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ADVANCED HOME CARE NURSES' EVERYDAY PRACTICE

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There is no greater gift of charity you can give than helping a person to die well

Sogyal Rinpoche, The Tibetan book of living and dying, 2002

ABSTRACT

The overall aim of this thesis was to explore nursing care within Advanced home care (AHC) through nursing documentation and nurses' perceptions of nursing care, in order to delineate the required nursing competencies

Background Home health care has increased significantly, in Europe, North America and other parts of the world. Many care recipients prefer to be treated at home and technical developments makes it possible to treat even severe sickness in the home environment. However, this also affects nursing care, and setting high demands on nurses.

Methods In study 1 nurses from four different AHC units were interviewed. In study 2 nursing records were collected from two different AHC units and nursing interventions were detected and described. Content analysis was used in both studies. A synthesis of both studies was conducted for this thesis.

Findings Study 1 comprises 2 domains; planned care and acute care. In study 2 three teams emerged; no ordinary day, daily joys and challenges and providing safe and secure care Synthesis of the 2 studies were sorted into four themes; contents of nursing care within AHC, nurse's perception of nursing care, nursing documentation within AHC and nursing competencies needed within AHC. Nursing care Within AHC was either planned or acute. Contents of nursing care was e.g. interventions, including intravenous infusions, blood transfusions and high technology utilization Other common nursing interventions were sampling, dressing and bandaging, administration of nutritional products and administration of pharmaceuticals. Contents of nursing care also included information and education. Nurses' perceived nursing care within AHC was that this was joyful, free, rewarding and challenging; they respected patients' autonomy and appreciated patients' families. Nurses found team work essential. However, work was performed mostly alone and they encountered situations where they felt insecure. Nurses' documentation was perceived as essential for patient safety. However, documentation was often fragmented, frequently lacked evaluation and information was hard to find. Most of the nurses interviewed lacked a specialist education but had long experience from nursing. Apart from personal qualities and maturity, nurses expressed competencies needed as high technology, pathophysiology, acute care, documentation and retrieving evidence based practice.

Conclusion There are no ordinary days within AHC and nurses perceive nursing care within AHC as joyful but challenging. To provide safe and secure care nurses need advanced knowledge and skills in advanced nursing comprising pathophysiology, high technology, medical techniques, pain and pain relief, psychology and communication. Furthermore, nurses need to appreciate PCC and FPCC. Documentation of nursing care In AHC was often fragmented and information hard to find. This could be a threat to patient

safety and accurate nursing records have to be a priority. Least but not last nurses need to develop their knowledge in information techniques in order to retrieve information about best practice.

Keywords: advanced home care, nursing, nursing competence, nursing documentation, patient safety, focus groups, documentary analysis, content analysis.

LIST OF PUBLICATIONS

I. Öhlén, A. Forsberg, C. Jirwe, M. and Broberger, E. Nurses' perceptions of nursing care within AHC. Submitted for publication

II. Öhlén, A. Forsberg, C. Broberger, E. (2013)Documentation of nursing care in advanced home care. Home Health Care Manage Pract 25 (4) 169-75.

CONTENTS

LIST OF ABBREVIATIONS

AHC	Advanced home care
ALS	Amyotrophic lateral sclerosis
EBP	Evidence based practice
HRQOL	Health related quality of life
KSA	Knowledge, skills and attitudes
PCC	Patient centered care
PFCP	Family and patient centered care
PSL	Patient safety law
QSEN	Quality and Safety Education for Nurses
VIPS	(In Swedish: Well-being, Integrity, Prevention and Security)
WHO	World health organization

1 PREFACE

I had been working as a nurse anesthetist for more than 20 years when I felt the need to experience nursing care from a different perspective. A nurse anesthetist often has very brief encounters with patients prior to surgery and sometimes during surgery, when patients' often are sedated. In my experience, nurse anesthetists are good in making that short encounter meaningful for patients. Nevertheless, to really get to know people in their home environment seemed appealing to me. Advanced Home Care (AHC) was at that time expanding and was, in some ways, totally different from municipal based home care and hospital care. Therefore, it was a challenge for my professional development in nursing care to start working within AHC. Through my work at AHC, and later as a lecturer in nursing education and through my scientific training at Karolinska Institutet I had the opportunity to get a new insight in scientific methods but also a deeper understanding of nursing care within AHC.

