

# HOW PATIENTS AND THEIR FAMILY MEMBERS' NEED OF SUPPORT AND COUNSELLING CAN BE ASSESSED BY WRITTEN MEASURES?

Literature review

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Bachelor's thesis October 2012 Degree Programme in Nursing

### **ABSTRACT**

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How Patients and Their Family Members' Need of Support and Counselling Can Be Assessed by Written Measures? Literature review Bachelor's thesis 45 pages, 1 Appendix October 2012

The purpose of this Bachelor's thesis was to examine through literature review the already existing written measures assessing the needs of the patients and their family members concerning support and counselling. The objective was to provide a "cross-section" of these. The focus of the thesis was on family nursing, which is part of the good nursing care of today. The idea for the thesis came from the Pirkanmaa Hospital District.

There are not that many written measures assessing the needs of the patients and their family members. The literature review resulted in seven different written measures that were taken under study. These written measures were all somehow disease specific. None of the measures were targeted both to patients and family members, they were only either or. However some of the measures assessed both the need of support and counselling, and not only one of the needs.

The author recommends further research of family nursing in adult setting and development of more universal measures assessing the need of support and counselling of patients and their family members, which could be adopted to use amongst different kind of patient groups.

Keywords: need, support, counselling, written measure, patient, family member

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# **EMILIA MERIMAA:**

Kuinka potilaiden ja heidän perheenjäsenten tuen ja ohjauksen tarvetta voidaan arvioida kirjallisilla mittareilla? Kirjallisuuskatsaus Opinnäytetyö 45 sivua, 1 liite Lokakuu 2012

Opinnäytetyön tarkoitus oli tutkia kirjallisuuskatsauksen kautta jo olemassa olevia potilaan ja hänen perheenjäsenten tuen ja ohjauksen tarvetta mittaavia kirjallisia mittareita. Näistä tavoitteena oli tuottaa läpileikkaus. Opinnäytetyön fokuksena oli perhehoitotyö. Perheiden huomiointi on osa potilaan hyvää hoitamista. Opinnäytetyön idea tuli Pirkanmaan sairaanhoitopiiriltä.

Potilaiden ja perheenjäsenten tuen ja ohjauksen tarvetta mittaavia kirjallisia mittareita ei ole monia. Tutkittavaksi kirjallisuuskatsauksen kautta löytyi seitsemän kirjallista mittaria. Nämä kirjalliset mittarit olivat jossakin määrin kaikki sairausspesifisiä. Yksikään mittari ei ollut kohdennettu sekä potilaille että perheenjäsenille, vaan joko tai. Kuitenkin jotkin mittarit arvioivat sekä tuen että ohjauksen tarvetta yhden tarpeen sijaan.

Tekijä suosittelee, että perhehoitoyöstä aikuispotilaiden keskuudessa tehtäisiin lisätutkimusta ja että kehitettäisiin enemmän yleisempiä kirjallisia mittareita arvioimaan potilaiden ja perheenjäsenten tuen ja ohjauksen tarvetta, jotka soveltuisivat käytettäviksi erilaisille potilasryhmille.

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### 1 INTRODUCTION

Family-centeredness is a standard notion guiding nursing care, an ethical value and one of the criteria of good nursing care (Aura, Paavilainen, Asikainen, Heikkilä, Lipponen & Åstedt-Kurki 2010, 15). According to Tarkka, Paavilainen, Lehti & Åstedt-Kurki (2003, 737) the sickness of an individual affects not only the individual itself, but also the whole family and its welfare. Keeping this in mind the literature review of the written measures assessing the need of support is applicable. Also counselling has been seen as an important factor in providing support and help (Potinkara & Åstedt-Kurki 2005, 2780–81). Therefore also investigating measures assessing the need of counselling is pertinent.

The co-operation partner of the Bachelor's thesis process is Pirkanmaa Hospital District, division 2. The topic was examined from the perspective of adult patients, since no child patients are included in the division. The Finnish topic of the Bachelor's thesis given by the Pirkanmaa Hospital District is "Miten potilaiden ja perheenjäsenten tuen ja ohjauksen tarvetta voidaan arvioida kirjallisilla mittareilla? Kirjallisuuskatsaus jo olemassa oleviin kirjallisiin mittareihin.", which can be translated as "How patients and their family members' need of support and counselling can be assessed by written measures? Literature review to the already existing written measures." The topic was selected by the author on the grounds that it considers patient counselling and support while taking the family members into account, which is relevant to today's nursing practice and is also in the author's personal interest.

# 2 PURPOSE AND OBJECTIVE OF BACHELOR'S THESIS

# 2.1 Purpose

The purpose of this Bachelor's thesis was to examine written measures used in the assessment of the need of support and counselling of patients and their family members. This thesis aims to provide a description of these written measures. The written measures were examined focusing on their target group, central results, psychometric properties and reliability. In order to provide this information a literature review about the already existing written measures was conducted. The literature review aimed to gather knowledge about the written measures in regard to the matters under interest mentioned above.

# 2.2 Objective

The objective of this thesis was to present a "cross-section" of the written measures under examination for the nursing staff to have a better picture of them, and also to clarify their utilization possibilities in nursing practice. The author hopes that through this thesis the nursing staff would get the needed information about the assessment of patients and their family members' need of support and counselling with written measures and with this information the nursing staff could meet these needs and through it implement better family nursing care. The ultimate goal of this thesis is to improve patients and their families' health and well-being.

# 2.3 Research questions

The main research question is: How patients and their family members' need of support and counselling can be assessed by written measures? The sub questions to be answered by the literature review are:

- 1. What are the target groups of the written measures?
- 2. What are the central results of the written measures?
- 3. What are the psychometric properties of the written measures?
- 4. How reliable are the written measures?

# 3 THEORETICAL FRAMEWORK

# 3.1 Family nursing

"Good nursing care means taking the family and not only the patient into consideration." (Astedt-Kurki & Kaunonen 2011, 116).

According to Hanson (2005, 9) family nursing, also referred as family health care nursing, is defined as the process of providing care for the health care needs of the families that are within the scope of nursing practice. Family nursing is an art and science that has developed since the 1980s as way of thinking about and working with families when one of the members is receiving nursing care (Hanson 2005, 4).

In family nursing it is considered that health affects all members of families; health and illness are family events; and families have an effect on the process and outcome of health care (Kaakinen, Hanson & Denham 2010, 4; Tarkka et al. 2003, 737; Astedt-Kurki & Kaunonen 2011, 116). When conducting family nursing nurses need to be aware that families vary in structure, function and processes. The variation happens even inside given cultures. The family variables are dependent on the health status of the patient, and the overall health status of the family. (Kaakinen et al. 2010, 4.) When one person of the family is ill it will have an effect on the whole family and it can cause changes in the family roles and in the everyday life of the family. If an individual of the family is in hospital, other members of the family usually want to visit him/her, which causes changes in the family's time management and everyday routines. (Åstedt-Kurki & Kaunonen 2011, 116–117.) In family nursing the patient and his family are seen as a unit of care (Kaakinen et al. 2010, 4; Rantanen, Kaunonen, Åsted-Kurki & Tarkka 2004, 164). With this view the nurses have wider perspectives in approaching the health care need of the patient and his family as a whole (Hanson 2005, 14; Rantanen et al. 2004, 164.)

