Caregivers’ experiences of unmet needs during palliative care

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Summary

Caregivers while, the biggest providers of palliative care for terminally sick patients, are often neglected in the process of providing care, which inadvertently affects their overall health and well-being. This study aims to explore the experiences of the unmet needs of the caregivers in palliative care. The literature review is based on seven quantitative, four qualitative and one mixed methodology approach studies. Results show a shortage of information given to caregivers regarding disease progression, symptomatology, support services and financial services. Furthermore the themes of unmet needs that emerged are physical, psychological, emotional, social and spiritual needs. Caregivers also reported the shortage of standard services provided by healthcare sector. A healthy relationship scenario, where caregivers are supported to look after themselves as well as their loved ones, would boost the support they render to the patients. The provision of needed services to caregivers, nurses, and healthcare personnel is required to fulfill a healthy relationship and further develop it by learning from the caregivers’ experiences. In conclusion, effective communication between caregivers and care providers is found to be a prerequisite for building trust and could contribute to satisfy the informational, medical, social and spiritual needs while helping to decrease health strains of caregivers.

Keywords: unmet needs, palliative care, caregiver, end life care, terminal care
Table of Content

Introduction ................................................................................................................................. 1

Background ............................................................................................................................... 1
  Palliative care ............................................................................................................................ 1
  Caregivers ................................................................................................................................. 2
  Caregivers in palliative care ................................................................................................. 2
  Basic Needs ............................................................................................................................... 3
  Family centered care ................................................................................................................ 3

Aim ........................................................................................................................................... 4

Material and methodology ........................................................................................................ 4
  Study Design ............................................................................................................................. 4
  Data collection .......................................................................................................................... 4
  Analysis ..................................................................................................................................... 5
  Ethical Consideration .............................................................................................................. 5

Results ...................................................................................................................................... 6
  1) Informational needs ............................................................................................................... 6
  2) Physical, psychological and emotional needs .......................................................................... 7
  3) Support services .................................................................................................................. 8
  4) Social and spiritual needs ..................................................................................................... 8
  5) Decision making needs ........................................................................................................ 9

Discussion ................................................................................................................................. 10
  Method ..................................................................................................................................... 10
  Result ...................................................................................................................................... 12

Conclusion and Clinical Implications .................................................................................... 14

Suggestions for further research ............................................................................................. 15

Reference list .............................................................................................................................. 16

Search route table 1 .................................................................................................................. 1
Search route table 2 .................................................................................................................... 1
Article Matrices table 3 ............................................................................................................. 2
Template for Quality control table 4 ........................................................................................ 5
Template for Quality control table 5 ........................................................................................ 7
Introduction

More than 90,000 people die in Sweden every year and almost 60 percent of them are over the age of 80 or older. In general, the amount of people dying every year has not been changed since 10 years. The most common diagnosis at the time of death is cardiovascular diseases and the next most common cause of death is cancer and tumors (Socialstyrelsen 2016a). Historically, it has been the family and the relatives who have been taking care of their elderly population at the time of need and sickness. However, that has gradually changed through years, where the regional government in the past and now the local municipalities are taking care of the elderly (Strang & Beck-Friis, 2012). Palliative care is defined as the health services that aim to relieve suffering and promote quality of life for the patients with progressive and incurable diseases. One of the most important constituents of the palliative care is the organized support for the relatives (caregivers) who are taking care of their loved ones. Caregivers are the biggest providers of care for terminally sick patients in palliative care, therefore, it is very important to provide them support and fulfill their needs that are connected to the patient (Socialstyrelsen, 2013; Regional cancer center in collaboration, 2012; ). Mental health, decreased amount of stress, reduced amount of depression, better physical health and lowered amount of financial problems are the factors needed for the caregivers to maintain and continue providing the optimal care to their loved ones (Aoun, Kristjansson & Oldham, 2006). With the incomplete and unaddressed needs of caregivers there is a high risk of lowered mental and physical health that consequently results in a lower opportunity to provide optimal care for their loved ones. Nurses and health care providers are in an urgent need of creating and establishing services and programs to identify, provide, administer and implement the unmet needs of the caregivers of the palliative patients (Hirdes, Freeman, Smith & Stolee, 2012). It is evident from literature that there are many caregiver needs to be fulfilled by the health professionals/nurses for example providing information about the nature and progression of the disease, better communication between caregivers, nurses and patients, providing emotional and psychological support and hands on care (DiGiacomo et al., 2016).

Background

Palliative care

Palliative care can be defined as the health services that aim to relieve suffering and promote quality of life for the patients suffering from progressive, incurable diseases or damage and that also implies to take into consideration the physical, psychological, social and existential needs as well as an organized support services to the caregivers (Socialstyrelse, 2016b). Palliative care not only provides basis for increased quality of life for the terminally ill patients, but also for the family and caregivers of the patients. In order to fulfill the arising needs, working with terminally ill patients, the health services should be ready to provide organized support and implement a team based approach both under the disease progression process and at the time of death (Regional cancer center in collaboration, 2012). The foundation of palliative health care services in Sweden is based on four cornerstones. The first cornerstone deals with relieving of difficult symptoms; for example pain, nausea and anxiety. While relieving the difficult symptoms, it is
important to have a consideration for keeping the person’s integrity and self-
determination. The second cornerstone discusses teamwork, cooperation and integration between different professions to fulfill the needs of the terminally ill patients. The third cornerstone emphasizes the continuity of the health care services and a good communication between the patient, health services and caregiver. Irrespective of the organization, the purpose should be to increase the life quality of the patients. The fourth and last cornerstone describes the importance of giving support to the caregivers. Caregivers should be provided with support from health care services because they constitute the fundamentals of providing end-life care to their loved ones (patients). It is crucial that the caregivers feel that they are getting the information they need and that their presence and participation in the end-life care is significant and meaningful. Caregivers should also be provided with opportunity to process their feelings and different kind of situations during the disease progression and after the time of death (Socialstyrelse, 2013; Regional cancer center in collaboration, 2012).

Caregivers

The term caregiver has been defined differently across many studies and literature. Some of the studies agree that an individual in the family or near family who is taking care of the sick person and while not being paid for their services, is called family caregiver. To illustrate the minimum amount of compensation provided to the family member who has been taking care of their sick relative, who we will call patient in this study, the word informal caregiver can also be interchangeably used. There are other criteria, like 1) what kind of help do they provide 2) the amount or measure of help they provide, which needed to be fulfilled to define the word caregiver (Bastawrous, 2013). For the purposes of this study caregiver is defined as a care provider who is a spouse, an adult, child, partner, friend or other relative who is close to the patient and give care or assistance in a variety of different needs (Stavrou et al., 2017). In this study “a person in need of care” would be denoted as “patient”.

