manage heart failure at home, reduced caregiving burden and improved both patient and family health. Nurses described the coaching program as helpful and feasible. Using the teach-back methods, nurses identified what families had learned and specific self-care areas, such as, dietary modification and weight monitoring that required reinforcement (Piamjariyakul et al. 2013.).

Family support

Nursing interventions designed to support families of patients in the early and terminal phase of a disease served two purposes. First, to helped family to become more competent and confident in facilitating and supporting their patient at whatever level agreed upon or stepping in as the main decision-maker and care provider during periods of physical and cognitive decline (Dionne-Odom 2015; Piamjariyakul et al. 2013; Ågren et al. 2012). Secondly, interventions that supported the family as client (Gusdal et al. 2016a). These interventions included psychoeducation, psychosocial support and therapeutic counselling, delivered to dyad or to family alone in nurse-led clinics, home or hospital settings, depending on patient/family preference (Dionne-Odom 2015; Gusdal et al. 2016a; Piamjariyakul et al. 2013; Shahriari et al. 2013, Ågren et al. 2012).

Psychoeducational interventions involved information provision through, nurse-led face-to-face and follow-up telephone sessions, and educative booklets about patient's disease, symptoms and management, other aspects of patient's physical/emotional/psychosocial care, available resources and how to access them (Dionne-Odom et al. 2015; Piamjariyakul et al. 2013; Shahriari et al. 2013; Ågren et al.2012). Psychosocial support involved using cognitive behavioral strategies, which involved, facilitating the development of skills needed to support patients' self-care behaviors, activating problem-solving skills needed by families to cope, identify and prevent caregiving strain, burnout or depression (Dionne-Odom et al. 2015; Piamjariyakul et al. 2013; Ågren et al.2012).

Family gained more confidence in supporting patient manage their disease at home (Ågren et al. 2012). In Bakitas et al. (2017) study, dyad experienced moderate improvement in quality of life and mental health, family caregiving burden and depression and small-to-moderate improvement in patients' hospitalization and emergency visits (Bakitas et al. et al. 2017).

The least frequent intervention was therapeutic counselling. Nurses organized one-on-one supportive counselling sessions with family members, where they can talk openly and freely, but always with respect to patients wishes, to create a therapeutic relationship and address family concerns related to patients' disease, caregiving burden and need for practical or emotional support (Gusdal et al. 2016a).

Managing disagreement

In cases of disagreement, nurse’s priority in decision-making was always their patient’s preferences as long as they were emotionally and mentally sound, family opinion came second (Laryionava et al. 2018). Although, nurses recognize the importance of family involvement and crucial role they play, patients with decision making capacity still hold the final say.

In addition, nurses have taken steps to limit disagreement and collusion by involving family as early on as possible in patients care process and getting to know the family structure, especially the important decision-maker(s), addressing treatment expectations and options, define roles and level of involvement (Dionne-Odom et al. 2015; Gusdal et al. 2018; Laryionava et al. 2018).

6 Discussion

7.1 Ethical considerations, reliability and validity

Ethics is a principle that describes what is expected in terms of right and wrong or correct and incorrect. Ethics in research are norms for conduct that guide the designing, collection, analysis, reporting and publication of information about research subjects, especially human participants (WHO 2011b). The main objectives in research ethics include, protection of human participants, ensuring the research is conducted in a way that serves the interest of the public, and respecting participants dignity, autonomy, informed consent and privacy. Adhering to ethical norms in research promote research aims, prevent errors, falsification and misrepresentation of data and promotes respect and accountability to the public (ibid.).

All research involving human subjects should be reviewed by an ethics committee to ensure that the appropriate ethical standards are being upheld (WHO 2011b.). This study is based on literature review where secondary data were used as raw materials and had no direct contact with the participants. Permission to carry out all the studies reviewed was granted by the Ethical Committee/Board of each organization, no ethical issue was raised. Participants were adults (≥ 18 years), they were of legal age to make own decisions.

Participation in all the studies was voluntary. Participants received verbal and written information on the study before the study started. Participants were also informed that their privacy will be respected, and that they could decline participation at any point in the process with no repercussion. Those who decided to participate gave written informed consent, including consent of publication before engaging in the study. Respect for patient's autonomy was expressed in all studies, and patients' consent to involve their family in each study was considered.

The current study was conducted in accordance with JAMK's standards set for scientific writing. The research topic was reviewed and approved by the thesis supervisor prior to writing. Plagiarism and fabrication were avoided by following recommended guidelines on quotations and referencing (TENK 2012).