# 3.1.1 Family nursing models and approaches

There are different models and approaches for family nursing practice (Kaakinen et al. 2010, 7–12). The models of family nursing can be defined and categorized in many ways (Åstedt-Kurki, Jussila, Koponen, Lehto, Maijala, Paavilainen & Potinkara 2008, 74). Kaakinen et al. (2010, 7) discuss two models of family nursing. In one model the conceptual framework of family nursing includes individual, family, nursing and society. In the other model of family nursing the family is seen conceptually as a convergence of integrated concepts from family therapy, family social science and nursing. (Kaakinen et al. 2010, 7–8.)

In different approaches to family nursing, family is looked from different perspectives. Kaakinen et al. (2010, 10–12) name four different approaches: family as context, family as client, family as system and family as component of society. These approaches are discussed below.

In family as context-approach the family is seen as context, the individual is seen as foreground and the family as background; this is the traditional nursing focus. In this kind of setting the family is seen as either a resource or a stressor to the individual concerning their health or illness. This model is usually used in maternity and paediatric health care settings. (Kaakinen et al. 2010, 10.)

In the family as a client approach the family is seen as client, family is seen as a foreground and the individual as background. In this approach every person is assessed and health care is provided for all family members and the family unit is not necessarily the focus in implementing care. This approach is usually used in primary care clinics. (Kaakinen et al. 2010, 10.)

In the family as system-approach the family is seen as system and as an interactional matter. The nursing interventions are targeted by the interactions inside the family between the members of it. This family nursing approach focuses at the same time on the individual and on the family. The core idea of this approach is that if one of the family members is affected by a health issue,

it affects the whole family. This kind of approach is usually used in psychiatric and mental health nursing. (Kaakinen et al. 2010, 10–11.)

In the family as component of society approach the family is seen as a component of society, as one of the many institutions in society. Family is considered as same kind of institution such as religious, health or economical institutions. As part of society family interacts with the other institutions. This kind of approach can be seen in use in community health nursing. (Kaakinen et al. 2010, 12.)

In addition to the previously mentioned models one way of looking at family nursing can be seeing it as an interaction between the family and the nursing staff and as the co-operation that comes along with it. With this kind of approach understanding the basic questions of the family, hearing the wishes of the family and recognizing the coping methods of the family is vital. (Åstedt-Kurki et al. 2008, 76.) Another way of looking at family nursing can be seeing the whole family as an entity and providing the care for the whole unit. This kind of approach requires estimating the family needs and surveying the resources of the family. (Åstedt-Kurki et al. 2008, 91–93.) The different life situations and life events in families may require special attention in the family nursing approaches and models (Åstedt-Kurki et al. 2008, 111–122).

# 3.1.2 Family nursing in adult setting

Co-operation between families with children and nursing staff's co-operation has been studied. However little is known about the experiences of the family members of adult patients (Åstedt-Kurki et al. 2008, 113–120). Family nursing does not only apply to the nursing care of families with children. It is adaptable at all stages of life and is not bound to a certain age group. (Åstedt-Kurki & Kaunonen 2011, 116.) The hospitalization process is a stressful situation not only for the patient, but also for the patient's family (Hirsch, Hoeksel, Dupler & Kaakinen 2010, 380). According to Hudak & Gallo (1994) when an adult patient is admitted to the hospital s/he is usually accompanied by her/his family. In this

kind of situation both the patient and the family are usually in an emotional crisis. (Hirsch et al. 2010, 380.)

The situation of the patient causes different worries for the family (Hirsch et al. 2010, 380). Studies (Holden, Harrison & Johnson 2002, 140–148; Jansen & Schmitt 2003, 347–353) show that when the whole family receives care, the family can be more supportive towards the patient, less anxiety is experienced and less disruption is caused in the family system (Hirsch et al. 2010, 380).

Families of whose member is admitted to the medical-surgical settings are faced with numerous stressors and changes in the family dynamics. Families in these settings are generally in need of support. Nurses play vital role in meeting this need. (Hirsch et al. 2010, 385). Nurses are in a position to provide the support needed in different incidents during the hospitalization (Hirsch et al. 2010, 385–392).

# 3.1.3 History of family nursing

Family nursing dates back to prehistoric times, but during the Nightingale era (from the 1860s to 1880s) the development of families and nursing became more direct. The development of family nursing proceeded slowly in forms of nurses assigned to families. In the 1960s nursing practice started to become systemized by the nursing theorists and the family-centred approach was used in some nursing areas. In the 1970s the nursing care was still focused more on the individual and not on the family. In the 1980s nursing care started to put focus on the family as a unit of care in the USA and Canada and family nurses started to define the family nursing practice and research on the matter increased. (Kaakinen at al. 2010, 16–17.)

# 3.1.4 Family nursing in Finland

According to Åsted-Kurki & Kaunonen (2011, 121) family orientation is one of the basic principles in Finnish nursing care. Various studies about family nursing have been done in Finland starting from the 1990s. These studies have produced a research evidence for the theoretical framework of family nursing in Finland. (Åstedt-Kurki & Kaunonen 2011, 117.) Nowadays in Finland research in family nursing is still conducted quite a lot. The findings of the studies have shown that nursing care should be emphasized in providing it to the family as a one entity. (Åstedt-Kurki & Kaunonen 2011, 117–120.) Written measures as a tool in nursing are used quite rarely (Hölttä, Hupli & Salanterä 2002, 12).

# 3.2 The need of support and counselling

There are various studies indicating that the needs of family members are frequently estimated inadequately by nurses (Verhaege, Defloor, Van Zuuren, Duijnstee & Grypdonck 2005, 502). It is important to take notice of the needs of the family members, because often the family members put the needs of the hospitalised family member over theirs (Verhaege et al. 2005, 504). Some studies report that family members get less help from the health care professionals compared to patients (Rantanen et al. 2004, 1620). The severity of the patient's health status may affect the family members in such a way that they are not able to ask anything from the nursing staff (Aura et al. 2010, 19). Sometimes the family members might just be a bit shy asking about things from the nursing staff (Mattila, Kaunonen, Aalto, Ollikainen & Åstedt-Kurki 2009, 301). Keeping this in mind it is important for the nursing staff to offer without asking the support and counselling and also ask for the need of it. Family members may prefer talking about the patient's health status over their own needs (Rantanen et al. 2004, 164). However, the needs of the family members should be discussed (Mattila et al. 2009, 301).

When one of the family members is hospitalized the other family members need the support along with the patient. Nurses need to acknowledge this and provide support for both. (Tarkka et al. 2003, 737.) During a hospitalization the coping and ways of coping of the family members should also be discussed (Mattila et al. 2009, 301). The family members hope that the nursing staff hear and pay attention to both them and the patient and also give support. However, sometimes they feel left aside (Aura et al. 2010, 18). Different factors may affect

the support provided to the family members. The family members of outpatient clinic patients receive more informational support than hospitalized patients' family members. The amount of received emotional support decreases once the nature of the ward gets more hectic. The number of patients staying at the ward affects the amount of informational support received by decreasing it. (Mattila et al. 2009, 299–300.)The same study (Mattila et al. 2009) states that family members receive more emotional support compared to informational support during the hospital stay. For the patient the family is usually the most important source of support and therefore it is vital to support the family in order for them to be able to support the patient. Nursing practice should be developed towards more family-centred care (Tarkka et al. 2003, 742.)

The way the health care professionals interact with the patient and the family have an effect how the support given by the health care professional is experienced (Liimatainen, Mattila, Koivula & Åstedt-Kurki 2011, 15). When the family members get support, it helps them to cope with the change in their loved one's health status and with the possible changes in everyday life (Liimatainen et al. 2011, 175).