Caregivers in palliative care

The involvement of caregiver is a crucial factor for a successful palliative care (Hudson et al. 2012). The support of a family member or other close relatives is an important prerequisite for a good end-life care, but majority of the caregivers usually are missing the experience of being a care provider to a patient (Milberg, Rydstrand, Helander & Friedrichsen, 2005). According to studies, caregivers usually have a lot of difficulty in managing their own feelings and experiences about what is happening in their own life and the life of patient (Brobeck & Berterö, 2003). The caregiver’s role in palliative care is both emotionally and physically challenging. Lack of adequate information to the caregivers from health services can lead to feelings of lack of control and being left out in the process of decision making that involves the patient (Bee, Barnes & Luker, 2009). The caregiver and the patient constitute a “unit of care” which means that both parts of the unit need to be offered support in managing their situations by the health services. The caregiver has an exclusive position for performing two different roles at the same time. They are the care providers to the patient and a link between the health services and the patient, but what is often forgotten is that caregiver is also a person with feelings and needs (Brobeck & Berterö, 2003). For many caregivers, the role of caregiving comes naturally and the role of caring and support act as an opportunity to show their love and concern about the patient (Bee et al., 2009). The role of caregiver should-be ethically assessed; the
family caregiver should be taking the role voluntarily and a plan about the continuous support together with the health care services should be constructed at an early stage (Brobeck & Berterö, 2003). Support and information about prognosis of the disease can give a sense of future orientation to the caregiver which in turn gives them a sense of security. A caregiver with a sense of security has a direct impact on the sense of security of the patient that is one of the conditions for the end-life care to be as good as possible (Strang & Beck-Friis, 2012).

**Basic Needs**
Progression and satisfaction in quality of life is based on a person’s and group’s ability to satisfy their needs. According to Max-Neef existential needs and elementary needs are the two kinds of human needs that should be fulfilled for a good quality of life. Existential needs are divided in four categories that are Being, Having, Doing and Interacting, and elementary human needs are divided in nine different categories that are Livelihood, Protection, Affection, Understanding, Participation, Idleness, Creation, Identification and Freedom. For actualization of needs, “satisfiers” are used that are defined as social habits, social values, social attitudes, social actions, different form of organizations and models in politics (Pelenc, 2016). Virginia Henderson describes the basic needs of a human being in her famous nursing need theory. Basics needs are in turn influenced by physical and psychological factors (Kirkevold, 2014) The need theory, stresses on the significance of developing and expanding patients autonomy by focusing nursing activities into fourteen different biological, psychological, spiritual and social needs. These fourteen needs are 1) normal breathing 2) proper food and liquids 3) elimination of body waste 4) mobility and maintenance of desirable posture 5) rest and sleep 6) suitable clothing-dressing and undressing 7) maintenance of normal body temperature 8) keep the body clean and protect the skin 9) avoiding dangers in the environment and injuring others 10) communication and expression of emotions, needs, fear and opinions 11) practice according to their faith 12) feeling a sense of accomplishment 13) engaging in recreational activities 14) learning, discovering and satisfying the curiosity that results in normal development (Ahtisham & Jacoline, 2015).

**Family centered care**
Family centered care is a model where the caregiver and patient are identified as a unit of care rather than focusing only on the patients or symptoms. According to this philosophy, a patient and his family should participate in all decisions regarding the patient’s self-care and health care in general. Holistic family-centered care includes planning, implementation and evaluation of the given care through cooperation between caregiver, patient and health services. One of the key components of family-centered care is the maintenance of good relationship between the caregiver’s family and health care services. The relationship is based on mutual respect, cooperation and support for the whole family. In family-centered care, respect is defined as recognition, cooperation is defined as partnership in care and finally, support is defined as taking into account specific family needs (Mitchell, Chaboyer, Burmeister & Foster, 2009). Family-centered care at the end of life provides an opportunity to support families and strengthen a well-functioning collaboration between family, patient and health services. Following effects have been noticed from research on family-centered care: 1) It provides the desired level of satisfaction, comfort and emotional support 2) Promotion of the ability for making of joint decisions 3) Focuses on the patient through friendly attitude and facilitate control over the daily
decisions 4) Complies with family members’ needs, both practical and emotional support to the caregivers before and after the death of the patient 5) Ensures proper coordination of care 6) Helps relieve stress and create an environment where the caregiver can feel appreciated in their roles which in turn gives greater self-esteem. Family-centered care also enables improved relationships between caregivers and patients (Kovacs, Bellin & Fauri, 2006).

Aim

The aim was to describe caregivers’ experiences and estimation of unmet needs, during palliative care.

Material and methodology

Study Design

The methodology used for this study was a literature review. Literature review is defined as a research method used to gain summarized understanding of the current research and state of knowledge in nursing related fields. This means to find out the existing research in order to understand what has been studied so far, what kind of methodologies and what aspects have been used in the scientific studies. In this review 12 scientific papers have been used. Out of 12 papers, 4 have qualitative design, 7 have quantitative design and 1 paper has mixed methodology that is both qualitative and quantitative. The motive of using quantitative design in this study is to design a tutorial or instructions, targeted for the adapted group, of how to carry out the current health recommendations that are in consideration to the patient’s actual needs and wishes. By using qualitative studies, it is possible to find deeper information and understanding regarding the patient’s experiences and needs (Friberg, 2012).

Data collection

For information retrieval two web search engines or databases, CINAHL and Medline, were used as shown in table 1 and 2. These two databases contain a large number of scientific papers related to the field of nursing and healthcare. The reason for using these two specific databases was that it is easy to structure and adjust searches in these engines. The key words used to find data were: unmet needs, palliative care and caregiver. To identify key words the aim of the scientific papers were first read. The search with following key words did not result in enough information therefore additional key words like: end life care, terminal care and dying were added to the search that resulted in many relevant studies. Key words used for the search were modified many times to access the papers that are matching the aim of the current review were saved and the rest of the data was excluded from the search. The abstract of the saved papers were all read, those that had similar aim, methodology and answered the research problem of the current study were included, while the rest of the studies were excluded. About 50 studies were read thoroughly to narrow down the search to 12 articles that have been reviewed as shown in table 1 and 2 (Friberg, 2012). For extended search for information retrieval the Boolean operators like “OR”, “AND” and “NOT” were used. The first inclusion criterion was to use studies after
2003 in order to get the latest information sources on the topics. The studies before year 2003 were excluded. The second criterion was to include the studies with full text on CINAHL and Medline. The third criterion was to include the articles that focus on caregivers experiences of unmet needs in palliative care. The fourth inclusion criterion was to only include the caregivers of palliative end life patients (Friberg, 2012). The selected studies quality was checked by the template provided by the School of Health and Welfare Jönköping (see table 4 & 5). Only high to middle high quality studies were selected for the current review.