7.2 Validity and reliability

Validity refers to the degree to which results of a study are likely to be truthful, free of bias and believable (Buckingham, Fisher, & Saunders 2008). Following these principles, the protocol for this study was carefully planned, the author was careful and honest when searching, evaluating, describing and reporting the results. This study was carried out by one author. The probability of bias and error should be higher, as the study did not benefit from discussions and criticism of another researcher (CRD 2008).

However, with this in mind, effort was made to reduce bias and increase reliability. Determining the scope of the study, thorough literature search, using different keywords, setting inclusion and exclusion criteria beforehand for consistency and unbiased approach to material selection. Assessment of study designs, data collection and interpretation, and conclusions drawn by article authors. Care was also taken to ensure the steps were clear and could be repeated. This was done to employ the principles of bias reduction and reliability (Houser 2008; Winchester, & Salji 2016).

Fifteen studies published between 2009 and 2018 were reviewed. The search was limited to articles from Medline and Cinahl databases, there may be studies that were unintentionally missed. 14 of the 15 articles were from developed countries and only one from a developing country (Iran). This might limit the generalization of the results considering the similarities in culture that the 14 countries share.

In addition, participants with limited proficiency were excluded from most studies. This exclusion criteria, may not provide an insight into the real world thereby limiting the applicability of these results to those who actually need them. Participants with more than one chronic disease were excluded from all studies reviewed. Results of this study may not closely reflect reality as patients, especially older patients often experience more than one chronic disease.

Ågren et al. (2012) advised caution in generalizing and interpreting their results, because data collection spanned almost four years. However, there was no significant change in treatment, diagnostic method or social reforms including patients and their families during the period of data collection (ibid.). Gusdal et al. (2018) also warned that because of the small sample size (22 out of 30 families contacted declined to participate), their study might have missed the families most in need of support. As a result, their data can only point toward tendencies and may not be transferable, however, it can inspire others to conduct similar study.

Three articles (Gusdal et al. 2016a; 2017), were written by the same authors and the disease focus in all articles was the same. This could introduce some bias. Although, the intervention methods, purpose of the study, health care settings and participants were different for each study, the disease status is already known.

The research methods included qualitative, quantitative and clinical trial, and the language of publication is English. A combination of different intervention methods was used in the studies. These articles had been researched on different health settings including, nurse-led clinics, hospitals, community centres and home settings, thereby increasing their credibility. The variety of methods used and the different settings allow for the results of this study to be transferred and applied in different clinical context of care.

7.3 Discussing the results

This study has identified the different strategies used by nurse to enhance family involvement in the care process of adult patients with chronic disease. Most studies applied a dyadic approach involving both patient and their family in the intervention, while a few focused solely on the family. Ten studies were led by nurses and four by health care professionals, including nurses.

In 10 (67%) of the 15 studies, better outcome was achieved when the strategy was tailored to respond to patient and family individual information and support needs. This was achieved by asking them to articulate these needs. These results are consistent with the finding that assessing and educating families based on patients' needs, improved patients' adherence to therapeutic regime (Nayeri et al. 2014). Due to the dynamic nature of chronic disease, and the diverse patient/family populations, patients/families' needs, roles and level of involvement in the care process varied (Manias 2015; Posma et al. 2009). All the strategies identified in this study, may not be applicable to every patient/family.

Exploring patient/family unique life story, capturing an awareness of their lived-experiences and recognizing their individual needs, were identified within all categories. These approaches created a foundation for building, supporting and strengthening patient/family resources, both within and outside, in order to empower them engage in collaborative care planning and decision-making responsive to their individual needs (Gusdal et al. 2016a; 2018; Manias 2015; Posma et al. 2009). Based on these results, exploring, acknowledging individuality and therapeutic action, could be considered the logical order of nursing strategies, which can enhance the successful integration of family in patients' care process.

An important issue raised within information sharing, was the under use of professional (trained) interpreters, which was found to be related to their limited availability (Galinato et al. 2016). All too often, nurses used ad-hoc (untrained) interpreters despite the increased risk of clinical errors (ibid.). Accordingly, Manias et al. (2015) suggested the use of interpreters with patient/family with limited language proficiency, as one of the strategies to improve medication management. Studies concerning nurses use of professional interpreters in chronic disease management are scarce. This study, thus, highlights the need to train more medical interpreters and ensure their availability in order to limit the risk of medical errors, improve patient safety and provision of ethical care.