In order to cope with the illness, to understand it and the treatment that it requires and also to have strength to support the family member affected with the illness, the other family members need counselling (Vihijärvi, Koivula & Åstedt-Kurki 2008, 16). When the patient receives enough information about his/her illness and its care s/he is able to make the decisions concerning his/her care better (Vihijärvi et al. 2008, 19). This is one reason why the patient him/herself needs counselling. Nowadays nursing care advocates for short hospital stays. As the hospital stays shorten the importance of informational support increases (Liimatainen et al. 2011, 176). This also means that the need of counselling increases. Information and support to one's own coping amongst with help coping with the feeling experienced during the illness of the loved one is longed for by the family members (Aura et al. 2010, 19). Family members are usually content with the information received about the health status of the patient, but hope to get more information to support their own coping. The family members long for spoken counselling both for the patients and

themselves besides the written information. (Aura et al. 2010, 19.) The information which is provided ought to be trustworthy (Liimatainen et al. 2011, 176).

A study made by Mattila et al. (2009, 299) about support of family members of hospitalized patients and matters related to it made shows that over one third of family members involved in the study felt that they were taken along to the patients' counselling sessions very or quite poorly and over half of the patients estimated that they got very poor information to support their own coping. More emphasis should be put on the individual needs of the patient and the family.

Sometimes the counselling that the patients receive is not the one they feel they would actually need. In this case the patient's need of counselling and the counselling provided by the health care professional do not meet (Suhonen, Nenonen, Laukka & Välimäki 2005, 1172–1174). It is not correct to think that every patient benefits from the same information given, but tailored information to meet the individual needs and interest of one should be provided (Suhonen et al. 2005, 1174). Finding out the individual needs of the patients can sometimes be troublesome for the health care professionals (Hölttä at al. 2002, 12). According to the Finnish act on the status and the rights of patients (Act on the Status and Rights of Patients 1992, 2) the health care provided to the patient should be high quality. Therefore the counselling should be of high quality too, since it is a part of the health care given. Patients long to have their family members included to the counselling sessions (Vihijärvi et al. 2008, 21). The families wish to have more counselling according to their needs and with a more family-centred touch (Vihijärvi et al. 2008, 19). By providing the family members a chance to be present in the counselling sessions and by involving them to the patient's care providing of their support can be promoted (Liimatainen et al. 2011 182). When the family members are included in the counselling sessions the focus is more on counselling families instead of implementing counselling that is focused on the individual (Mattila et al. 2009, 301). Some families feel they get the support and counselling they need, while others feel these matters have been left inadequate. Sometimes more attention to the time of counselling should be given. (Vihijärvi et al. 2008, 18.)

A nurse plays an important role in assessing the patient's situation properly and is responsible for providing the needed counselling as well as support according to the situation provide (Suhonen et al. 2005, 1174). Nurses often put down their role in meeting the needs of the family members, especially considering providing information (Verhaege et al. 2005, 507). Not all family members need the same counselling or support; there are also differences inside the family. Special attention needs to be put into certain groups of people considering counselling, for example elderly of the family members and those with lower education level. (Verhaege et al. 2005, 507.) The factors related to the need of information and through it to the need of counselling can be seen as age, education level and sex. The older people require more information than the younger ones, the lower educated ones require more information than highly educated and men usually require more information compared to women (Kattainen, Meriläinen & Jokela 2004, 154; Hölttä et al. 2002, 14). This may, however, differ depending on the reason of hospitalization or form of care (Kattainen et al. 2004, 155). The information given about the patient's situation will usually calm the patient. It is important to give the information at the right time and place. While information is provided it is important to take into consideration the family member's ability to take in information along with his/her need to ask questions. (Potinkara & Astedt-Kurki 2005, 2780.)

### 3.3 Definitions

Blackwell's Nursing Dictionary (2005, 382) defines need as "a lack of something that is required for survival or as to require". The dictionary has no definition for support, but it defines supportive in the following way: "refers to any person, device or measure that assists, supports, maintains or, in any other way helps a patient "(Blackwell's nursing dictionary 2005, 583). Keeping this definition in mind support can be seen as the form of action of this adjective. Counselling is defined by the above mentioned dictionary as "a process of consultation and discussion between two individual, one of whom (the counsellor) offers advice or guidance to the other (client), helping to identify and clarify problems while

providing support as the client makes adjustments to overcome or come in terms with them" (Blackwell's nursing dictionary 2005, 153).

# 3.3.1 Adult patient

According to Blackwell's nursing dictionary (2005, 16) "adult is person who is fully developed and mature". Finnish law (Laki holhoustoimesta 1999, 1) considers a person, who is 18 as an adult and that is by which adult is also defined in this thesis. Patient is defined in the dictionary as "a person who is physically or mentally ill or who is undergoing treatment for physical or mental illness" (Blackwell's nursing dictionary 2005, 440).

### 3.3.2 Written measure and assessment

Measure, also referred as instrument is defined by Polit & Beck (2010, 557) as the device to collect data (e.g., a questionnaire, test, observation schedule). Blackwell's nursing dictionary (2005, 56) defines "assessment as a judgement made after evaluating or examining a situation or condition.

### 4 METHODOLOGY

### 4.1 Literature review

"A literature review is a critical summary of research on a topic of interest, often prepared to put a research problem in context." (Polit & Beck 2008, 575). A review of literature ought to give an understanding of the research problem and provide evidence that the research was based on present information of the problem at hand (Burns & Grove 2003, 113). A literature review consists of what is known and what is not about a certain research problem focusing on the present research at hand (Burns & Grove 2003, 114).

When conducting a literature review there are three main steps that can be identified in the process:

- 1. using the library
- 2. identifying relevant research sources and
- 3. locating these sources (Burns & Grove 2003, 117).

During the process, as research sources are identified and located, keywords are selected and searches done. The research literature is read, summarized and body of knowledge is gathered. (Burns & Grove 2003, 118 & 131–32.) According to Burns and Grove "a literature review should document the current knowledge of selected topics and indicate the findings that are ready for use in practice." (2003, 129–131). The literature review is conducted to deliver the current knowledge of the topic under interest and it should determine the knowledge of phenomenon by the comparison and combination of the findings (Burns & Grove 2005, 93).

# 4.2 Literature searches

The information to this literature review was acquired by literature searches done in the electrical databases CINAHL and MEDLINE and also by manual search from the libraries. A librarian was consulted for the searches. CINAHL and MEDLINE were chosen for the electrical databases to be used in the

searches, because they are the most appropriate nursing databases (Burns & Grove 2003, 119). The searches were first done more widely and then the results were limited so that the search terms were in the title. The search terms used in the electrical database searches were different combinations of the words presented in Table 1. OR term is used to make the search terms as alternatives to each other, AND terms are used to connect the search terms and NOT to exclude references with similar term or qualities (Burns & Grove 2003, 119).

Table 1. Search terms

support need	A N	measure	A N	family
OR	D	OR	D	OR
need of support		measurement		family member
OR		OR		OR
need of counselling		assessment tool		family-centred care
OR		OR		OR
counselling need		questionnaire		significant other
				OR
				next of kin

There are multiple approaches, such as year, language and full text that can be used to make limitations to the searches (Burns & Grove 2003, 122). Literature review should include sources not older than 5–10 years of the publication of the report (Burns & Grove 2003, 114). The searches of this literature review were limited by the publishing year (2001–2012) and target group (adults; over 18–year of age). However, the electrical search databases the limitation option for adults was defined as over 19 years of age.