Analysis

Analysis of the current review was performed using a model developed by Friberg. The scientific papers were read multiple times to analyze if the papers have clear headings, methodology, aim, selections policy and results. The studies were read one more time to understand the complete overall picture and details. The investigation of different parts of the studies in an overall picture of the same studies could be named as analysis. The 12 selected papers were studied many times while focusing on their results. Key concepts in each study’s result were identified and a summary was formed. All the summaries were read and connected to each study’s result to confirm that the key concepts are understood in the right way. All the study’s results were searched to find similarities and differences in the data. Similar data was fused together in categories. The categories represented the “unmet needs of the caregivers” according to their own experiences of being a caregiver of patients in palliative care. The main data collected from the four studies with a qualitative design results in the following unfulfilled needs of the caregivers 1) unmet informational needs 2) unmet physical, psychological and emotional needs 3) unmet needs for support services 4) unmet social needs and 5) unmet communicational needs. The seven studies with quantitative design confirmed the same result concluded from the qualitative studies, with three new additional categories of information that were overrepresented in all the studies with quantitative design. This was done by comparing the results of quantitative data to the results of qualitative data obtained. These new categories were 1) unmet financial needs 2) unmet decision making needs 3) unmet spiritual needs. To confirm the validity of the new unmet needs from the quantitative studies, the four qualitative studies were read again to find if these new unmet needs were represented in them too. It was found that these three new unmet needs were also present in the qualitative studies. The one study that was both qualitative and quantitative gave the same result as all other articles. As a result, seven different categories were formed after first synthesis. After second synthesis five final categories were formed and were presented in the result (Friberg, 2012).

Ethical Consideration

According to Forsberg and Wengström (2013), ethical consideration should be done before doing a review of literature based on selected articles “data collection” and presented “results”. With regard to increase the scientific value of the current review, only authorized scientific papers by the ethical committee were included in this review, or it was confirmed that the papers have made careful ethical consideration (Wallengren & Henricson, 2012). The selection of participants, how did they receive information about the study and how could they had been influenced in the study highlights the importance of doing ethical consideration (Gustafsson, Hermerén & Petersson, 2005). While searching for the articles to be included in the literature
review it’s important to have a critical thinking and not to selectively choose the papers that are wanted and neglecting the unwanted papers, to avoid weakening the results of the study (Friberg, 2012).

Results

The analysis revealed five categories that are 1) informational needs, 2) physical, psychological and emotional needs, 3) support services, 4) social and spiritual needs and 5) decision making needs.

1) Informational needs

Caregivers described the difficulties and struggles they had to go through in the initial stages of their caregiving to get information regarding the diagnosis, the nature and long term implications of the disease. Caregivers were forced to ask a lot of questions to the health care services and after not getting enough information, they would have to search information by themselves (Hasson et al., 2009). The primary and appropriate source of information that could be trusted among caregivers was the health care services that were supposed to provide information regarding treatment of the patient, disease progression, community resources and support services, but the information provided was usually insufficient (Manganese, 2003). Information, regarding when to expect symptoms, that needed to be given to the caregivers by the health care services was found to be unmet among 57% of the 54 participating caregivers. Fifty-six percent of 52 participants also expressed shortage of information for whom or how to contact health services in case of emergencies or when they simply needed help (Ullrich et al., 2017). Twenty-three percent out of 100 caregivers were also wishful to get access to more information about disease prognosis, 10% were in need of information about treatment of the patient, 32% were in need of information regarding symptom management and 38% to find help with the problems in their homes (Hwang et al., 2003). There was shortage of information about the existing health support services, the availability of services and finally it was embarrassing for caregivers to ask for help in some cases (Hasson et al., 2009). According to caregivers, they had shortage of theoretical and practical knowledge in providing care to their patients, for example recognizing pain and suggesting medication. Insufficient knowledge about cancer, terminal diseases and chemotherapy was also one of the unmet needs. Difference in emotional state of the caregiver and support services made it very difficult to deliver information to the caregivers, because it was difficult to understand each other when there was a huge gap between the levels of understanding of the health issue according to caregivers (O’Connor, Gardner, Millar, & Bennett, 2009). Ten percent out of 47 participants expressed shortage of information that led caregivers not to be completely prepared for taking their role as caregivers and unpreparedness can result in caregiving stress and increased physical needs (Goy, Carter & Gazini, 2008). The need of financial advice and support was highlighted by the caregivers as most of them had not received any kind of information while on the other hand the caregivers who had received information regarding the benefits and entitlements of being a caregiver, had information sources like hospital leaflets or social workers visits to the hospital. No or very little formal information on the financial and economic matters were given to the caregivers by the health support services. In order to adapt their houses to the benefit of patients, caregivers had difficulty finding the right kind of equipment
provided by the health services. Even if they managed to find the right kind of appliances and accessories, caregivers were compelled to wait in long waiting lists that resulted in having to buy it themselves (Hasson et al., 2009). In one of the quantitative articles, while comparing demographics with unmet needs, a statistically significant correlation was observed where families with high monthly expenditure had higher number of unmet needs compared to families with lower expenditure, which consequently increased caregivers’ economic burden (Jihyeon & Chiyoung, 2017).