In collaborative partnership, different roles were important. Recognizing the unique contribution and expertise of each member of the care team contributed significantly to the development and promotion of effective care coordination (Gusdal et al. 2016a; 2018; Manias 2015). Families maintained their responsibility to their patients in hospitals and after hospital discharge, in the same way, they provided valuable information to care providers about patients' health status, identified and rectified problems related to patients' medication (Gusdal et al. 2016a; Manias et al. 2015).

Another issue raised within collaborative partnership, was that, patients identified their family caregiver, and the level of family involvement in the care process was agreed upon by both parties. However, family still over stepped set boundaries. In one study, family members sometimes put their patient at risk by not adhering to patients' fluid and dietary restrictions, as they will bring food and/or dinks and give to the patient, against nurses' advice (van Rosse at al. 2016b). Decision making in the context of collaborative partnership is not without disagreement (Blacker 2016). Sometimes, it becomes difficult to balance patients' autonomy, and the role and level of involvement of their well-intentioned family in the care process. Nurses should be aware of the potential of such dynamics, and advocate for their patients, inform them of their rights, including the right to make own care decisions (Laryionava et al. 2018).

Within the category of support patterns, the different strategies designed to support families, mainly focused on supporting them maintain their caregiving responsibility to their patient's needs, while those supporting family as a client were limited (Bakitas et al. 2017; Gusdal et al. 2016a; 2018; Piamjariyakul et al. 2013; Shahriari et al. 2013; Ågren et al. 2012). Caregiving can be physical and emotional demanding, and chronic disease affects both patients and families (Golics et al. 2013). Therefore, designing strategies responsive to both patient and family needs, as well as promote and maintain the health and well-being for both, is imperative (Bakitas et al. 2017; Gusdal et al. 2016a; Ågren et al. 2012).

Integrating palliative care education and support earlier in the disease trajectory, when patients are still relatively healthy and functional was identified in this study to be beneficial to all, not just for the patients diagnosed with advanced-disease stage and their families (Bakitas et al. 2017; Dionne-Edom 2015; Gusdal et al. 2018). The severity of chronic disease changes over time, thus, during periods of physical and cognitive decline, it becomes easier for nurses and other care givers to continue the care process with family members already known. In addition, knowing the family structure early on provide an opportunity to identify differences that exist between family members, engage in thoughtful conversations and clarify potential misunderstandings between family members (Gusdal et al. 2018; Laryionava et al. 2018.).

8 Conclusion

Family support has great potential to help functionally limited and independent patients to better manage their disease in different settings. Tailoring various strategies to individual needs can improve whole person care and outcome. These results can be used by nurses and other health care workers in different health settings, during education sessions and follow-up care after hospital discharge when working with families and patients. This study highlights the need for more education in family nursing, and for experienced nurses to encourage and support younger and less experienced nurses. These results can also be used for educational purposes.

Further research is needed to identify similarities and differences in strategies used among individuals with multiple diseases. In addition, further research is needed to determine whether these results or strategies are applicable to family members across different cultures, considering that Hobbs, Landrum, Arora, Ganz, van Ryn, Weeks, Mack, and Keating (2015) found cultural differences regarding the role of family in decision-making in cancer treatment.

Reference

Allen, D., Scarinci, N., & Hickson, L. 2018. The Nature of Patient- and Family-Centred Care for Young Adults Living with Chronic Disease and their Family Members: A Systematic Review. *International Journal of Care*, 18.

Almborg, A. H., Ulander, K., Thulin, A., & Berg, S. 2009. Discharge planning of stroke patients: the relatives' perceptions of participation. *Journal of Clinical Nursing*, 18, 857-865.

Aveyard, H. 2014. Doing a Literature Review in Health and Social Care: A Practical Guide 3rd Ed.Maidenhead, England: McGraw-Hill Education.

Bakitas, M., Dionne-Edom, J. N., Pamboukian, S. P., Tallaj, J., Kvale, E., Swetz, K. M., Frost, J., Wells, R., Azuero, A., Keebler, K., Akyar, I., Ejem, D., Steinhauser, K., Smith, T., Durant, R., & Kono, A. 2017. Engaging patients and families to create a feasible clinical trial integrating palliative and heart failure care: results of the ENABLE CHF-PC pilot clinical trial." *BMC Palliative Care*, 16.

Bélanger, L., Desmartis, M., & Coulombe, M., 2018) "Barriers and facilitators to family participation in the care of their hospitalized loved ones. *Patient Experience Journal, 5, 56-65.*

Blacker, L. 2016. Compromised autonomy: When families pressure patients to change their wishes. *Journal of Hospice & Palliative Nursing*, 18, 284-289.