Inclusion criteria are criteria or characteristics that a subject must have to be included into the bigger entity and exclusion criteria are criteria or characteristics that according to which a subject may be excluded from the bigger entity (Burns & Grove 2003, 234–235). The chosen inclusion and exclusion criteria ought to be reasoned in a valid way (Burns & Grove 2003,

343). The developed criteria ought to be formed according to the subject under research (Burns & Grove 2005, 342). The inclusion and exclusion criteria of this literature review were chosen to provide the wanted information and knowledge about the subject under study. Researches are chosen to the inclusion regarding their quality and relevancy to a selected problem (Burns & Grove 2003, 126). The inclusion criteria for the searches were the publishing language (English), full text and relevancy to the subject; articles concerning the assessment of need/counselling, concerning patients/family members in hospital setting and mentioned an assessment tool/questionnaire etc. in the abstract. The exclusion criteria were that the articles were dealing with psychological conditions (mental health/state issues), were considering other than hospital settings, nursing students/health care professionals/care givers or discussed some other need than the need of support/counselling or did not concentrate on the assessment of the need, but on the perceived need of individuals (Figure 1).

The searches to MEDLINE were first conducted more widely and then narrowed by the limitations. First the words in the first column of Table 1 were searched which produced 6667325 results and then the words in the second column of Table 1 were searched, which produced 968949 results. Then these two search term combinations were added together and this produced 485048 results. Searches by the search terms in the third column of the Table 1 were done and this produced 622624 results. These searches were combined to the previous combination search and there were 35377 hits. Then the limitations regarding language, year and age were applied and there were 13888 hits. Then the searches were done by the ages not wanted and this produced 2841189. Then it was applied that the search results would only contain the desired age groups and the undesired ages were excluded from the searches. This process produced 8287 results. Then the limitation nursing was added, this produced 421370 results. Again the age limitations were added and there were 1177 results. The limitation of full text was added to the searches and there were 474 hits. Next the search terms in the first column of Table 1 were searched to be in the title and this produced 133216 results. The search terms in the second column of Table 1 were added to the search along with the search terms in the third column of the Table 1. This produced 2141 results. After this the nursing

limitation was added to this search and the hits went down to 513. Next the age limitations were added and there were 194 hits. Then the "unwanted ages" were again excluded and the hits went down to 194. The limitation full text was added and the hits were then 88. Finally the already limited full texts were excluded and the final result with the search terms and all limitations was 106 (Figure 1). The above described search process is demonstrated in Table 2.

# Table 2. MEDLINE searches.

Searches	Hits
need of support OR support need OR need of counselling OR counselling need	6667325
measure OR measurement OR assessment scale OR questionnaire	968949
need of support OR support need OR need of counselling OR counselling need AND measure OR measurement OR assessment scale OR questionnaire	485048
family OR family member OR next of kin OR significant other OR family centred care	622624
need of support OR support need OR need of counselling OR counselling need AND measure OR measurement OR assessment scale OR questionnaire AND family OR family member OR next of kin OR significant other OR family centred care	35377
limit need of support OR support need OR need of counselling OR counselling need AND measure OR measurement OR assessment scale OR questionnaire AND family OR family member OR next of kin OR significant other OR family centred care to English language and year 2001-2012 and adult (over 19)	1388
infant OR child OR adolescent	2841189
English language and year 2001-2012 and adult ( over 19) not infant OR child OR adolescent	8287
nursing	421370
English language and year 2001-2012 and adult ( over 19) NOT infant OR child OR adolescent AND nursing	1177
English language and year 2001-2012 and adult ( over 19) not infant OR child OR adolescent AND nursing limit to full text	474
need of support OR support need OR need of counselling OR counselling need in title	133216
measure OR measurement OR assessment scale OR questionnaire AND family OR family member OR next of kin OR significant other OR family centred care AND need of support OR support need OR need of counselling OR counselling need in title	2141
nursing AND measure OR measurement OR assessment scale OR questionnaire AND family OR family member OR next of kin OR significant other OR family centred care AND need of support OR support need OR need of counselling OR counselling need in title	
limit nursing AND measure OR measurement OR assessment scale OR questionnaire AND family OR family member OR next of kin OR significant other OR family centred care AND need of support OR support need OR need of counselling OR counselling need in title to English and year 2001-2012	304
limit nursing AND measure OR measurement OR assessment scale OR questionnaire AND family OR family member OR next of kin OR significant other OR family centred care AND need of support OR support need OR need of counselling OR counselling need in title to English and year 2001-2012 not infant OR child OR adolescent	
limit nursing AND measure OR measurement OR assessment scale OR questionnaire AND family OR family member OR next of kin OR significant other OR family centred care AND need of support OR support need OR need of counselling OR counselling need in title to English and year 2001-2012 not infant OR child OR adolescent to full text	
nursing AND measure OR measurement OR assessment scale OR questionnaire AND family OR family member OR next of kin OR significant other OR family centred care AND need of support OR support need OR need of counselling OR counselling need in title to English and year 2001-2012 not infant OR child OR adolescent NOT full text	

After applying the limitations of the searches of MEDLINE produced 106 results, but after exclusion 5 articles were found suitable. In order to conclude whether the sources found through literature searches are relevant to the study the abstracts of the sources need to be read and reviewed (Burns & Grove 2003, 114). The abstracts of found articles were read through, their relevancy to the subject estimated and inappropriate sources excluded by the following reasoning. 16 articles were excluded for considering psychological conditions, 8 for considering other than hospital setting, 24 for dealing with nursing students/health care professionals/care givers, 36 for considering some other need or support that the ones under interest, 13 for considering with perceptions of need and 4 for being unrelated to the subject in other way (Figure 1).

Also the searches from CINAHL were first done widely and then narrowed by the limitations. Firstly the searches were done by the search terms in the first column which resulted in 2399 results. Then the searches were conducted by the terms in the second column of Table 1, which provided 243285 hits. Next the searches were done by the search terms in the third column of the Table1 and this resulted in 147763 results. All the search terms in the presented in Table 1 when then searched together and there were 228 results. Then the limitations considering publication year and the age were included and this search provided 110 hits. The limitation of peer-revision was added and the hits went down to 105. Then the searches were done by the term nursing and there were 22383 results. Lastly the searches were done with the combination of all search terms along with the limitations and nursing, which ended up in 20 results. No full text limitation was used, because the sample was already so small without it. The search process in entity is shown in the form of table in Table 3.

Table 3. CINHAL searches

Searches	Hits
need of support OR support need OR need of counselling OR counselling need	2399
measure OR measurement OR assessment scale OR questionnaire	243285
family OR family member OR next of kin OR significant other OR family centred care	147763
need of support OR support need OR need of counselling OR counselling need AND measure	228
OR measurement OR assessment scale OR questionnaire AND family OR family member OR	
next of kin OR significant other OR family centred care	
limit need of support OR support need OR need of counselling OR counselling need AND	110
measure OR measurement OR assessment scale OR questionnaire AND family OR family	
member OR next of kin OR significant other OR family centred care to year 2001-2012, age	
over 19 and English language	
limit need of support OR support need OR need of counselling OR counselling need AND	105
measure OR measurement OR assessment scale OR questionnaire AND family OR family	
member OR next of kin OR significant other OR family centred care to year 2001-2012, age	
over 19, English language and peer-reviewed	
nursing	22383
limit need of support OR support need OR need of counselling OR counselling need AND	22
measure OR measurement OR assessment scale OR questionnaire AND family OR family	
member OR next of kin OR significant other OR family centred care to year 2001-2012, age	
over 19, English language and peer-reviewed AND nursing	

In the end the searches of CINAHL produced 22 results of which three articles were found suitable, but two of which had already been found from the searches of MEDLINE. The abstracts of the articles found through the literature search were read and articles excluded by following reasons. One article was excluded considering psychological conditions, one for considering other than hospital setting, 12 for dealing with nursing students/health care professionals/care givers, one for considering some other need or support that the ones under interest and four for being unrelated to the subject in other way (Figure 1).