2) Physical, psychological and emotional needs

Daily activities that need physical effort were described to be the most challenging for caregivers. Seventy-five percent out of 47 of the caregivers found hard to help the patients with toilet visits. From the same study 50% thought housekeeping was difficult and 60% had trouble with helping the patients to walk. The same research indicated that helping to move the patients was a harsh task for 80% of the caregivers, as well as helping with transportation, which most caregivers (88%) mentioned as challenging activity (Goy et al., 2008). Caregivers were so concerned and preoccupied with patients that they did not want to eat, exercise, stopped caring about themselves and started to lose body weight. They compared caregiving to a crisis situation where it was not the priority for them to plan about the future rather than the immediate and vital responses they had to do in order to survive (Manganese, 2003). Some of the caregivers regarded caregiving as very stressful and had negative reactions towards it. Though it was not the nature of caring for the patient’s itself that was the problem, instead it was the hard work that physically made caregivers very tired and put an increased amount of burden on their minds and bodies. Long term caregiving resulted in caregivers’ feelings of being left alone and feelings that no one was concerned about them. This resulted in their life being dominated by feelings of sadness and depressive behavior. Finally, they were not able to cope and consequently sought psychological help and some of them even began to use psychiatric treatments (Shanmugasundaram, 2015). Caregivers described that they did not have any time for taking care of themselves, caregiving drained them from all of their energy and they felt fatigued and exhausted. Caregiving often resulted in mental fatigue, tension, anxiety, mild depression, lower threshold to be irritated and disrupted daily life activities and routines (Khan Joad, Chaturvedi & Mayamol, 2011).

One of the unmet needs of the caregivers that was constant during 12 months before the patient’s death was their effort to lower the stress level of the patient. From the 10 months to 12 before the death 24% of caregivers out of 41 participants reported this feeling, and it only kept increasing. From 7 to 9 months, it escalated to 38% out of 52 participants sharing this unmet need. As death got closer, the number of caregivers that were having problems with lowering the stress level of the patients stabilized with 42% out of 52 participants 4 to 6 months prior to death and 42% out of 26 participants 0 to 3 months prior to death. From the same study it was observed that 39% of the caregivers out of 52 participants reported lack of acknowledgement from health services and their surrounding people (Butow et al., 2017). There was also a need of thoughtfulness and helpfulness from health services and physicians regarding the issues of anxiety, physical problems and role strain (Manganese, 2003). Other caregivers described their feelings of helplessness, guilt and distress when they were not able to fulfill the patients’ needs. Feelings of frustration with patients were also common (Hasson et al., 2009).
3) Support services

Thirty-five percent caregivers out of 1,529 participants expressed the need of training programs in nursing care, enhanced practical education, disease education and education about challenges with the specific kind of disease, such as lifting techniques or supporting the patient in different kind of situations. One of the biggest problems in palliative care was the unmet need of pain management where the speed of the treatment was expressed to be unsatisfied among 36% out of 1,493 caregivers and furthermore 25% of the caregivers out of 1,527 were unsatisfied with attention given to the symptomatology of the patients (Pidgeon et al., 2017). Management of medication, physical symptoms, patient’s condition and disease progressions are some of the other unmet needs. Ineffective pain relief of patient resulted from shortage of time and rudeness of health personnel. Caregivers expressed dissatisfaction, annoyance and feelings of anger regarding the ineffective pain management that gave rise to unnecessary suffering and increased pain. According to caregivers, nurses would not take the patient’s increasing and continuous pain seriously and when they wanted to give pain medication, it took them a very long time. Caregivers also revealed that usually the patients would not have the right kind, amount and dose of pain-relief medication. Because of the pain, it was necessary for the caregivers to stay with their patients for a longer time than expected which, put a great deal of burden on their life (Shanmugasundaram, 2015). First in the lack of services category is shortage of medical staff and practical support services. Shortage of medical staff was rated to be more than 66% and shortage of practical support services was rated to be more than 53% among 101 caregivers (Jihyeon & Chiyoung, 2017). Caregivers wanted to have more individual time with the nurses and health care services independent of patient involvement. They also reported lack of continuity of services and health care personal (O’Connor et al., 2009). Lack of support services resulted in disagreement between patient and caregiver about what services to ask for (Hasson et al., 2009). There was a huge intensified dissatisfaction and annoyance regarding the prolonged stays in waiting rooms of the hospitals prior to appointments, medical investigations and administrative work among caregivers (Manganese, 2003). Despite the government’s support, there was a prevalent dissatisfaction and frustration, withstanding the cost of medical equipment such as wheelchairs, batteries, and hearing aids. Some of the caregivers also reported quitting their jobs to take the role of caregiving and that consequently added a very big strain on their finances (Shanmugasundaram, 2015). Financial difficulties were reported by caregivers due to the patient’s state of illness. Furthermore, there was evidence that to pay the medical bills and treatment, some caregivers had reimbursements from the companies they were working for. Caregivers revealed the decreased opportunities in their career growth and advancement due to their caregiving role. Some of the caregivers were also dependent on extensive financial and economic support from their family members and friends (Khan Joad et al., 2011).

4) Social and spiritual needs

Caregivers reported no time for social gatherings, daily life activities, children and social activities. Providing support to the patient, affected caregiver’s relationships and interactions negatively. Family and friends visiting the patient was considered a very big source of help to the caregivers because it gave them psychological support, boosted their morale and stopped them in engaging in their depressive behaviors. Help and support from socio-religious organizations was also greatly appreciated by the caregivers. There was a need of organizing family reunions among caregivers in
the last stages of patients’ disease progression. Most of the caregivers with children felt that they could not give enough time to their children, which affected the children’s studies and their general health. Caregivers with spouses also felt that they could not have quality time with each other and that affected their relationship negatively (Khan Joad et al., 2011). Lack of support from close family members and the lack of the extended family living close by caused an increased pressure on caregivers because they were not able to participate in social activities around them and they lost a lot of valuable relationships and friends as a result (Shanmugasundaram, 2015). Planning the daily life routines around the patient reduced the social life of the caregiver (Hasson et al., 2009). Fifty-four percent out of 54 caregivers expressed the feelings of loneliness and wanted someone in their life to be concerned about their health (Ullrich et al., 2017). In social contexts, it was difficult for the caregiver to handle the topic of cancer or terminal diseases. This problem was reported to be present among 22% out of 41 participants before 10-12 months of the patient’s death and in 30% out of 50 participants before 7-9 months before death (Butow et al., 2017). Support groups consisting of other caregivers that had the experiences of caregiving were identified as a good source of fulfilling social needs. According to many caregivers, the experiences of other people who had encountered similar situations as them could help them to cope with their present situation and could provide them with the necessary long-term information and consequences of being a caregiver (O’Connor et al., 2009). General lack of effective communication and in particular lack of dialogue about treatment, side effects of drugs and disease prognosis with health care service were noticed among 23% of caregivers out of 47 participants (Goy, et al., 2008). Caregivers also experienced problems in communication with patients and found it difficult to talk about the disease with them. Some of the caregivers were also dependent on extensive financial and economic support from their family members and friends (Khan Joad et al., 2011). Out of 110 participants 50,9% caregivers reported unmet spiritual needs. One of the most important needs that were identified by the caregivers was to surround themselves with their families. Praying, reading religious texts, talking with someone about existential matters and going to the services were reported to be the unmet needs of caregivers. Staying positive, reading inspirational material, being surrounded by a positive and happy health personal and being with friends and family were some of the important needs that are not usually fulfilled. It was very much appreciated from health care services to always have positive body gestures like smiling or delivering the message in a positive constructive way while meeting with patients and caregivers (Buck & McMillan, 2008). Caregivers revealed a need for receiving religious support from nurses in form of prayers or spiritual care that would give them the opportunity to accept the fact that death for their loved ones is inevitable and would decrease the uncertain fear of death. Spiritual needs were rated to be 33% unfulfilled by 101 caregivers and a statistically significant correlation was found between unmet spiritual needs and burden of care. This resulted in caregivers reporting a very hard time providing good care and accepting the current condition of the patient (Jihyeon & Chiyoung, 2017).