Buckingham, J., Fisher, B. & Saunders, D. 2008. Clinical Epidemiology Glossary: Validity. Evidence Based Medicine Toolkit. Accessed 20 June 2019. Retrieved from http://www.ebm.med.ualberta.ca/Glossary.html

Caminiti, C., Meschi, T., Braglia, L., Diodati, F., Lezzi, E., Marcomini, B., Nouvenne, A., Palermo, E., Prati, B., Schianchi, T., & Borghi, L. 2013. Reducing unnecessary hospital days to improve quality of care through physician accountability: a cluster randomised trial. *BMC Health Services Research*, 13.

Conner, B. T. 2014. Demystifying literature reviews. *American Nurse Today*, 9, 13-14.

Clark, A. M, Reid, M. E, Morrison, C. E., Capewell, S., Murdoch, D. L., & McMurray, J. J. 2008. The complex nature of informal care in home-based heart failure management. *Journal of Advanced Nursing*, 61, 373-383.

Chan, E. A., Jones, A., & Wong, K. 2 0 1 3. The relationships between communication, care and time are intertwined: a narrative inquiry exploring the impact of time on registered nurses’ work. *Journal of Advanced Nursing* 69, 2020–2029.

CRD (Centre for Reviews and Dissemination). 2008. Systematic Reviews: CRD`s Guidance for Undertaking Reviews in Health Care. University of York. Accessed on 2 February 2019. Retrieved from https://www.york.ac.uk/media/crd/Systematic_Reviews.pd

Cronin, P., Ryan, F., & Coughlan, M. 2008. Undertaking a literature review: a step-by-step approach. *British Journal of Nursing,* 17, 38-42

Dionne-Odom, J. N., Azuero, A., Lyons, K. D., Hull, J. G., Tosteson, T., Li, Z., L., Z., Frost, J., Dragnev, K. H., Akyar, I., Hegel, M. T., & Bakitas, M. A. 2015. Benefits of early versus delayed palliative care to informal family caregivers of patients with advanced cancer: outcomes from the ENABLE III randomized controlled trial. *Journal of Clinical Oncology*, 33,1446–52.

Drageset, S., Lindstrøm, T. C., Giske, T., & Underlid, K. 2011. ‘‘The Support I need ’’Women’s Experiences of Social Support After Having Received Breast Cancer Diagnosis and Awaiting Surgery. *Cancer Nursing,* 35, E39-47.

Elo, S. & Kyngäs, H. 2008. The qualitative content analysis process. *Journal of Advanced Nursing,* 62, 107-115.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. 2014. Qualitative Content Analysis: A focus on Trustworthiness. *SAGE Open*.

Finke, E- H., Light, J., & Kitko. L. 2008. A systematic review of the systematic effectiveness of nurse communication with patients with complex communication needs with a focus on the use of augmentative and alternative communication. *Journal of Clinical Nursing*, 17, 2101-2115.

Fink, A. 2009. Conducting Research Literature Reviews. From Internet to paper. 5th Edition. USA: Sage Publications ltd.

Galinato, J., Montie, M., Shuman, C., Patak, L., & Titler M. 2016. Perspectives of Nurses on Patients with Limited English Proficiency and Their Call Light Use. *Global Qualitative Nursing Research, 3.*

Golics C. J., Barra M. K., Salek, M. S., & Yule A. 2013. The impact of patients’ chronic disease on family quality of life: an experience from 26 specialties. *International Journal of General Medicine,* 6, 787–798

Gusdal, A. K., Josefsson, K., Adolfsson, E. T. & Martin, L. 2016a. Registered Nurses’ Perceptions about the Situation of Family Caregivers to Patients with Heart Failure - A Focus Group Interview Study. *PLoS ONE* 11.

Gusdal, A. K., Josefsson, K., Adolfsson, E. T. & Martin, K. 2016b. Informal caregivers’ experiences and needs when caring for relatives with heart failure: An interview study. *Journal of Cardiovascular Nursing*, 31, E1-E8.

Gusdal, A. K., Josefsson, K., Adolfsson, E. T. & Martin, K. 2017. Nurses' attitudes toward family importance in heart failure care. *European Journal of Cardiovascular Nursing,* 16, 256-266.

Gusdal, A. K., Josefsson, K., Adolfsson, E. T., & Martin, L. 2018. Family Health Conversations Conducted by Telephone in Heart Failure Nursing Care: A Feasibility Study. *SAGE Open Nursing, 4.*

Herrin, J., Harris, K. G., Kenward, K., Hines, S., Joshi, M. S., & Frosh, D. L. 2016. Patient and family engagement: a survey of US hospital practices. *BMJ Quality & Safety*, 25, 182-189.