2 BACKGROUND

2.1 HOME HEALTH CARE

During the 20th century society and hospitals, to a great extent, took responsibility for health care and giving birth, being sick and dying was institutionalized (Gaunt, 1996). However, industrialization in the Western world has changed prerequisites for care during the last century. Care shifted from personal homes to hospitals (Cartier, 2003; Lang, Edwards & Fleiszcher, 2008) and in the new century rehabilitation and care is executed in home health care instead of in hospitals (Cartier, 2003). Accordingly, organization of health care has undergone many changes during recent decades in Europe as well as in North America (Cartier, 2003: Glajchen & Bookbinder, 2001; Modin & Furhoff, 2004; Lang et al, 2008) parts of Asia (Lim et al, 2014) and Saudi Arabia (Al Mazrooa, 2011). It is now possible to treat severely sick persons in their homes but at the same time hospital beds are decreasing (Socialstyrelsen, 2008), leading to less possibility to get admitted to hospital.

When shifting care from hospital to personal homes, it sets high demands on communication between different care providers, which sometimes can prove to be complicated. Sangeloty Higgins, Shugue Ruiz and Robison (2014) address a need to establish a coordinated system of medically and culturally competent health care staff providing person centered care. In 1999, interviews with patients and staff groups working within advanced home care (AHC) in Sweden, were conducted by the Stockholm county council. Overall, patients were satisfied with care at that time. However, the report emphasizes the importance of support for families and co-ordination with other health care providers (Stockholms läns landsting, 2000).

2.2 NURSING IN HOME HEALTH CARE

Nurses working in different settings with palliative care, are dedicated to their work, find it a great responsibility and they regard cooperation with colleagues and patients and their families as essential (Wallerstedt & Andershed. 2007). Nurses meet daily challenges when, in different home environments, assessing and treating patients symptoms and problems, managing for example medication, injections, infusions, advanced technology and cooperation with other health care providers (Berland, Gundersen &Bentsen 2012; Socialstyrelsen, 2008). Nursing in home health care comprises assessment, planning, intervention, evaluation, patient education, coordination of different health care services and use of advanced technology (Fex, Flenser, Ek &Söderhamnl, 2011 ;Furåker, 2013;Mc Hugh, Horne & Chalmers, 2009;Ruggiano; Edvardsson &Stempel, 2013). Consequently, nursing care gets more complex and demands special skills when patients are to be treated at home. A

Canadian study Seow et al (2014) showed that most palliative care was provided by different organizations with little coordination and with variable quality. In implementing special palliative care teams the possibility to stay at home towards end of life increased significantly (Seow et al, 2014). Also in Sweden the organization of home care differs slightly between municipals and county councils. Some care is provided by health centers in the community, and in many communities, more advanced care is provided by the city council, advanced home care, (AHC). In AHC severe sick persons can receive care from multiprofessional teams delivering care including advanced nursing and the use of advanced technique and medicine. Care within AHC is mainly palliative but can also be curative (Socialstyrelsen, 2008). Most people automatically associate palliative care with incurable cancer. However, palliative care may also include patients with for example heart and vascular diseases, lung diseases and some neurological diseases such as amyotrophic lateral sclerosis (ALS) (Enck, 2013).

When caring for severely sick people in their homes one major part of nursing care in AHC will involve existential issues, in order to support patients and family members (Eriksson, Wahlstedt, Bergström & Melin- Johansson, 2013). Mutual trust between nurses, patient and family is of great importance in order to deliver safe and secure care within AHC (Pusa, Hägglund, Nilsson & Sundin, 2014).

2.3 PATIENTS AND FAMILIES IN HOME HEALTH CARE

Many care recipients prefer to be treated at home (Higginson, Sarmento, Calanzani, Benalia, & Gomes, 2012), and technological progress allows more serious conditions (Fex et al., 2011), such as ALS (Enck, 2013; Ushikubo, 2014), chronic heart failure (Fergenbaum, Birmingham, Krahn, Alter, & Demers, 2015; Öhlén, Forsberg, & Broberger, 2013) or kidney failure, to be treated at home (Vestman, Hasselroth, & Berglund, 2014). However, the wish to stay at home might weaken towards end of life (Asbjoern Neergard et al., 2011; Gerrard et al., 2011); yet, with the diminishing number of hospital beds (Socialstyrelsen, 2008), the possibility of being admitted to hospital if the need occurs is decreasing.

A person in need of care faces disadvantages on three levels: institutionally, existentially, and cognitively. The patient is dependent on the care provider to get treatment and is therefore found at the lowest level of an institution's hierarchy. The patient is existentially threatened by an illness and cognitively knows less than the care providers concerning the illness and what has to be done (Kristensson Uggla, 2014). This thesis uses the concept of family. However, family can be regarded in either a traditional way, e.g., spouses or children, or as a

physiological structure; that is, whom the patient regards as family. Hence, "family" can refer to friends, partners, or even neighbors (Kirkevold, 2003).