5) Decision making needs
Sharing the information with caregivers regarding patients’ treatment, medication and disease course, and involving the caregivers in decision making process was one of the important unmet needs. This was reported to be 29% among caregivers out of 1,441 participants (Pidgeon et al., 2017). Lack of joint decision making between caregiver, patient and health service providers is also a need expressed by caregivers
Caregivers felt that they have not been receiving enough attention from the patient and health services. It was very important for the caregivers to be a part of all end-life issues and decision makings, as it provided them with the feeling that they have done enough and contributed in their patient’s dignifying and peaceful death (Hasson et al., 2009). There was a huge need of improved and better, interpersonal and communications competence among the health support providers specifically near end-life care. To understand each other and make joint decisions about the patient, there was a huge need of building trust between caregivers and health services, and communication was regarded as the most important tool to do so. According to caregivers, one of the major priorities of the health care personnel should be to include them in the conversations that concerns the patient they are caring for and to be more open, direct and honest with them (Manganese, 2003). In the last few months of patients’ life, when there was dissatisfaction with the lack of recovery and a general fear of cancer spreading that resulted in uncertainty, 39% of caregivers out of 26 participants were in increased need of support in decision making (Butow et al., 2017). A statistically significant correlation between burden of care and the number of caregivers was found. The ability to make important decisions, for example, increased sedation for pain management or preparation for death was compromised in caregivers due to the lack of family support or lower number of caregivers based on the correlation (Jihyeon & Chiyoung, 2017).

Discussion

Method

Literature review was used as methodology in this study in order to describe and estimate the unmet needs of the caregivers of palliative patients. Literature review is used to create an overview of the existing knowledge and information within a particular care-related area, or an overview of a specific problem in the field of expertise of nurses. The process of a review involves finding out the existing research in order to gain an idea of the studied literature, the methods and theoretical basis used in that specific area. Literature review is the right methodology to be used in this study because it can create an overview of the experiences of the caregivers (Friberg, 2012). To have a better and deeper understanding of caregiver experiences and to generate a wider and broader result by asking specific questions that are related to the aim of this study, a qualitative study design with interviews could have been used. But due to the shortage of time and lack of experience it was not possible to perform such a study. For professionals within the health sector for example nursing, it is very important to have the ability to evaluate research material that can be accomplished by doing a review of literature. By reviewing the existing scientific material, nurses can get an enhanced understanding and knowledge when dealing with interpretation of different kind of material or research (Granskär & Höglund-Nielsen, 2012). The studies and research done in health care and rehabilitation consists of studies with quantitative, qualitative and mixed methodology. In order to get an accurate and reasonable result we need to include all of the above in a review (Fitzgerald, Rumrill & Merchant, 2015). For this reason, four studies with qualitative design were included in this paper to get a deep understanding of the caregivers’ experiences of unmet needs. Seven studies with quantitative design were used to get an estimation and overview of the unmet needs. Finally, one study with mixed methodology was used to facilitate the critical analysis of the results obtained. The studies with quantitative
design resulted in an overall description and presentation of caregiver needs that were assembled in compressed categories of information. Questions asked from the caregivers were usually instrument based, had a yes/no answer and did not provide a deeper understanding of experiences, due to which there was a tendency that useful information about unmet needs, could be missed. The studies with qualitative design gave a detailed and thorough understanding of caregiver experiences. Some of the semi-structured interviews used in studies with qualitative design were based on quantitative research but the presence of the researcher gave the possibility to ask more in depth and follow up questions. Caregivers showed an overall satisfaction of their needs in the quantitative part of the mixed methodology study, while the same data resulted in many unmet needs of the caregivers in the qualitative part of the study. The inclusion of both qualitative and quantitative articles gives a deeper understanding and higher credibility to the study (Forsberg & Wengström, 2013). Credibility shows how reasonable or believable the result of a study is and can be strengthened by letting outsiders read the study. The current study has been reviewed by classmates and supervisor several times that gives it a high credibility and clearer result. Dependability can be defined as the discussion of handling the preconceived notions and understandings, while collecting data and performing analysis. High dependability has been accomplished by first reading the data collected individually and then in discussion with the supervisor while keeping the preconceived notions and understandings in mind. High conformability has been accomplished in the current review by detailed description of data collection and analysis process. Transferability of study is based on securing the credibility, dependability and conformity of the study. After securing credibility, dependability and conformity in the current review it can be discussed that caregivers are one of the most important part of the palliative care. Studies from all over the world have been included in this review and results have yielded similar experiences that show the high transferability of this review (Wallengren & Henricson, 2012).