Ho, A. 2008. Relational autonomy or undue pressure? Family's role in medical decision-making. *Scandinavian Journal of Caring Science*, 22, 128-135.

Hobbs, G. S., Landrum, M. B., Arora, N. K., Ganz, P. A., van Ryn, M., Weeks, J. C., mack, J. W., & Keating, N. L. 2015. The Role of Families in Decisions Regarding Cancer Treatments. *Cancer*, 121, 1079-1087.

Houser, J. 2008. Precision, Reliability, and Validity: Essential Elements of Measurement in Nursing Research. *Journals for Specialists in Paediatric Nursing*, *13*.

Institute for Patient- and Family-Centered Care 2007. Patient- and Family-Centered care defined. Accessed on December 20 2018. Retrieved from https://www.ipfcc.org/about/pfcc.htmlhttps://www.ipfcc.org/bestpractices/sustainable-partnerships/background/pfcc-defined.html

Johnson, B., Abraham, M., Conway, J., Simmons, L., Edgman-Levitan, S., Sodomka, P., Schlucter, P., & Ford, D. 2008. Partnering with patients and families to design a patient-and family-centered health care system: Recommendations and promising practices. Bethesda MD: Institute for Family-Centered Care and the Institute for Healthcare Improvement. Accessed on 20 December 2019. Retrieved from https://www.ipfcc.org/resources/PartneringwithPatientsandFamilies.pdf

Johnson, B. H., & Abraham, M. R. 2012. *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities.* Bethesda, MD: Institute for Patient- and Family-Centered Care. Accessed on 12 January 2019. Retrieved from https://www.ipfcc.org/about/pfcc.html.

Kiwanuka, F., Shayan, S. J., & Tolulope, A. A. 2019. Barriers to patient and family-centred care in adult intensive care units: A systematic review. *Nursing Open*, 6, 676–684.

Lainscak, M., Blue, L., Clark, A. L., Dahlström, U., Dickstein, K., Ekman, I., McDonagh, T., McMurray, J., Ryder, M., Steward, S., Strömber, A. & Jaarsma, T. 2011. Self-care management of heart failure: practical recommendations from the Patient Care Committee of the Heart Failure Association of the European Society of Cardiology. *European Journal of Heart Fail*, 13, 115–126.

Laryionava, K., Pfeil, T. A., Dietrich, M., Reiter-Theil, S., Hiddemann, W., & Winkler, E. C. 2018. The second patient? Family members of cancer patients and their role in end-of-life decision making. *BMC palliative care*, *17*.

Lloyd, B., Elkins, M., & Innes, L. 2018. Barriers and enablers of patient and family centred care in an Australian acute care hospital: Perspectives of health managers," *Patient Experience Journal*, 5, 55-64.

Luttik, M., Goossens, E., Ågren, S., Jaarsma, T., Mårtensson, J., Thompson, D., Moons, & P., Strömberg, A. 2017. Attitudes of nurses towards family involvement in the care for patients with cardiovascular diseases. *European Journal of Cardiovascular Nursing*, *16*, 299–308.

Machi, L. A. & McEvoy, B. T. 2009. The literature review: Six Steps to Success. USA: Corwin Press.

Manias, E. 2015. Communication relating to family members' involvement and understandings about patients' medication management in hospital. *Health expectations, 18*, 850–866.

Michael, N., O'Callaghan, C., Baird, A., Hiscock, N., & Clayton, J. 2014. Cancer caregivers advocate a patient- and family-centered approach to advance care planning. *Journal of Pain Symptom Manage*, 47, 1064-1077.

Mirlashari, J., Brown, H., Fomani, F. K., de Salaberry, J., Zadeh, T. K., & Khoshkhou F. 2020. *Journal of Pediatric Nursing,* 50, e91-e98.

Nayeri, N. D., Mohammadi, S., Razi, S. P., & Kazemnejad, A. 2014. Investigating the effects of a family-centered care program on stroke patients' adherence to their therapeutic regimens. *Contemporary Nurse* 47, 88-96.

National Quality Forum 2016. Endorsed Measures for Person- and Family-Centered Care Phase 2. National Quality Forum. Endorsed measures for Person- and Family-Centered care phase 2. Washington, DC: National Quality Forum. Accessed on 20 May 2019. Retrieved from file:///C:/Users/Junior/Downloads/pfcc_final_report_phase_2.pdf

NHS 2018a. Asthma. Accessed on 10 April 2019. Retrieved from https://www.nhs.uk/conditions/asthma/

NHS 2018b. Guide to reducing long hospital stays. Accessed on 9 February 2020. Retrieved from https://improvement.nhs.uk/documents/2898/Guide_to_reducing_long_hospital_stays_FINAL_v2.pdf

Nkrumah, J., & Abekah-Nkrumah, G. 2019. Facilitators and barriers of patient-centered care at the organizational-level: a study of three district hospitals in the central region of Ghana. *BMC Health Service Res*earch, 19.