When a family member is suffering from a severe disease, the whole family is affected in different ways (Wright, Watson, & Bell, 2002; Björneheim Hynne, 2003). Persson, Östlund, Wenman-Larsson, Wengström, and Gustavsson (2008) showed that the health related quality of life (HRQOL) in family members of cancer patients is affected significantly in many ways. On the other hand, care providers are also affected by their personal experiences and attitudes toward patients and families (Wright et al., 2002). It is important to recognize that family members are individuals in different stages of their lives (Björnheim Hynne, 2003). Home health care frequently uses advanced technology in caring (Fex et al., 2011). This might stress the patient and the patients' families, when they feel they have to check the equipment. Hence, nursing in home care frequently involves and set high demands on patients' families in caring for the patient. Interaction with family members includes ensuring that patients and family caregivers have the appropriate knowledge to play an active role in the caring process (Bee, Barnes, & Luker, 2007; Higginson et al., 2012).

2.3.1 Patient- and family-centered care

In patient-centered care (PCC), nurses work closely with patients and, when applicable, family caregivers to make care assessments and decisions. It seems clear that PCC should be an obvious philosophy in home health care (Ruggiano et al., 2013). Furthermore, working in a person-centered way seems to improve nursing care and rehabilitation and result in more efficient health care (Ekman, 2014). Nurses working in home health care acknowledge PCC but they express difficulties combining being a guest and a professional in patients' homes (Öresland, Norberg, Winter Jörgensen, & Lutzen, 2008). In home health care, family is frequently a part of the caring team. Thus, interaction with family members includes making sure the patient and the family caregivers have the appropriate knowledge to be an active part of this process (Ruggiano et al., 2013). To enable family members to participate in giving care, it is essential for them to be prepared for their involvement (Årestedt, Persson, & Bentzén, 2014). Accordingly, in home environments, it may be more accurate to label care as patient- and family-centered care (PFCC) (Ewart, Moore, Gibbs, & Crozier, 2014). With PCC and/or PFCC, the patients and families have increased opportunities to use their own resources and fulfill the needs, wishes, and feelings of being respected. However, it may prove difficult to follow standardizations, deliver safe care, and simultaneously accommodate patients' and families' personal desires. Therefore, family relationships may sometimes be

difficult to manage (Wilson et al., 2014). Funk (2013) reflected upon whether staying at home is always a choice and whether expectations on the family's responsibility are realistic.

2.4 NURSING DOCUMENTATION

Nursing documentation is one of the most important quality indicators and tools for the development of nursing care. Registered nurses are required by law—the Patient safety law (PSL) (2008, p. 335)—to document nursing interventions. Several systems have been implemented in Europe that attempt to standardize nursing records (Thoroddsen, Saranto, Ehrenberg, & Sermeus, 2009). The nursing process model—assessment, diagnosis, outcomes, planning, implementation, and evaluation—is commonly used as a structure for nursing documentation. NANDA International, previously the North American nursing diagnosis association, has created classifications that are also used to some extent. In Sweden, the Well-being, Integrity, Prevention and Security model (VIPS) was developed to structure documentation in nursing care (Ehrenberg, Ehnfors, & Thorell-Ekstrand, 1996). The use of VIPS has increased understanding of the nursing process, had positive effects on the quality of nursing documentation, and has the potential to facilitate nursing care and documentation. However, nursing documentation still has flaws and standardized nursing terminology is still lacking in Europe (Thoroddsen et al., 2009). However, there is some criticism toward using standardized nursing terminology, which is said to possibly inhibit care plans and focus on tasks rather than personal perspectives and needs (Turjamaa, Hartikainen, Kangasniemi, & Pietilä, 2014).

2.5 SAFETY IN HOME HEALTH CARE

Safety is essential in all nursing care, but in home health care, it sometimes may prove difficult to follow all regulations. The concept of patient safety is strongly connected to medical techniques. However, safety is related to many aspects of nursing and medicine (Ödegård, 2013). Berland et al. (2012) expressed concern about patient safety in home health care since nurses have great responsibilities and often feel insecure about how to handle various situations. Nurses have also reported a lack of competence among some coworkers. According to the PSL (2008, p. 335), the caregiver is required to lead a systematic control of patient safety. Thus, there is a responsibility for health care employees to report potential safety hazards or incidents that pose a threat to patient safety. Berland et al. (2012) reported that nurses, out of loyalty, often fail to report such risks. Safety in home health care includes not only patient safety, but also that of caregivers, who are often vulnerable when visiting someone's personal home alone. Lang et al. (2008) argued that the safety of patients and

caregivers in home health care is at potential risk since many elderly patients live alone and care providers often travel alone to isolated places without direct support from colleagues. Robyn et al. (2008) addressed potential hazards as unsanitary conditions, smoking, threats from neighbors or the patients' family, and angry pets. Furthermore, there are often flaws in nursing documentation, complicating the next visit to the patient by subsequent team members.