Databases CINAHL and Medline were used to get access to articles from both nursing and medical fields. Using databases that focus on nursing also contributes to increase the credibility of the current study (Henricson, 2017). One of the advantages of using these databases was the opportunity to use Boolean operators and truncation that specified and narrowed down the search process. On the other hand, the disadvantage of using these databases was the inability to access some of the relevant and high credibility articles that could not be fully accessed but only the abstract could be read. The seven studies with quantitative design, four qualitative design and one mixed methodology included in this review that are from Germany, Australia, USA, South Korea, India and Northern Ireland, ranging from home-palliative care to hospice palliative or advance palliative care, that have resulted in yielding of similar categories, shows the high validity of this review. Internal validity is defined as the degree of the correctness of research design to answer the hypothesis or research question (Twycross & Shields, 2004). The quality of all the 12 articles was controlled by a template provided the School of Health and Welfare Jönköping where all the studies included showed a high or middle high quality that also increases the validity of this review (see table 4 and 5). Reliability is regarded as consistency of measure. Participants expressed similar unmet needs in many of the quantitative articles included in the current review that shows high reliability of this study (Twycross & Shields, 2004).
Result
The results in the current review showed that caregivers were in need of more information regarding diagnosis, implication of long and short term diseases, disease progression and health care services. Understanding is one of the nine elementary needs of a human being and for the satisfaction of this need, it is required that a person is provided with the opportunity, in this case a caregiver, of education, investigation, stimulation and studying (Pelenc, 2016). In a study from 2008, it was found that irregular, discontinuous and sporadic information from health care services to caregivers regarding health conditions, disease prognosis, disease consequences and the amount of care provided to the caregivers resulted in increased unmet needs that are similar to the results found in current review (Spence et al., 2008). Informational needs of the caregivers are highlighted by the Swedish National Board of Health and Welfare where it is considered as one of the four cornerstones of the palliative care (Socialstyrelse, 2013). Furthermore, the results of this review show a lack of information given to the caregivers about the availability of the services from palliative care. These results are similar to another study, where interviewing caregivers reported lack of knowledge provided about the facilities and services to the caregivers as well as the patients (Spence et al., 2008). It is important to notice that the unmet informational need is being continuously found in the studies since 1992 and is still a very commonly expressed unmet need according to current review. Hileman reported that one of the most commonly found unmet need was the informational need (Hileman, Lackey & Hassanein, 1992). Studies highlighted that information and education given to the caregivers of palliative patients gave them an understanding of their own needs and provided them with an opportunity to be prepared as a caregiver that’s also relevant in the current review (Holm et al., 2015; Abernethy et al, 2008). According to studies the most important needs of the families of patients are giving them information, reassurance and closeness that makes it very important for the nurses to be aware of the family needs and the promotion of family-centred care as the standard care (Khalaila, 2014). Virginia Henderson’s theory that has been discussed in this study also describes the basics needs and the way nurses or health professionals can satisfy these needs. By supporting a person in this case caregiver to have more information, educating the caregiver and promoting physical and psychological health to have an autonomous life (Kirkevold, 2014).

According to Given (2017) extensive, increased and prolonged amount of hands-on care and the continuously changing nature of this need caused the caregiver’s exhaustion and resulted in problems like sleep disturbances, gastrointestinal disorders, fatigue, loss of strength, weight loss and increased morbidity. The health care services need to provide standardized assessments on regular basis in relation to caregivers health needs, resources at their disposal and their capacity so that they would be able to provide care to the patients (Given, 2017). These finding are in agreement with the current review that also shows the compromised physical health of the caregiver where the unmet needs were expressed due to lack of help with daily activities that resulted in burnouts, fatigue and many compromised physiological functioning of the body. Unmet emotional needs including; feelings of disappointment, helplessness, frustration, guilt and distress were reported by the caregivers. It was also found that usually elderly female spouses that provided six hours of everyday care and as a result became very exhausted and unable to cope physically. These results are consistent with a study from 2000 where it was found that 40 % of the people did not receive any emotional support from the health care services while only 8 % of the people got some kind of emotional support. Ninety-six
percent of the caregivers reported that palliative health care providers had never or only once or twice been asked about their feelings regarding their patients (Eriksson & Lauri, 2000). Feelings of sadness, mild depressive behavior, mental fatigue, tension, anxiety and mental strain were found to be dominating in caregivers, in some cases it caused the caregivers to seek professional psychological help and take psychiatric medication in the current review. These results were confirmed by a study where the mental strain, anxiety and worry amongst caregivers could give rise to increased amount of vulnerability for psychological and physical health related problems. It was also found that psychological problems could be a threat for the caregivers to continue providing care to the patients while a positive ground of thinking could be significant in lowered amount of stress and anxiety among caregivers (Hirdes et al., 2012). The theory of Virginia Henderson that focuses on physical, psychological, social and spiritual needs could be used by the health care services to fulfill the different dimensions of unmet needs of the caregivers. Virginia Henderson explains that physical and psychological forces combined with education or information, the will of the person in care and support from nurses can be big indicators of promoting health in these persons (Ahtisham & Jacoline, 2015; Kirkevold, 2014). Family centered care could also be counted as an important tool to fulfill the unmet physical, psychological and emotional needs of the caregivers because it focuses on providing the family with desired level of satisfaction, comfort, emotional support and stress relief. It also complies with the needs of family members and provides an appreciative environment to the caregivers where they can feel valued and recognized, that results in higher self-esteem and consequently provides a positive thinking or attitude towards caregiving (Kovacs et al., 2006).

The result of the current review highlighted the need for practical training programs and practical assistance for the caregivers that could be provided by the health services which was consistent with other sources that described the importance of knowledge in practical assistance and was one of the unmet needs (Abernethy et al., 2008; Kristjanson & Aoun, 2004; McIlfatrick, 2007). It was recorded in the current review that ineffective pain management in palliative care services resulted due to care providers’ attitudes, lack of time, poor communication and poor pain management strategies. These findings were mirrored in another study where poor communication between caregivers and care providers are highlighted that resulted in unmet needs. Education in pain management and problem solving skills for the caregivers was required to be able to effectively contribute in the pain relief of the patients. Moreover it was recommended to the palliative team services to recognize the role of the caregivers in pain management that increases pain relief in the patients as well as minimized the unmet needs (Chi & Demiris, 2016). It is worthy to note that the first and the most important pillars of the palliative care highlights to relieve and manage the difficult symptoms like pain in cooperation with caregivers, while maintaining the integrity and self-determination of a person that was reported to be unfulfilled most of the times in the current review (Socialstyrelse, 2013; Regional cancer center in collaboration, 2012). Findings from the current review also focused on lack of financial support and information from palliative care services, that are also consistent with other studies, where financial support and informational problems, increased care burden among caregivers (Given, 2017; Kristjanson & Aoun, 2004; Loiselle & Sterling, 2011).