Piamjariyakul, U., Smith, C. E., Werkowitch, M. & Elyachar, A. 2012. Part 2: Enhancing heart failure home management: integrated evidence for a new family caregiver educational plan. *Applied Nursing Research* 25, 246-250.

Piamjariyakul, U., Smith, C. E., Russel, C., Werkowitch, M. & Elyachar, A, 2013. The feasibility of a telephone coaching program on heart failure home management for family caregivers. *Heart Lung,* 42, 32-39.

Pihl, E., Fridlund, B., & Mårtensson, J. 2011. Patients' experiences of physical limitaitons in daily life activities when suffering from chronic heart failure; a phenomeographic analysis. *Scandinavia Journal of Caring Science*, 25, 3-11.

Poitras, M. E., Chouinard, M. C., Gallagher, F., & Fortin, M. 2018. Nursing Activities for Patients with Chronic Disease in Primary Care Settings: A Practice Analysis. *Nursing Resource*, 67,35–42.

Posma, E. R., van Weert, J. C. M., Jansen, J., & Bensing, J. M. 2009. Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nursing*, 8.

Rahimi, F., & Gharib, A. 2017. Analysis of the concept of family-centered care in chronic diseases: Rodgers's evolutionary approach. *Chronic Disease Journal*, 5, 28-36.

Riley, B. H., White, J., Graham, S., & Alexandrov, A. 2014. Traditional/ restrictive vs patient-centered intensive care unit visitation: Perceptions of patients' family members, physicians and nurses. *American Journal of Critical Care,* 23, 316–324.

Rosland, A. M., Heisler, M., Choi, H., Silveira, M., & Piette, J.D. 2010. Family influences on self management among functionally independent adults with diabetes or heart failure: Do family members hinder as much as they help? *Chronic Illness,* 6,22–33.

Rosland A.M, Piette J. D, Choi, H., &, Heisler M. 2011. Family and Friend Participation in Primary Care Visits of Patients with Diabetes or Heart Failure: Patient and Physician Determinants and Experiences. *Medical Care*, 49, 37–45.

Rosland, A. M., Heisle,r M., & Piette , J. D. 2012.The impact of family behaviors and communication patterns on chronic illness outcomes: a systematic review. *Journal of Behavioral Medicine*, 35, 221–239.

Rosland, A. M., Heisler, M., Janevic, M. R., Connell, C. M., Langa, K. M., Kerr, E. A., & Piette, J. D. 2013. Current and potential support for chronic disease management in the United States: the perspective of family and friends of chronically ill adults. *Families, Systems & Health*, 31, 119–131.

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., Redeker, N. S., Reynolds, N., & Whittemore, R. 2012. Processes of self-management in chronic illness. *Journal of nursing scholarship,* 44, 136–144.

Sedig, L. 2016. What's the Role of Autonomy in Patient- and Family-Centered Care When Patients and Family Members Don't Agree? *American Medical Association Journal of Ethics*, 18, 12-17.

Shahriari, M., Ahmadi, M., Babaee, S., Mehrabi, T., & Sadeghi, M. 2013. Effects of a family support program on self-care behaviors in patients with congestive heart failure. *Iranian journal of nursing and midwifery research*, *18*, 152–157.

Stamp, K. D., Dunbar, S. B., Clark, P. C., Reilly, C. M., Gary, R. A., Higgins, M., & Ryan, R. M. 2016. Family partner intervention influences self-care confidence and treatment self-regulation in patients with heart failure. *European Journal of Cardiovascular Nursing*, 15, 317–327.

Tay, L. H., Ang, E., & Hegney, D. 2012. Nurses' perception of the barriers in effective communication with inpatient cancer adults in Singapore. *Journal of Clinical Nursing*, 21, 2647-2658.

TENK (Finnish Advisory Board on Research Integrity). 2012. Responsible conduct of research and procedures for handling allegations of misconduct in Finland. Accessed on March 10 2020. Retrieved from https://www.tenk.fi/en/responsible-conduct-of-research

Vaismoradi, M., Turunen, H., & Bondas, T. 2013. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*, 15, 389-405.

van Rosse, F., de Bruijne, M., Suurmond, J., Essink-Bot. M. L., & Wagner, C. 2016a. Language barriers and patient safety risks in hospital care. A mixed methods study. *International Journal of Nursing Studies*, 54, 45-53.

van Rosse, F., Suurmond, J., Wagner, C., de Bruijne, M., & Essink-Bot, M. L. 2016b. Role of relatives of ethnic minority patients in patient safety in hospital care: a qualitative study. *BMJ Open*, 6.