2.6 NURSING COMPETENCE IN HOME HEALTH CARE

As home health care is growing and the number of hospital beds is decreasing, many nurses will work in AHC in the near future. A specialist education is presently not required when working as a nurse within AHC. AHC consists largely of palliative care, but it is also related to different curative treatments (Socialstyrelsen, 2008), making the different care needs complex. Hence, establishing the necessary competence for nursing care is also complex.

Gronroos and Perala (2008) showed a lack of self-reported competence among home care nurses in terms of finding evidence-based patient information. According to Kohen and Lehman (2008), one significant barrier to using evidence-based practice (EBP) is the limited knowledge of how and where to search for relevant scientific information. To develop evidence-based palliative care, it is suggested that the evidence must be gained from many fields of science such as oncology, pharmacology, communication strategies, and psychology (Rutledge & Kuebler, 2005).

Competence is a complex concept, and the concept has no clear consensus. However, competence involves skills, attitudes, motives, and maturity (Axley, 2008). Professional competence in nursing should be considered in its entirety, but such competence is related to context and consists of, for example, knowledge, technical skills, communication skills, and personal morals (Epstein & Hundert, 2002).

In order to develop nurses' competencies in health care, quality and safety competencies for nurses (QSEN) has been constructed. The proposed targets are presented as Knowledge, Skills, and Attitudes (KSAs) within six different areas: patient-centered care, team work and collaboration, EBP, quality improvement, safety, and informatics. In Sweden, The Swedish Society of Nursing has formulated these six core competencies for registered nurses. However, The Swedish Society of Nursing has chosen the concept of person-centered care instead of patient-centered care.

As mentioned earlier, organization and perquisites for care have changed and affect the way nurses work. Nursing care has evolved to become more complex and technically advanced, and thus requires specific knowledge (Furåker & Nilsson, 2013). Therefore, it is essential to delineate the contents of nursing care and competencies needed within AHC.

3 AIM

The overall aim of this thesis was to explore nursing care within AHC through nursing documentation and nurses' perceptions of nursing care, in order to delineate the required nursing competencies.

3.1 SPECIFIC AIMS

3.1.1 Study 1

To describe nurses' perceptions of advanced nursing care within Advanced Home Care (AHC) in Sweden.

3.1.2 Study 2

To describe documentation of nursing care within AHC.

4 METHOD

Both studies in this thesis have a qualitative approach using inductive content analysis (Elo & Kyngäs, 2008), which is recommended when knowledge of the subject is sparse (Beck & Polit, 2012). At this stage, it was not relevant to use an alternative qualitative or quantitative approach since the collected data is descriptive and does not allow a deeper analysis for a meaning of a phenomenon. The manifest content has been analyzed; however, in seeking a higher order and meaning of the interpreted content, the latent meaning is shown (Graneheim & Lundman, 2004). Data were collected through focus group interviews (Study 1) and document analysis of nursing documentation within AHC (Study 2) (Table 1).

Table 1. Collected data

Unit	Location/serving areas	Data collection	Numbers
AHC 1	Suburban/rural	Focus group interview	5 nurses
AHC 2	Urban/rural	Focus group interview	4 nurses
AHC 3	Urban	Focus group interview	6 nurses
AHC 4	Suburban/rural	Focus group interview	6 nurses
AHC 5	Urban/suburban	Nursing records	30 records
AHC 6	Suburban/rural	Nursing records	30 records

4.1 FOCUS GROUPS

Focus groups, commonly used in marketing research, have become customary in social science. In focus group interviews, qualitative data are obtained through interactions within the group (Kreuger & Kasey, 2000). When using a focus group, the interaction should be seen as part of the method (Kitzinger, 1995). A focus group is a group of people with something in common, who are asked to discuss a specific topic which they share and of which they have some experience. When choosing focus groups as a method of data collection, consideration has to be given to the purpose and to whether the required data can be elicited to answer the aim of the study. The recruitment of participants in the focus groups is essential and requires planning. The size of a focus group should be small enough for all participants to participate, yet large enough to gather a number of different experiences. The groups are interviewed by an experienced interviewer, the moderator, and an observer is often present to take notes. However, the moderator plays a subordinate role by merely presenting topics and open-ended questions for discussion. When needed, the moderator steers the discussions back on track. It is important that the setting for the interviews is relaxed and permissive so that the group members feel free to express their opinions (Krueger & Casey, 2000). Individual statements may be developed and/or contradicted (Webb & Kevern, 2002). Therefore, this data collection method is unsuitable for reaching a consensus or discussing sensitive matters. A focus group interview is suitable when, for example, the purpose is to view a topic from different aspects or when the aim is to have the group members inspire each other and get new ideas. In Study 1, focus groups were used for data collection in order

to gather opinions and needs, and for group members to inspire each other and gain a deeper meaning of phenomena and new insights.