Caregivers reported a lack of time for themselves, their social life and had unmet spiritual needs. Caregiving affected their relationships with their children and their spouses negatively. Feelings of being left alone were dominating in many caregivers due to the lack of support from their family and friends. Many communication
problems were expressed by caregivers while communicating with the health services and discontinuity of the staff made the communication much more difficult. Other studies are in agreement with these findings, where caregivers explained their need for social support from their family and friends so that they could have some time for themselves, their relationships, not to feel alone and not be the only person taking all decisions regarding their loved ones. Caregivers also revealed that they felt like they were prisoners in their own home, their children would even miss school and had no time to spend with their spouses due to their caregiving duties (Chan & Chang, 1999; Emanuel et al., 2010; Poot et al., 2003; Weibull, Olesen, & Neergaard, 2008). In palliative and family-centred care, caregiver and patient are treated as a unit of care, supporting both, identifying their needs and managing their situation with acceptable and satisfying communication and continuity is considered essential in providing good end life care (Brobeck & Berterö, 2003; Milberg et al., 2005; Regional cancer center in collaboration, 2012; Socialstyrelse, 2013; Kovacs et al., 2006). The findings of current review recorded unmet spiritual needs that were surrounding oneself with family, positive gestures, attitudes and support from health care services that approved previous studies which had described spiritual needs to play a very significant role in the quality of care provided to the caregivers (Buck, 2006; Haley, 2003). The theory of Virginia Henderson provide grounds for nurses to deliver care and services to the people in regard to social, spiritual, biological and psychological needs because it is described that mind and body are inseparable (Ahtisham & Jacoline, 2015).

The findings of the current review presented that caregivers felt their needs had not been fulfilled for decision making. Family and friends were needed in the time of important health decisions regarding the patient for consultation and counseling but this was revealed to be an unmet need. Caregivers had unmet requirements of joint decision making together with health care services due to lack of attention, lack of information, lack of trust and lack of communication that resulted in caregivers not feeling the sense of accomplishment with their care provided to patients. These findings were backed by other studies where caregivers had revealed that caregivers were not considered as partners by the health care services that resulted in misunderstanding, bitterness and distrust between them (Allen, Allen, Hilgeman, & DeCoster, 2008); Andersen, 2008; Conner & Chase, 2014). According to family centered care patient, family members and health care services should participate, cooperate and be part of decision making while planning, implementing and evaluating care that is provided to the patient. By choosing family centered care, health services can contribute in maintenance of good relationship, recognition and partnership with caregivers that results in caregivers having control over their daily lives and decisions (Kovacs et al., 2006; Mitchell et al., 2009).

**Conclusion and Clinical Implications**

In conclusion, this study underlines the highly demanding physical, psychological and emotional strains encountered by the caregivers of palliative patients. This which could be minimized by palliative care services sharing comprehensive medical information, better pain management, information about the availability of services, better access to medical equipment and practical training programs to the caregivers. Caregivers need to be given social support and attention so that they could be able manage their daily life activities by effective communication, joint decision making and building of trust from palliative care services and the availability of family members for the support. Unmet informational needs that are crucial could be
satisfied by giving more personal and individual time to the caregivers in meeting with palliative care services. At end of life care, there was a huge need for spirituality and feelings of hope that could be accomplished by friendly and positive meetings from healthcare and surrounding the caregivers and patients with the presence of families. There was a need of helping caregivers with their economies and shortage of giving counseling regarding the economic help provided to the caregiver. Family centered care could be applied by the health care services to meet the unmet needs of information about drug side-effects, symptomatology, the nature of disease and it’s progression that can build trust in order to maintain a good relationship with the family that in turn can relieve and support the unmet feelings of sadness, mental fatigue, exhaustion and being left alone.
This literature review contributes in understanding and providing more information regarding the unmet needs of caregivers in palliative care. It highlights the importance of giving more information, social support, individual time and friendly meeting that nurses can provide practically in palliative care to the caregivers in order to minimize the unmet needs. Nurses can in addition increase the involvement of caregivers while making decisions that involve the patient.

**Suggestions for further research**

Unmet needs are an interesting topic that can be developed in health care in order to increase the quality of life and prosperity among the caregivers as well as patients. Informational and pain management needs are expressed extensively for a long period of time despite a lot of research done in the area. Further research in informational, health care services and family-centered care is needed in palliative care.


Khalaila, R. (2014). Meeting the needs of patients’ families in intensive care units. Nursing Standard, 28(43), 37-44. doi:10.7748/ns.28.43.37.e8333


### Search route table 1

<table>
<thead>
<tr>
<th>Search result in CINAHL</th>
<th>Number of hits</th>
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<td>2</td>
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<td>40</td>
<td>3</td>
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<tr>
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</tr>
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<td>24</td>
<td>3</td>
</tr>
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<td>Unmet needs AND palliative care OR end of life care OR terminal care OR dying AND caregiver</td>
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<td>22</td>
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<tr>
<td>Author, (year), Journal, country</td>
<td>Title</td>
<td>Aim</td>
<td>Methodology</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------</td>
<td>-----</td>
<td>-------------</td>
</tr>
<tr>
<td>Buck, H., &amp; McMillan, S. (2008). Journal Of Hospice &amp; Palliative Nursing, USA</td>
<td>The unmet spiritual needs of caregivers of patients with advanced cancer.</td>
<td>To identify the spiritual unmet needs of caregivers, and relationship between unmet needs, distress and depressive symptomology.</td>
<td>Questionnaires like the spiritual needs inventory was used in this study with 110 participating caregivers.</td>
</tr>
<tr>
<td>Hasson, et al., (2009). Journal of palliative care. Northern Ireland</td>
<td>Experiences and needs of bereaved Carers during palliative and end-of-life care for people with chronic obstructive pulmonary disease</td>
<td>To explore the experiences of caregivers in palliative care.</td>
<td>Semi-structured interviews were used with 9 caregivers after 6-24 months of patients’ death.</td>
</tr>
<tr>
<td>Author, (year), Journal, country</td>
<td>Title</td>
<td>Aim</td>
<td>Methodology</td>
</tr>
<tr>
<td>---------------------------------</td>
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</tr>
<tr>
<td>Hwang et al., (2003). Palliative Supportive care. USA</td>
<td>Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center</td>
<td>To identify caregivers unmet needs and characteristics.</td>
<td>100 caregivers answered three questionnaires regarding unmet needs were used. Qualitative</td>
</tr>
<tr>
<td>Manganese, PA. (2003). Palliative and supportive care. USA</td>
<td>Caregiving near the end of life: unmet needs and potential solutions</td>
<td>To identify the unmet needs of caregivers to assist clinical interventions</td>
<td>Qualitative study using focus groups and content analysis, where 7 focus groups were identified.</td>
</tr>
<tr>
<td>O'Connor et al., (2009) Collegian (Royal college of nursing Australia).</td>
<td>Absolutely fabulous--but are we? Carers' perspectives on satisfaction with a palliative homecare service</td>
<td>To explore unmet needs and level of satisfaction of caregivers in home palliative care.</td>
<td>300 Caregivers answered the survey questionnaires. Three focus groups were formed. Quantitative /qualitative study</td>
</tr>
<tr>
<td>Author, (year), Journal, country</td>
<td>Title</td>
<td>Aim</td>
<td>Methodology</td>
</tr>
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<td>---------------------------------</td>
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</tbody>
</table>
| Pidgeon et al., (2017). Palliative & support care. Australia | Perceptions of the care received from Australian palliative care services: caregiver perspective. | To explore caregiver perceptions receiving care from specialist palliative care services. | A survey study with 1529 caregivers using questionnaires like “caregiver satisfaction with the healthcare providers to the family and patient from the caregiver point of view”. | Unmet physical, psychological and home-care came into light. | DEL 1:4/4  
DEL 2: 8/8 |
| Shanmugasundaram, S. (2015). Journal of Hospice & Palliative Nursing. Australia | Unmet Needs of the Indian Family Members of Terminally Ill Patients Receiving Palliative Care Services | To explore the needs of the caregivers of Indian families living in Australia with palliative care | 6 caregivers were recruited using purposive sampling and interviewed with Semi-structured interviews. | | DEL1 : 4/4  
DEL2: 8/8 |
| Ullrich et al., (2017). BMC palliative care. Germany | Quality of life, psychological burden, needs, and satisfaction during specialized inpatient palliative care in family caregivers of advanced cancer patients. | Investigation of unmet needs, quality of life, psychological burden and care satisfaction of caregivers in advanced cancer patients. | 54 caregivers answered different questionnaires for example unmet needs questionnaire. | Unmet informational, physical, psychological and social needs. | DEL 1: 4/4  
DEL 2: 8/8 |
# Template for Quality control table 4