As a part of the literature search process manual search was done. Through manual search six articles concerning patient's support in hospital setting and one PhD was found and through them seven written measures of which two were also found through the electrical database searches. The literature search process is presented in Figure 1.

### Research question:

"How patients' and their family members' need of support and counselling can be assessed by written measures?

**Search terms:** support need or need of support or need of counseling or couselling need, and measure or measurement or assessment tool or questionnaire, and family or family member or family-centered care or significant other or next of kin

### Limitations:

- the publishing year (2001-2012)
- target group (adults; over 18- year of age- in databases >19)

Databases: CINAHL (n=106), MEDLINE (n=22) and Manual search (n=6)

### Inclusion criteria:

- criteria for the searches were the publishing language (English)
- full text
- relevancy to the subject; articles concerning the assessment of need/counseling, concerning patients/family members in hospital setting and mentioned an assessment tool/questionnaire etc. in the abstract

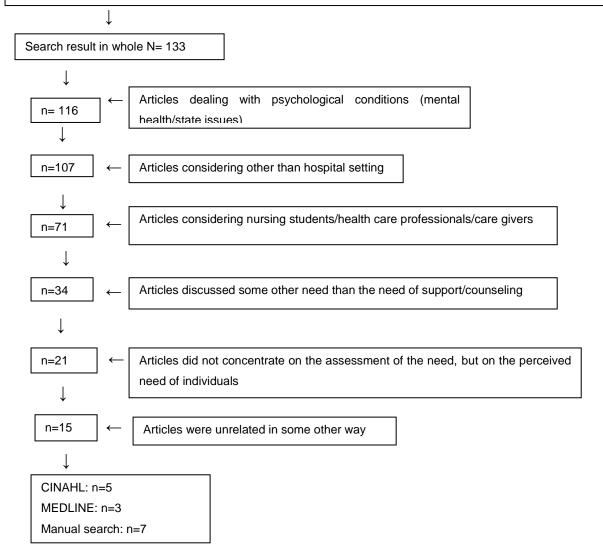


Figure 1. The process of literature searches

# 4.3 Data analysis

The importance of sources for a certain study can be decided by analysis. The analysis should be conducted in two stages. First the individual studies ought to be reviewed and then in the second stage the studies should be compared between one another. The revision of individual sources includes the steps of comprehension, comparison, analysis, evaluation and conceptual clustering. As the first stage of analysis proceeds, the relevant material is chosen. During the second stage the data is viewed more from the perspective of the study question. A literature review summary table is usually used to summarize the findings of the data analysis. (Burns & Grove 2005, 105.) The data analysis of this Bachelor's thesis followed the above mentioned framework of analysis.

Qualitative content analysis is a method of analysis where words, sentences or phrases are classified into categories according to their similarity (Burns & Grove 2005, 554–555). It is a process where material is organized and integrated from documents (Polit & Beck 2012, 723). In the case of this thesis qualitative content analysis means organizing and integrating information gained from the literature under review. The sources are synthesized by assembling the data from the chosen studies, analysing, and defining the categorized findings. The content gathered from the researches integrated is categorized to designate the relevant state of study-based awareness for a specific area of clinical practice. (Burns & Grove 2003, 128.) While the data gained through the articles are reviewed and summarised, it ought to be decided whether there is sufficient information in order to make changes in clinical practice (Burns & Grove 2003, 128).

When doing the data analysis first the articles chosen were read through several times and then the information to gain the answers to the research question and sub questions of it were looked for in the articles. The reviewer used underlining the main point of the articles as a tool to help to gain the main points and answers to the questions. The data were classified into eight (8) groups. These groups were: title, author, year & place of publication, name of the written measure, developers of the written measure, purpose of the written measure, target group of the written measure, contents of the written measure,

psychometric assessment of the written measure, results and observations. The categories are presented in Appendix 1. The groups were analysed according to the main and sub research questions.

### 5 RELIABILITY & LIMITATION

"Reliability is concerned with how consistently the measurement technique measures a variable or a concept" (Burns & Grove 2003, 45). To ensure reliability in the thesis process only professional, scientific databases and peer-reviewed scientific journals were used as materials in the literature review. The database searches were made to the most relevant nursing databases: CINAHL and MEDLINE (Burns & Grove 2003, 119). The articles to the literature review were collected by inclusion and exclusion criteria and the search limitations to results were strict, which may in addition increase the reliability. The fact that the searches were narrowed quite a bit and that the data searched for the literature review was very specific there were not that many results in the end.

According to Polit & Beck (2010, 551) Cronbach's alpha is a widely used reliability index that estimates the internal consistency of a measure composed of several subparts. The reliability of written measures can be measured by the Cronbach's alpha and it should be over the level of 0.70 to be acceptable (Burns & Grove 2003, 313). When the Cronbach's alpha is on the level of 0.80-0.90 it indicates that measurement provides fine discrimination on the level of construct (Burns & Grove 2003, 273). The Cronbach's alpha was almost exceptionally over 0.80 in the written measures. In just few measures a level of 0.60-0.70 was reported. However, in these cases the levels were usually of subscales included in the measures— not the levels of the measures as an entity. Considering the levels found in the written measures under interest the measures were at least satisfactory on their reliability (Appendix 1).

This was the first literature review conducted by the author. Therefore considering the inexperience of the reviewer some decisions may have been taken which could have had an effect on the reliability of the review. However, the review process was clearly planned by the reviewer. There were some limitations regarding the literature review process. Due to the fact that the reviewer was a student the chances to use databases were limited and the access to the articles was not always possible. In some occasion the articles could not be found or retrieved although they were found through the literature

searches. Also a fact to be noted is that the measures themselves were hard to get hands on, so due to it the data was collected and analysed according to the information gained from the articles found through the literature searches.

### 6 FINDINGS

The findings of the literature review are presented in Appendix 1. The target groups of the written measures reviewed in this thesis were either patients or their family members. Three out of the seven measures were targeted to family members (Chalmer, Luker, Leinster, Ellis & Booth 2001; Mason 2005; Molter & Leske 1983) and the rest of them were targeted to the patients (Liao, Chen, Chen & Chen 2007; Galloway, Bubela, McCay, McKibbon & Ross 1996; Pigott, Pollard, Thomson & Aranda 2009; Kattainen et al. 2004). None of the measures were universal that could be used in different wards. All the measures were somehow disease specific. Most of the written measures were targeted to cancer patients or their family members (Chalmer et al. 2001, Liao et. al. 2007, Mason 2005 & Pigott et al.2009). Two of the measures were targeted to patients in cardiological ward and one of the measures was targeted to ICU patients' family members. All except two (Pigott et al.2009 & Mason 2005) of the written measures were assessing both the need of support and information and by it the need of counselling. The ones that were not measuring both were measuring the need of counselling out of the two needs (Appendix 1).

Through almost all, five out of seven, the studies made with the measures it was reported that patients have unmet or inadequately met needs (Chalmers et al 2001, Hölttä et al. 2002, Liao et al. 2007, Mason 2005 & Pigott at al. 2009). Three studies out of seven indicated that needs of the patients and family members change during the different stages of care (Hölttä et al.2002, Kattainen et al.2004 & Liao et al. 2007). Two studies mentioned the need for individualized approach in providing support or counselling (Liao et al.2007 & Mason 2005). Four studies designated the health care professional's responsible and desired sources for providing the support or counselling (Chalmers et al. 2001, Liao et al. 2007, Omari 2009 & Pigott 2009). Two studies mentioned the need for development of more measures (Kattainen et al. 2004 & Pigott et al. 2009).