4.2 DOCUMENT ANALYSIS

Document analysis is used for analyzing and/or comparing different kinds of documents such as policy documents (Ellahai & Zaka, 2015), theoretical frameworks, (Jiwe, Gerrish, & Emami, 2006), or clinical records (Shermon, Vernon, & McGrath, 2015). The data used in a document analysis are already documented and are therefore convenient and easily accessible. Another advantage when analyzing documents is that the risk of influencing actual data is minimal. The approach can be quantitative (Shermon et al., 2015) or qualitative (Ellahai & Zaka, 2015). The document analysis of patient records in this thesis is qualitative, using content analysis (Elo & Kyngäs, 2008).

4.3 STUDY 1

4.3.1 Sample

Study 1 was based on four focus group interviews with nurses from purposefully selected units, with the aim of obtaining as many aspects of nurses' daily work and environments in AHC as possible. The rationale for choosing focus group interviews as a data collection method was for the participants to become inspired by each other, thus deepening and broadening the contents of the discussions. The heads of the units were contacted prior to recruiting the focus groups. A letter inviting the nurses within the selected units to participate in the study was sent by mail prior to the interviews. Participation was voluntary, and we requested a varied group of five to eight participating nurses with different experiences and numbers of work years within AHC. The four units recruited include one unit located in the center of a large city, one unit in a suburban area of the same city, one unit in a smaller city that also served some rural areas, and one unit in a suburban, rural area. The final focus groups consisted of twenty-one nurses, 17 women and 4 men, with four to six registered nurses in each group (Table 2).

Table 2. Participating nurses' work experience and post graduate education

Gender	**Years as registered nurse**	**Years in AHC**	**Specialist education**	**Short courses**
Man	9.5	9	-	Counseling, Palliative care Communication
Woman	30	9	Medicine/Surgery	Counseling, Palliative care Communication
Woman	19	11	-	Counseling, Palliative care Communication , Nutrition
Woman	35	22	Oncology	Counseling, Palliative care Communication , Leadership
Woman	21	4	-	Counseling, Nutrition, Ulcer care, Palliative care, Communication
Woman	18	8	-	
Woman	8	6	-	
Man	19	7	-	
Woman	6	4	-	Trainee program
Woman	2	6 months	-	Oncology
Woman	26	9	-	Oncology
Woman	9	9	-	Oncology, Leadership
Woman	36	6	-	Oncology
Man	6	3 months	-	
Woman	36	6	Anesthesia and intensive care	Leadership and organization development
Woman	22	10	-	Complementary medicine
Woman	35	8	Medicine/Surgery, Intensive care	
Man	8	3	-	Pain, Pedagogic
Woman	17	6	-	
Woman	25	3	Oncology	Dermatology, Dementia
Woman	20	3	Oncology	Pedagogic, Counseling

4.3.2 Data collection

The focus group interviews were conducted in a secluded place in the AHC units and lasted for approximately one hour each. Two researchers participated in each interview group acting as a moderator (the first author) and an observer (one of the co-authors). The moderator asked open-ended questions to lead the interviews. Prior to the interviews, the nurses were requested to think of a special event or a specific patient in their daily practice. All interviews started with a request to describe an ordinary day, followed by questions regarding rewarding, demanding, and complicated care situations. At the end of the interviews, the nurses were asked which competencies they found important in AHC nursing care. The focus group interviews were audio recorded and transcribed verbatim within a week.

4.3.3 Data analysis

Data analysis was performed using content analysis (Elo & Kyngäs, 2008). To get an overall picture of the content, the transcript was read several times, by all authors. The text was organized and sorted into groups with similar content. Parts consistent with the aim of the study were highlighted and codes and probable headings were written in the margins—open coding. The open coding was then transferred to coding sheets. Analysis continued with constant comparison with the original text and probable categories were created and compared. The findings were continuously discussed among the authors. Probable meaning was also discussed among the authors until an agreement and mutual understanding was reached. Probable meanings of the text generated abstractions describing the content of the data. The abstractions are in findings presented as themes.

4.4 STUDY 2

Study 2 is based on 60 nursing records from two AHC units in urban and suburban parts of a large city in Sweden.

4.4.1 Sample

The sample was purposive, consisting of computerized nursing records from 60 patients enrolled at two AHC units. Since the communities consisted of different areas and demographics, the AHC units comprised urban, suburban, and some rural areas of a large city in Sweden. Thirty patient records were collected at each unit, which was estimated to be two thirds of the records from patients admitted to the AHC unit at the time of data collection.