## Omvårdnad Examensarbete, 15 hp

### Protokoll för basala kvalitetskriterier för studier med kvantitativ metod

| Titel: |  
| Författare: |  
| Årtal: |  
| Tidsskrift: |  

## Del I
Beskrivning av studien

| Beskrivs problemet i bakgrund/inledning? | Ja | Nej  |
| Kunskapssläget inom det aktuella området är beskrivet? | Ja | Nej  |
| År syftet relevant till eftersom det betar? | Ja | Nej  |
| År urvalet beskrivet? | Ja | Nej  |

Samtliga frågor ska besvaras med ja för att artikeln ska inkluderas till fortsatt granskning. Vid Nej på någon av frågorna ovan exkluderar artikeln.

## Del II
Kvalitetsfrågor

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<td>Beskrivs statistiska metoder/analys?</td>
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<tr>
<td>Beskrivs datainsamlingen?</td>
<td>Ja</td>
<td>Nej</td>
</tr>
<tr>
<td>Beskrivs etiskt tillstånd/förhållningssätt/ställningstagande?</td>
<td>Ja</td>
<td>Nej</td>
</tr>
<tr>
<td>Diskuterar metodik mot kvalitetssikringsbegrepp validitet och reliabilitet i diskussionen?</td>
<td>Ja</td>
<td>Nej</td>
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<tr>
<td>Diskuterar huvudfynd i resultatdiskussionen?</td>
<td>Ja</td>
<td>Nej</td>
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<tr>
<td>Sker återkoppling till nyare forskning i relation till huvudfynden i diskussionen?</td>
<td>Ja</td>
<td>Nej</td>
</tr>
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</table>
Omvårdnad Examensarbete, 15 hp

Är resultatet relevant för ert syfte?
Om ja, beskriv:

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..............................................................................................................................

Om nej, motivera kort varför och excludera artikeln:
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..............................................................................................................................

Forskningsmetod/-design (t ex RCT, tvärsnittsstudie)
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Deltagarkaraktäristiska
Antal.........................
Ålder.........................
Man/Kvinna.................

Granskare sign: .................................................................
Omvårdnad Examensarbete, 15 hp

**Protokoll för basala kvalitetskriterier för studier med kvalitativ metod**

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<td>Tidskrift:</td>
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**Del I.**
Beskrivning av studien

<table>
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<th>Beskrivs problemet i bakgrund/inledning?</th>
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<td>Kunskapsläget inom det aktuella området är beskrivet?</td>
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<td>År syftet relevant till ert examensarbete?</td>
<td>Ja □ Nej □</td>
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<tr>
<td>År urvalet beskrivet?</td>
<td>Ja □ Nej □</td>
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Samtliga frågor ska besvaras med ja för att artikeln ska granskas med hjälp av frågorna i Del II. Vid Nej på någon av frågorna ovan exkluderas artikeln.

**Del II**
Kvalitetsfrågor

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<td>Hänger metod och syfte ihop?</td>
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<tr>
<td>(Kvalitativt syfte – kvalitativt metod)</td>
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<tr>
<td>Beskrivs datainsamlingen?</td>
<td>Ja □ Nej □</td>
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<tr>
<td>Beskrivs dataanalysen?</td>
<td>Ja □ Nej □</td>
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<td>Beskrivs etiskt tillstånd/förhållningssätt/ ställningstagande?</td>
<td>Ja □ Nej □</td>
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</tbody>
</table>

Diskuteraras metoden mot kvalitetssäkringsbegrepp (t ex tillförlitlighet och trovärdighet) i diskussionen? | Ja □ Nej □ |

Diskuterar huvudfynd i resultatdiskussionen? | Ja □ Nej □ |

Sker återkoppling, från bakgrunden gällande, teori, begrepp eller förhållningssätt i diskussionen? | Ja □ Nej □ |
Omvårdnad Examensarbete, 15 hp

Är resultatet relevant för ert syfte?
Om ja, beskriv:
.................................................................................................................................
.................................................................................................................................
.................................................................................................................................

Om nej, motivera kort varför och exkludera artikeln:
.................................................................................................................................
.................................................................................................................................
.................................................................................................................................

Forskningsmetod/-design (t ex fenomenologi, grounded theory)
.................................................................................................................................
.................................................................................................................................

Deltagarkarakteristika
Antal............................
Ålder............................
Man/Kvinna...................

Granskare sign: .................................................................