Over half, four out of seven, of the reviewed articles indicated that further studies ought to be made about the measures (Chalmer et al. 2001, Liao et. al. 2007, Mason 2005 & Kattainen et al. 2004) mentioned in them. Two measures (Chalmer et al. 2001 & Kattainen et al. 2004) were mentioned to need more development and modifications in them before wider use. In all the articles the measures under investigation were mentioned to be helpful in gaining information about the patients and their family members' needs (Appendix 1).

### 7 DISCUSSION

Family nursing means taking not only the patient into consideration, but also the rest of the family. It is taking care of the whole family while taking care of the patient him/herself and by this seeing the family as a one entity (Hanson 2005, 9; Kaakinen, Hanson et al. 2010, 4; Rantanen et al. 2004, 164; Åstedt-Kurki & Kaunonen 2011, 116). The roots of family nursing go back to prehistoric times (Kaakinen et al. 2010, 16-17). It has been studied in Finland since the early 1990s and up today a lot of research is still going on the area (Astedt-Kurki & Kaunonen 2011, 117). Family nursing ought to be part of competent nursing (Åstedt-Kurki & Kaunonen 2011, 116). Family nursing has been studied on the area of child patients, however not many studies have been conducted with the focus on adult patient setting (Astedt-Kurki et al. 2008, 113-120). Family nursing is not only a concept of paediatric nursing, but is as much a matter to be acknowledged in the adult care setting as it is that of the paediatric care setting (Åstedt-Kurki & Kaunonen 2011, 116). Admission of one family member affects the whole family, raises different kind of feelings and causes changes in family dynamics (Hirsch et al. 2010, 380; Astedt-Kurki & Kaunonen 2011, 116–117).

In order to conduct family nursing the needs of the family should be acknowledged by the nursing staff (Liao et al. 2007, 297). The needs are often estimated inadequately or remain unmet (Chalmers et al. 2001, 499; Hölttä et al. 2002, 16; Liao et al. 2007,290; Mason 2005, 559; Pigott at al. 2009,34 & Verhaege et al. 2005, 502). Nurses should discuss not only the needs of the patients but also these of the family members' (Mattila et al. 2009, 301; Chalmers et al. 2001, 503; Omari 2009, 33; Pigott et al. 2009, 33). The counselling should be individualized to meet the individual needs of patients but also families (Suhonen et al. 2005, 1172–1174; Liao et al.2007; Mason 2005) Nurses play an important role in providing the adequate support and counselling (Chalmer et al. 2009, 503; Suhonen et al. 2005, 1174). Nurses should be aware of these needs of the patients and family members.

Written measures are good way to acquire the information about the needed support and counselling of patients and family members (Kattainen et al. 2004, 159). Nowadays these kinds of measures are not that frequently used in the nursing practice as a tool (Hölttä et al. 2002, 12). Commonly it seems and according to the result of this study there are not that many written measures measuring the need of support and counselling of patients and their family members. This literature review shows that the written measures at hand measure mostly the needs of the patients than those of the family members. Still it is vital to acknowledge the needs of the family members also (Verhaege et al. 2005, 504). This is important because the hospitalization of one family member affects the family as a whole (Kaakinen at al. 2010, 4; Tarkka at al. 2003, 737 & Åstedt-Kurki & Kaunonen 2011, 116). So in order to provide good care for the whole family it would be crucial to develop more of measures assessing also the needs of the family members.

Through the study that was made in this thesis it can be pointed out that the measures that do exist are reliable, since mostly their Cronbach's alpha was over the level of 0.80. The Cronbach's alpha is a figure to describe the reliability of a written measure and it should be over 0.70 to be considered acceptable and on the level 0.80–0.90 to be even more acceptable (Burns & Grove 2003, 273 & 313). Mostly the existing measures are measuring both the need of support and counselling (Chalmers et al. 2001, Liao et al. 2007, Molter & Leske 1983, Galloway et al. 1996 & Kattainen et al. 2004). However primarily the measures are somehow disease specific and there is no universal written measure to be adapted into different situations (Appendix 1). There is a need of development of more written measures to be used in the nursing practice (Kattainen et al. 2004 & Pigott et al. 2009).

In every study there might be some risks. However, the value of the information gained by the study should outdo the risks. The ethics should be taken into consideration while conducting a study (Burns & Grove 2005, 83.) The ethical considerations of this study were that the study was done carefully and the sources to the study were read attentively. This study followed a scheme of

literature review (Burns & Grove 2003, 117). This thesis was done in respect of the reader and it was meant to be informative and easily readable.

### 8 CONCLUSION AND RECOMMENDATIONS

The area of family nursing in the adult patient setting has not been studied much (Åstedt-Kurki at al. 2008, 113–120). Further study ought to be made to expand the family nursing concept to the adult setting as well, since it is a nursing concept that can be used not only amongst child patients, but also adult patients (Åstedt-Kurki & Kaunonen 2011, 116). Family nursing is a way of nursing in which not only the patient, but also the family is included in the nursing care (Hanson 2009, 5; Kaakinen et al. 2010, 4; Rantanen et al. 2004, 164; Åstedt-Kurki & Kaunonen 2011, 116). In order to provide the nursing care to the whole family the nursing staff ought to be aware of the needs of the family members (Liao et al. 2007, 297). Written measures can work as a helpful tool in assessing the needs of the patients and family members and the change in them (Kattainen at al. 2004, 159).

In general it seems that there are not that many written measures assessing the need of support and counselling of patients and their family members'. According to the review of this thesis the ones that do exist are more targeted to the patients than to the family members. However, it is important to be also aware of the needs of the family members (Verhaege et al. 2005, 504). The needs of the family members are important to take into account, because when one of the family members is hospitalised it affects the whole family and its dynamics (Kaakinen at al. 2010, 4; Tarkka at al. 2003, 737; Åstedt-Kurki & Kaunonen 2011, 116). Keeping this in mind there ought to be more measures assessing also the needs of the family members.

The findings of this thesis indicate that the measures at hand are reliable, but most of them need further development and studies before wider use. Most of the measures reviewed are disease specific.(Appendix1.) There were no universal measures to be applied to in different wards. It could be useful to develop a written measure(s) assessing the need of support and counselling, which would be easy to be used in different wards. All in all further studies about family nursing in adult patient setting should be done. In addition further

development of the written measures assessing the support and counselling needs of the patients and family members' is relevant.

## **REFERENCES**

Act on the Status and Rights of Patients 17.8.1992/785.

Aura M., Paavilainen E., Asikainen P., Heikkilä A., Lipponen V. & Åstedt-Kurki P. 2010. Aikuispotilaiden läheisten kokemuksia hoitotyöntekijöiltä saadusta tuesta. Tutkiva Hoitotyö. Vol. 8 (2). 14–21.

Burns N. & Grove S.K. 2003. Understanding Nursing Research. 3<sup>rd</sup> edition. Philadelphia: Saunders.

Burns N. & Grove S.K. 2005. The Practice of Nursing Research: Conduct, Critique and Utilization. 5<sup>th</sup> edition. Missouri: Elsevier

Chalmers K.I., Luker K.A., Leinster S.J., Ellis I. & Booth K. 2001. Information and Support Needs of Women with Primary Relatives with Breast Cancer: development of the information and support needs questionnaire. Journal of Advanced Nursing 35 (4) 497–507.