4.4.2 Procedure

Permission to collect data was obtained from the heads of the AHC units. The secretary of each unit was instructed to extract 30 computerized records from currently admitted patients. Names, social security numbers, and other identification data were removed from the records prior to analysis.

4.4.3 Data analysis

The process of the analysis consisted of three phases: preparing, organizing, and reporting data (Elo & Kyngäs, 2008). Only the manifest content was analyzed using an inductive approach. To get an overall picture of the content, all records were read several times. According to the aim of the study, all documentation describing nursing care was extracted from the records and copied verbatim to data coding sheets.

To organize the data, probable headings or codes were written in the margin in open coding. The text was then organized into categories with similar content. Abstraction of data was performed by searching for suitable headings that represented a higher order (Elo & Kyngäs, 2008). In this phase, the categories were sorted into domains. In the last step of the analysis, the domains were compared and a final sorting of the text was conducted.

5 ETHICAL CONSIDERATIONS

This thesis contains two studies:

Study 1. Nurses' perceptions of nursing care within AHC.

Study 2. Documentation of nursing care within AHC.

5.1 STUDY 1

Approval from the heads of the four selected units was obtained prior to data collection. All participants in the focus groups were informed that their participation was voluntary and that the collected data would be handled with strict confidentiality. Participants also signed consent-to-participate forms. The moderator of all the interviews is an experienced group supervisor and was, therefore, prepared to manage situations that might arise within the focus groups.

5.2 STUDY 2

Approval from the head of the two selected units was obtained prior to data collection. The records were anonymous for the researchers and data prepared in a way so that it could not be traced to a specific patient, patient family member, or health care professional.

Ethical approval was requested from the regional ethics committee Dnr 20077554-31. The ethical committee decided that consent not was required for either study.

6 FINDINGS

Study 1 generated three themes: no ordinary day, daily joys and challenges, and providing safe and secure care.

Study 2 generated two domains: planned care and acute care.

The findings presented in this thesis are a synthesis of findings from both studies.

Six units from urban, suburban, and rural areas are represented in the two studies. The findings show contents of nursing care within AHC. Care was either planned or acute (Study 2). However, patients' diagnoses were not equivalent between the units, as variations were evident between the types of nursing care at each unit. Some units almost exclusively provided palliative care for cancer patients, whereas other units had patients with other diagnoses and other caring needs (Study 1). Consequently, some nurses expressed an increase in workload caused by patient diagnoses shifting from being mostly cancer patients in a palliative stage to more curative stages, and other diagnoses such as heart and vascular diseases, obstructive lung diseases, and neurological diseases. All nurses had access to a cell phone and a significant amount of nursing assessments were made over the telephone (Study 1). Nurses working within AHC also spent a notable amount of time in the car, driving from one patient's home to another. Owing to the locations of the unit and the patients, some nurses were required to drive long distances and/or in heavy traffic (Study 1 and 2).

6.1 CONTENTS OF NURSING CARE WITHIN AHC

Working days within AHC started in a similar way at all the AHC units included in the two studies. All patients admitted to AHC had a care plan for the nurses to follow (Study 2). The most common nursing interventions were administering intravenous infusions, blood transfusions, peripheral and central venous catheters, peripheral inserted central catheter (Piccline), urine catheters, and advanced techniques such as infusion pumps. Other common nursing interventions were sampling, dressing and bandaging, and administering nutritional products and pharmaceuticals, mainly intravenously (Studies 1 and 2).

The dialogue between nurses and patients frequently concerned medication, pain management, medical technical interventions, symptoms, and nutritional issues. Furthermore, some documented dialogues had the character of information and education to patient and family members. Information and education concerned e.g. nutritional issues, injection techniques and managing medical devices such as oxygen and infusions. Nursing documentation consisted largely of coordination and team work with physicians and other

health care providers such as physiotherapists, occupational therapists, dieticians, and social workers. Contacts with other parts of the health care organization were also common (Study 2).

Nursing care within AHC also consisted of acute care, mainly due to emergency calls made by either the patient or a relative for pain, unexpected bleeding, or a fever. Patients often had a standing prescription of medication, but the emergency calls sometimes led to contact with the physician on call or admittance to a hospital, when the problems could not be resolved at home (Study 2).