Voltelen, B., Konradsen, H., & Østergaard, B. 2016. Family Nursing Therapeutic Conversations in Heart Failure Outpatient Clinics in Denmark: Nurses' Experiences. *Journal of Family Nursing*, 22, 172–198.

Vrontaras, N. 2018. Cancer patients' views of the family changes and the family social support. *Journal of European Psychology students*, 9, 16-27.

Webb, C. & Roe, B. 2008. Reviewing Research Evidence for Nursing Practice: Systematic Reviews. Chichester: Wiley.

Whittemore, R., & Dixon, J. 2008. Chronic illness: the process of integration. *Journal of Clinical Nursing*, 17, 177–187.

WHO 2010. People-centred care in low- and middle-income countries. Accessed on 1 January 2019. Retrieved from https://www.personcenteredmedicine.org/doc/genevathree/geneva2011i.pdf

WHO 2011a. Global Health and Aging: new disease patterns. Accessed on 9 December 2018. Retrieved from https://www.who.int/ageing/publications/global_health.pdf?ua1/41

WHO 2011b. Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants. Accessed on 10 April 2020. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/44783/9789241502948_eng.pdf;jsessionid=FC1BFB3283DE58C31E0C80AED38826B0?sequence=1

WHO 2014. Global status report on noncommunicable diseases. Accessed on 20 March 2020. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/148114/9789241564854_eng.pdf;jsessionid=B8702F9AD16C82568B05D84EB5C62277?sequence=1

WHO 2018. The top 10 causes of death. Accessed on 21 November 2018. Retrieved from http://www.who.int/en/news-room/fact-sheets/detail/the-top-10-causes-of-death

Winchester, C. L., & Salji, M. 2016. Writing literature review. *Journal of Clinical urology,* 9, 308-312.

Wingham, J., Frost, J., Britten, N., Jolly, Kate., Greaves, C., Abraham, C., Dalal, H. & REACH-HF research investigators 2015. Needs of caregivers in heart failure management: A qualitative study. *Chronic illness*, 11, 304-319.

Wittenberg, E., Reb, A. & Kanter, E. 2018. Communicating with Patients and Families Around Difficult Topics in Cancer Care Using the COMFORT Communication Curriculum. *Seminars in Oncology Nursing*, 34, 264-273.

Young, J., Eley, D., Patterson, E., & Turner, C. 2016. A nurse-led model of chronic disease management in general practice: Patients' perspectives. *Aust Fam Physician*, 45, 912–916.

Ågren, S., Evangelista,L. S., Hjelm, C., & Strömberg, A. 2012. Dyads affected by Chronic Heart Failure: A Randomized Study Evaluating Effects of Education and Psychosocial Support to Patients with Heart Failure and Their Partners. *Journal of cardiac Failure*, 18, 359-399.

Appendices

Appendix 1. Articles reviewed presented in alphabetical order.

Author(s)	Publishing year and country	Title	Research method	Key findings
Bakitas, M., Dionne-Edom, J. N., Pamboukian, S. P., Tallaj, J., Kvale, E., Swetz, K. M., Frost, J., Wells, R., Azuero, A., Keebler, K., Akyar, I., Ejem, D., Steinhauser, K., Smith, T., Durant, R., & Kono, A.	2017 USA	Engaging patients and families to create a feasible clinical trial integrating palliative and heart failure care: results of the ENABLE CHF-PC pilot clinical trial.	Feasible clinical trial: individual and focus group	Patients and families experienced moderate improvements in quality of life and mental health, family care giving burden and depression, and small to moderate improvements in patients’ hospital and ICU days and emergency visits
Dionne-Odom, J. N., Azuero, A., Lyons, K. D., Hull, J. G., Tosteson, T., Li, Z., L., Z., Frost, J., Dragnev, K. H., Akyar, I., Hegel, M. T. & Bakitas, M. A	2015 USA	Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients with Advanced Cancer: Outcomes from the ENABLE III Randomized Controlled Trial	Randomized controlled trail using a fast tract or wait-control design: individual and focus group	Early group caregivers had lower depression and stress burden.
Galinato, J., Montie, M., Shuman, C., Patak, L., & Titler, M.	2016 USA	Perspectives of Nurses on Patients with Limited English Proficiency and Their Call Light Use.	Qualitative descriptive study: focus group	Eloquence™, an analogue call light system facilitate communication with patients with limited language proficiency better.
Gusdal, A. K., Josefsson, K., Adolfsson, E. T. & Martin,	2016a Sweden	Registered Nurses’ Perceptions about the Situation of Family Caregivers to Patients with Heart Failure -	Qualitative study: focus group	Nursing interventions used to improve family caregiving situation were tailored support and information and bridging the contact. Involving family in the care process created a win-win situation.
Gusdal, A. K., Josefsson, K., Adolfsson, E. T. & Martin,	2017 Sweden	Nurses' attitudes toward family importance in heart failure care.	Quantitive study: Cross-sectional, multicentre design	Nurses in general viewed family as important source of support for patient, however, attitudes in actively inviting families