Freshwater D. & Malin-Prothere S.E. (ed.) 2005. Blackwell's Nursing Dictionary. 2<sup>nd</sup> edition. South Africa: Blackwell Publishing.

Hanson S.M.H.2005.Family health care nursing: an introduction. In Hanson S.H.M., Gedaly-Duff V. & Kaakinen J.R. (ed.) 3<sup>rd</sup> edition. Family health care nursing: theory, practice & research. Philadelphia: F.A. Davis Company, 3–37.

Hirsch A.M, Hoeksel R., Dupler A.E., Kaakinen J.R. 2010. Nurses and families in adult medical-surgical setting. In Kaakinen J.R., Gedaly-Duff V., Coelho D.P. & Hanson S.M.H. (ed.) 4<sup>th</sup> edition. Family health care nursing: theory, practice and research. Philadelphia:F.A Davis Company, 379–414.

Holden J., Harrison L., & Johnson M. 2002. Families, Nurses and Intensive Care Patients: A Review of Literature. Journal of Clinical Nursing, 11, 149–169.

Hudak C.M. & Gallo B.M. 1994. Critical Care Nursing: A Holistic Approach. Philadelphia: J.B.Lippincott.

Hölttä R., Hupli M. & Salanterä S. 2002. Sepelvaltimoiden ohitusleikkauksessa olleiden potilaiden oppimistarpeet. Hoitotiede 14 (1). 11–18.

Jansen M.P.M. & Schmitt N.A. 2003. Family-focused Interventions. Critical Care Nursing Clinics of North America, 15 (3), 347–354.

Kaakinen J.R., Hanson S.M.H. & Denham S.A. 2010. Family Health Care Nursing: An Introduction. In Family Health Care Nursing: Theory, Practice and Research. 4<sup>th</sup> edition. Philadelphia:F.A Davis Company, 3–33.

Kattainen E., Meriläinen P. & Jokela V. 2004. CABG and PTCA Patients' Expectations of Informational Support in Health-Related Quality of Life Themes

and Adequacy of Information in 1 Year Follow-Up. European Journal of Cardiovascular Nursing. 3. 149–163.

Laki holhoustoimesta 1.4.1999/442

Liao M-N., Chen M-F., Chen S-C. & Chen P-L. 2007. Health Care and Support Needs of Women with Suspected Breast Cancer. Journal of Advanced Nursing 60 (3) 289–298.

Liimatainen T., Mattila E., Koivula M. & Åstedt-Kurki P. 2011. Avanneleikattujen potilaiden läheisten tuensaanti hoitojaksojen aikana. Hoitotiede 23 (3). 175–184.

Litchfield M.C. 2011. Family Nursing: A Practice and Systemic Approach to Innovation in Health Care. 285-307. In Svavarsdottir E.K & Jonsdottir H. (ed.) Family nursing in action. Reykjavik: University of Iceland Press.

Mason T.M. 2005. Information Needs of Wives of Men Following Prostatectomy. Oncology Nursing Forum 35 (3) 557–563.

Mattila E., Kaunonen M., Aalto P., Ollikainen J. & Åstedt-Kurki P. 2009. Sairaalapotilaiden läheisten tuki ja siihen yhteydessä olevat tekijät. Hoitotiede 21 (4). 294–303.

Omari H.F. 2009. Perceived and Unmet Needs of Adult Jordanian Family Members of Patients in ICUs. Journal of Nursing Scholarship. 41 (1) 28–34.

Pigott C., Pollard A., Thomson K. & Aranda S.2009. Unmet need in cancer patients: development of a supportive needs screening tool (SNST). Support care cancer 17. 33-45.

Polit D.F & Beck C.T. 2008. Nursing Research. Generating and Assessing Evidence for Nursing Research. 8<sup>th</sup> edition. Philadelphia: Lippincott Williams & Wilkins.

Polit D.F. & Back C.T. 2010. Nursing Research. Appraising Evidence for Nursing Practice. 7<sup>th</sup> edition. China: Lippincott Williams & Wilkins.

Polit D.F. & Beck C.T. 2012. Nursing Research: Generating and Assessing Evidence for Nursing Practice. 9<sup>th</sup> edition. China: Lippincott Williams & Wilkins.

Potinkara H. & Åstedt-Kurki P. 2005. Tiedon antaminen kriittisesti sairaan potilaan läheiselle. Suomen lääkärilehti 25–26. 2779–2782.

Rantanen A., Kaunonen M., Åstedt-Kurki P. & Tarkka M-T. 2004. Coronary Artery Bypass Grafting: Social Support for Patients and Their Significant Others. Journal of Clinical Nursing.13.158–166.

Suhonen R., Nenonen H., Laukka A. & Välimäki M. 2005. Patients' Informational Needs and Information Received Do Not Correspond in Hospital. Journal of Clinical Nursing. 14.1167–1176.

Tarkka M-T., Paavilainen E., Lehti K. & Åstedt-Kurki P. 2003. In-Hospital Social Support for Families of Heart Patients. Journal of Clinical Nursing. 12. 736–743.

Verhaege S., Defloor T., Van Zuuren F., Duijnstee M. & Grypdoncj M. 2005. The Needs and Experiences of Family Members of Adult Patients in An Intensive Care Unit: A Review of Literature. Journal of Clinical Nursing. 14. 501–509.

Vihijärvi S., Koivula M. & Åsted-Kurki P. 2008. Perheiden kokemuksia ja toiveita nivelreuman hoidon ohjauksesta. Tutkiva hoitotyö. 6 (4).16–22.

Virtanen H. ,Johansson K., Heikkinen K., Leino-Kilpi H., Rankinen S. & Salanterä S. 2007. Kirurgisen potilaan oppimistarpeet–katsaus oppimistarpeita arvioiviin mittareihin. Hoitotiede 19 (1) 33–48.

Åstedt-Kurki P., Jussila A-L, Koponen L., Lehto P., Maijala H., Paavilainen R. & Potinkara H. 2008. Kohti perheen hyvää hoitamista Helsinki: WSOY.

Åstedt-Kurki P. & Kaunonen M. 2011. Family Nursing Interventions in Finland: Benefits for Families. 115–129. In Svavarsdottir E.K & Jonsdottir H. (ed.) Family Nursing in Action. Reykjavik: University of Iceland Press

# Appendix 1. Articles used in literature review for the written measures

	Author, year & place of publication	Name of written measure	Developers of measure	The purpose of the measure	Measure contents	Psychometric assessment (Cronbach's alpha)	Results & observations
support needs of women with primary relatives with breast cancer: development of the Information and	Chalmers K.I. , Luker K.A. , Leinster S.J. , Ellis I. & Booth K. 2001. Journal of advanced nursing 35 (4), 497-507.	Information and Support Needs Questionnaire	Same as authors.	Assessment of information and support needs of women with primary relatives with breast cancer	3 subscales - the Importance Scale - the Needs Met Scale - the Adequacy scale 29 statements - Information (18) - Support needs (11) 4-point Likert scale	the Importance Scale: 0.95 the Needs Met Scale:0.92 the Adequacy scale: 0.91	Women with primary relatives with breast cancer have many needs left unmet. These women's highest priority needs were survival issues. Needs for information and support to address concerns related to their family member with breast cancer as well as their own health and risk for breast cancer. Needs for information and support are not adequately met. Mostly information is received from health care professionals. However nurses are the desired source of information and support. Providing up-to date information and support is an intervention nurses are able to perform.