6.2 NURSES PERCEPTIONS OF NURSING CARE WITHIN AHC

Nurses perceived work within AHC as free and rewarding, and joyful but challenging. The nurses in different focus groups discussions revealed both engagement and respect for patients, families, and patients' autonomy. Nurses expressed that it was easier to see the person behind the sickness in patients' homes than in a hospital ward. The expression, "a guest in someone's home," appeared in every interview. Nurses perceived families as part of the team and an asset in caring for the patient. However, nurses also expressed the need to be patient in various situations, and they often accepted things they would not have accepted in a hospital ward such as patients smoking or having pets in their bed. Working in AHC meant working alone most of the time. Nurses expressed that they could always phone a colleague or a physician when they needed help, but they seldom had the time to visit a patient together. Some nurses expressed difficulties assessing a patient's caring needs over the phone, when unable to see the patient during an assessment. Nurses also described the hazards of leaving the patient after having administrated large doses of analgesics or an ongoing infusion pump (Study 1). Such situations made the nurse feel concerned about the patient's response to the analgesics administered and their safety. The problem could partly be solved with a phone call to the patient for evaluation. Nurses often described confidence and trust in the rest of the team and the importance of that confidence in performing safe and secure nursing care. When nurses felt uncertain, they habitually called a colleague for advice (Study 1).

The nurses were engaged in discussions about making a patient feel safe and secure. They expressed that having a ward connected to the unit, where patients easily could be admitted when they could not manage at home, gave the patient and patient's families a feeling of safety and security. If the patients or families could not manage the situation, the nurses expressed the importance of having that alternative option (Study 1).

6.3 DOCUMENTATION OF NURSING CARE IN AHC

Nurses perceived documentation of care as essential for ensuring patient safety, getting updates, or finding out about the patients' caring problems. Some nurses expressed extreme situations when the documentation was insufficient, which could cause serious problems (Study 1).

Nursing documentation showed two domains: planned and acute care. Planned care was mostly conducted according to care plans or subscriptions from a physician, while acute care was often due to an emergency call by the patient or a relative. The most common reasons for acute care were bleeding, pain, or a fever related to infections. Documentation of planned care was brief and, most of the time, simply noted as "done." Some documentation showed a path of the nursing assessment, planning, intervention, and evaluation. However, documentation of acute care often described a situation more thoroughly and with more words (Study 2). Documentation occasionally followed the nursing process. However, a great amount of nursing documentation was fragmented, lacked evaluation, and information was frequently hard to find.

6.4 NURSING COMPETENCIES NEEDED WITHIN AHC

The majority of the nurses interviewed lacked a specialist education (Table 2). However, most nurses had long-term experience of working in nursing, and they considered personal qualities as vital as formal education. Personal qualities such as maturity and experience from nursing and life were perceived as essential. The AHC units did offer some courses such as communication, and the physicians at the units also presented lectures to the staff. Aside from personal qualities, the nurses expressed a need for the competence to handle advanced medical equipment. These skills were often passed from one nurse to another. Other areas where nurses felt they needed more education were advanced nursing, pathophysiology related to the most common diseases, acute care, pharmacology, documentation, and information technology in order to retrieve evidence-based information (Study 1).

7 DISCUSSION

The overall aim of this thesis was to explore nursing care within AHC through nursing documentation and nurses' perceptions of nursing care, in order to delineate the required nursing competencies.

Every day is different for the nurses working within AHC. Nursing care in AHC was perceived as independent, various, and involving both joys and challenges. However, the challenges were sometimes complex and difficult. Situations described as difficult included the amount of different diagnoses, managing large wounds, and advanced technology such as infusion pumps. Furthermore, nursing in AHC consists of both planned and acute care that requires very different approaches. In AHC, the context is very varied, and although the nurses mostly perceived that as positive, it places high demands on nursing competence. According to Andersson and Heyman (1987), factors that influence nursing care are the type of care related to acute or long term care, and whether the care is focused on the relation to the patient and/or executing tasks. This could be explained as nursing care being related to context (Epstein & Hundert, 2002). Most of the nurses who participated in the interviews were very experienced in nursing but very few had a specialist education. Although professional competence is perceived to increase with age and experience (Numminen et al., 2014), nurses with specialist education considered their competence higher than nurses without a specialist education (Karlstedt, Wadensten, Fagerberg, & Pöder, 2014).

The discussion of the findings in this thesis is based on the six core competences. The core competences developed by QSEN and formulated by the Swedish society of nursing are patient-centered care, team work and collaboration, EBP, quality improvement, safety, and informatics. However, the Swedish society of nursing uses the concept of person-centered care.

7.1.1 Person- and family-centered care

Home health care typically involves the whole family and aims to consider patients' autonomy and family wishes. Bergdahl, Benzein, Ternstedt, Elmberger, and Andershed (2012) described the nurse-patient relationship in AHC as warm, friendly, and person-centered. This was also the case for the nurses who were interviewed in Study 1. The nurses described work in this context as joyful but also challenging. Patient autonomy seemed essential to nurses in AHC and family caregivers were described as an asset to patient care. However, the nurses often encountered situations in which they felt insecure and lacked

accurate knowledge and skills. This could be because nurses are alone with their patients most of the time. When caring for a severely sick person in their home, unexpected events are bound to happen occasionally. The nurses mentioned occasional communication problems with patients and family members. However, this was typically related to different languages or hearing problems. The nurses seldom described problems with emotional support, though the reason why was unclear. The nurses' long-term experience could explain why they did not see this as a problem. However, different perspectives of communication problems could be another explanation. Norell Pejner et al. (2015) explained that emotional support could be seen as an actual part of nursing; however, nurses sometimes might feel inadequate and lack the required knowledge to meet the patients' emotional needs.