				to participate in patient care were less supportive
Gusdal, A. K., Josefsson, K., Adolfsson, E. T. & Martin,	2018 Sweden	Family Health Conversations Conducted by Telephone in Heart Failure Nursing Care: A Feasibility Study	Qualitative and quantitative study: semi structured interview and questionnaires with pretest-posttest design	FamHCs improved the nurse–family relationship, relationship between family members and provided nurses with new knowledge about the families.
Laryionava, K., Pfeil, T. A., Dietrich, M., Reiter-Theil, S., Hiddemann, W., & Winkler, E. C	2018 Germany	The second patient? Family members of cancer patients and their role in end-of-life decision making.	Descriptive qualitative study: focus group	Families play vital role in patients' end-of-life care. Thus, involving them in treatment and care planning early on, providing them with more information regarding patients' prognosis and treatment options, helped them create a realistic view of patients' situation
Manias, C.	2015 Australia	Communication relating to family members' involvement and understandings about patients' medication management in hospital. *Health*	Ethnographic research design: in-depth interviews	Families involved in the decision-making regarding medication, identified and rectified problems related to patients' medication
Piamjariyakul, U., Smith, C. E., Russel, C., Werkowitch, M. & Elyachar, A.	2013 USA	The feasibility of a telephone coaching program on heart failure home management for family caregivers	Quasi-experimental, non-randomized design: mixed method designs	Nursing telephone coaching program decreased caregiving burden and increased family confidence and preparedness for heart failure management at home.
Posma, E. R., van Weert, J. C. M., Jansen, J., & Bensing, J. M.	2009 Netherland	Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals	Qualitative design: face-to-face and focus group interviews.	By asking patients/families to articulate their needs, treatment goals and expectations, individualized information and support that meet their needs were provided.

Shahriari, M., Ahmadi, M., Babaee, S., Mehrabi, T., & Sadeghi, M.	2013 Iran	Effects of a family support program on self-care behaviors in patients with congestive heart failure.	Pre- and post-test case and control clinical trial	Nurse-led family focused supportive program improved self-care behaviors in heart failure patients
Wittenberg, E., Reb, A. & Kanter, E.	2018 USA	Communicating with Patients and Families Around Difficult Topics in Cancer Care Using the COMFORT Communication Curriculum.	Qualitative study: focus group	Using the COMFORT Communication model, nurses elicited patients’/families’ life story, which they used to provide needed care.
Wingham, J., Frost, J., Britten, N., Jolly, Kate., Greaves, C., Abraham, C., Dalal, H. 2 on behalf of the REACH-HF research investigators.	2015 UK	Needs of caregivers in heart failure management: A qualitative study.	Qualitative study: individual and focus group interviews	Identification of the current role and needs of patient’s caregiver was used to provide tailored education and skills needed to support patients manage their disease.
van Rosse, F., Suurmond, J. Wagner, C., de Bruijne, M. & Essink-Bot, M. L.	2016 Netherlands	Role of relatives of ethnic minority patients in patient safety in hospital care: a qualitative study	Qualitative study: focus groups semi-structured interviews	Family provided social support, and took over the role of interpreters for their patients but sometimes put patients at risk by not adhering to set dietary regimes.
Ågren, S., Evangelista, L. S., Hjelm, C. & Strömberg, A.	2013 USA	Dyads Affected by Chronic Heart Failure: A Randomized Study Evaluating Effects of Education and Psychosocial Support to Patients with Heart Failure and Their Partners	Qualitative and quantitative study: randomized controlled trial design with follow-up assessment.	Nurse-led integrated dyad psychoeducation and support was effective in enhancing patients’ levels of perceived control over the cardiac condition after 3 but not after 12 months