Article heading	Author, year & place of publication	Name of written measure	Developers of measure	The purpose of the measure	Measure contents	Psychometric assessment (Cronbach's alpha)	Results & observations
							Further validation needs to be done before wider use. Answer option "not applicable" ought to be added. Preferably to be used face to face.
Healthcare and support needs of women with suspected breast cancer	Liao MN., Chen MF., Chen SC. & Chen PL. 2007. Journal of advanced nursing 60 (3), 289-298.	Breast Cancer Patient's Needs Questionnaire	Same as authors.	Assessment of the health care and support needs of women with suspected breast cancer	40 statements with 8 factors - Information about treatment ( 8) - Information about disease (7) - Emotional support (6) - Health care services for diagnosis (5) - Follow-up and consultation (4) - Involvement of family and friends (4) - Companionship (4) - Resources (3) 4-point Likert scale	The questionnaire:0.96 5 of the 8 factors: 0.93 6: 0.80 7: 0.86 8:0.76	There is a great need for informational support from health care professionals. Needs are not universal, but based on individual characteristics and health care professionals should be aware of the needs. Needs of the breast cancer patients are mostly related in physical and emotional well-being, social support & health care system. Adequate information is not received by the patients. Needs vary in different diagnostic stages and health care professionals should be aware of this. Needs of breast cancer patients are highest before biopsy and lowest after diagnosis is done.

Article heading	Author, year & place of publication	Name of written measure	Developers of measure	The purpose of the measure	Measure contents	Psychometric assessment (Cronbach's alpha)	Results & observations
							The level of education is correlated to the level of needs. Individualized support should be offered by to the patients to meet the individual needs of the patient. Further studies needed to be done. The type of Likert scale may lead to ceiling effect →results ought to be interpreted with
Information needs of wives of men following prostatectomy.	Mason T.M. 2005. Oncology nursing forum 32 (3) 557- 563.	The Family Inventory of Needs- Wives	Same as author; modified version of Kristjanson L.J.,Atwood J. & Degner L.F. 1995.The Family Inventory of Needs-Husbands	Assessment of information of wives of men following prostatectomy	2 subscales - Importance of Needs - Degree of Being Met 30 items 5-point Likert scale	Importance of Needs:0.94  Degree of Being Met:0.87	discretion.  The older one is the less likely one's needs are going to be met. The Needs were higher between the time of diagnosis and treatment.  By assessing educational needs and how they are met can guide the nurses in the providing counselling. Nurses ought to tailor the counselling to meet the needs of the patient and family members. Patient and significant other may have same needs.  Wives have need for relevant information, but so not find it easily. Information helps significant others to get ready for what is coming.

Article heading	Author, year & place of publication	Name of written measure	Developers of measure	The purpose of the measure	Measure contents	Psychometric assessment (Cronbach's alpha)	Results & observations
							Needs of the wives are vital cause wives can play a vital role in the men's recovery and quality of life.  Future research is recommended for assessment of other family caregiver apart from wives.
Perceived and unmet needs of adult Jordanian Family members of patients in ICU	Omari H.F.2009. Journal of nursing scholarship, 41 (1), 28-34.	Critical Care Family needs Inventory	Molter N. & Leske J.S. 1983	Assessment of needs of family members of ICU patient	5 subscales 45 need statements with five factors - Support - Comfort - Information - Proximity - Assurance	The questionnaire:0.88 Support:0.83 Comfort:0.78 Information:0.62 Proximity:0.67 Assurance:0.60	Family members identify needs related to the ICU environment and are able to distinguish the relative importance among items.  Concerns are focused on their loved one's care and recovery. Nurses may lack the knowledge to help & support family members.  Co-operation between different health care professionals ought to be done to enable meeting the needs of family members.

Article heading	Author, year & place of publication	Name of written measure	Developers of measure	The purpose of the measure	Measure contents	Psychometric assessment (Cronbach's alpha)	Results & observations
Sepelvaltimoiden ohitusleikkauksessa olleiden potilaiden oppimistarpeet (The learning needs of the patients done through coronary artery bypass)	Hölttä R., Hupli M. & Salanterä S. 2002. Hoitotiede 14 (1), 11-18.	Learning Needs Scale	Galloway S.C., Bubela N., McCay E., McKibbon A. & Ross E. 1996.	Measurement of learning needs of patients done through coronary bypass on common level	40 statements with 5 factors related to discharging - Support and care in community (10) - Medications (8) - Treatment and activities of living (8) - Complications and symptoms (8) - Ilness-related concerns (6) 5-point scale - 1 Insignificant - 2 Less important - 3 Relatively important - 4 Very important - 5 Extremely important	The questionnaire: 0.96/0.97 Support and care in community:0.88/0,92 Medications: 0.86/0.88 Treatment and activities of living:0.80/0.83 Complications and symptoms:0.82/0.86 Illness-related concers:0.84/0.88	It is challenging for health care professionals to know the patients' individual learning needs. It is possible that learning needs of the patient cannot be met during hospitalization. Learning needs were greater before than after discharge, however the same areas were seen important before and after discharge.: the biggest learning needs were considering - information of complications and symptoms - medical treatment and the effects of medical treatment. Women have greater learning needs than men. Patient groups with more learning needs should be given needed extra attention. Different factors affect the level of needs. Measure can be used to measure the learning needs of the patients gone through cardiac surgery.  By using the measure the nursing staff can get detailed information from the patients.

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							By surveying the learning needs of patients counselling can be focused on the areas needed and targeted to those patient groups who have need for counselling.
Unmet need in cancer patients: development of a supportive needs screening tool (SNST)	Pigott C., Pollard A., Thomson K. & Aranda S.2009. Support care cancer 17. 33-45.	Supportive Needs Screening Tool	Same as authors.	Screening of supportive needs of oncology patients.	41 questions 5 factors - Information - Physical - Social - Psychosocial - Spiritual - The majority answered by yes/no.	Not mentioned. The measure still needs to be psychometrically tested to be proved as a valid and reliable tool.	Identification of the needs is the first step towards meeting the needs. Usually in practice there is a lack of written measures to survey the needs. Even though supportive care needs are known, there is evidence that they are not always identified. Health care professionals are responsible of discussing the needs of patients with the patient. Patients have unmet needs. The written measure alone can bring information of the needs, but interviews of the health care professionals alongside are preferable. The measure is useful to be used in out-patient setting.It gives a quick and easy administration → user-friendly.

Article heading	Author, year & place of publication	Name of written measure	Developers of measure	The purpose of the measure	Measure contents	Psychometric assessment (Cronbach's alpha)	Results & observations
CABG and PTCA patients' expectations of informational support in health-related quality of life themes and adequacy of information in 1-year follow-up.	Kattainen E., Meriläinen P. & Jokela V.2004.	Nursing Information and Support Scale	Same as authors.	Assessment of learning needs of CABG & PTCA patients.	2 subscales: - Factors related to health and quality of life (14+14) - Questions related to disease  * CABG (6+6) * PTCA (5+5) Four factors - Disease specific items concerning recovering - Psychosocial items - Physical functioning items - Emotional support 4-point scale	Factors related to health and quality of life: 0.70-0.86 Questions related to disease:0.94-0.96	Patients' needs are focused on the information about recovery and psychosocial functioning before and after discharge. Needs of patients change during different stages of care. It is a challenge for nurses to develop support into more individual direction. Different factors affect the level of needs. More measures to measure ought to be developed. Further development and testing needed, especially concerning the emotional support part.