7.1.2 Team work and collaboration

The nurses shared their perceptions of the team as essential for safe and secure care within AHC. However, they expressed that contact with other team members was usually by phone, and team members rarely had the opportunity to visit their patients together.

Working in a team means supporting each other within the team, but it can also mean collaboration with other caregivers outside the unit (Berlin, 2013). This thesis shows the collaboration between nurses and other health care providers and organizations. The obvious team work was between nurses and nurses' aides, although nursing documentation formed a large part of the coordination and team work, not only with physicians but also with other health care providers such as physiotherapists, occupational therapists, dieticians and social workers. Contact with other parts of health care organizations was also common.

7.1.3 Evidence-based practice

Although most of the nurses interviewed had long-term experience in nursing, they did not consider themselves good at finding and retrieving new research (Study 1). However, all of the AHC units had local lectures performed mostly by physicians. The units also arranged for short courses in subjects such as communication. Using EBP in nursing involves finding the best way to execute safe nursing care, while considering the patients' personal needs and wishes, and best practices for specific actions (Willman, 2013). The nurses laid their trust in other nurses' and physicians' knowledge. Nurses expressed that they occasionally searched for a specific item on Google to get new insights. Based on this statement, the need for knowledge on how to retrieve new research and EBP is of major importance.

7.1.4 Informatics

Study 2 showed that nurses' documentation largely consists of medical technical tasks and planned nursing interventions. Although medical technical tasks were most frequently documented, acute care and emotional issues consisted of considerably more text, where the nurses' assessments and consequent interventions could be followed. Within AHC, nurses and other health care providers visit the patient homes at different times of the day and night; thus, it is important that information concerning the patient's status and follow ups is regularly updated. Study 2 showed that this was not always the case. Documentation was often fragmented and it was hard to find certain information to follow the nursing process. Previous studies had similar findings. Paans, Sermeus, Nieweg, Roos, and van der Schans (2010) found nursing documentation to be mainly chronological and descriptive, rather than problem-based according to diagnoses and interventions. An observational of how nurses executed their records (Keenan, Yakel, Lopez, Tschannen, & Ford, 2013) showed that nurses spent a significant part of their time retrieving information, communicating, and documenting. Nurses in the study by Keenan et al. (2013) had access to computers and electronic documentation but chose to communicate with each other and with other members of the team orally, and information concerning nursing care was written on scraps of paper. This type of documentation is inefficient and the risk of information getting lost in the process is high. It is not only nurses that are dependent on the documentation of nursing care, physicians often need to access nursing documentation for treatment follow ups but they often find the information hard to access (Törnvall & Wilhelmsson, 2008). The importance of standardized nursing records has previously been studied (e.g., Ehrenberg et al., 1996; Thoroddsen et al., 2009). Several systems in Europe have attempted to standardize nursing records, e.g., NANDA classification or the nursing process model (WHO, 1997). However, nursing records still have flaws (Thoroddsen et al., 2009), and there is some criticism toward standardized nursing terminology concerning comprehensiveness and lack of evaluation and inflexibility. Nursing documentation is task oriented rather than person-centered and shows patients' actual needs (Turjamaa et al., 2014). Study 2 showed that nurses interpreted the terminology in VIPS differently, which could lead to misunderstandings and difficulty finding the right information, leading to potential safety risks. Attempts to standardize nursing records with accurate terminology have the opposite effect when they become too complex and hard to grasp, leaving nurses to rely on scraps of paper.

7.1.5 Safety

The above-discussed core competencies relate to delivering safe and secure nursing care not only for the patient and the family but also for the staff. This thesis has recognized some main issues concerning safety in AHC that need to be highlighted. First, information about the patient in nursing documentation was occasionally fragmented, hard to find, and frequently lacked evaluation. Contents of nursing records are essential information for other nurses, physicians, and rest of the team. Inadequate records could pose a potential risk for patient safety. The nurses sometimes felt they lacked the proper knowledge of different diagnoses, advanced technology, and retrieval of evidence-based information.

However, there are other potential risks, not only for patients but also the nurses themselves. Nurses drive by car to visit the patients, sometimes long distances or in heavy traffic. A study performed in Norway showed that driving time took up to a third of the nurses total workday (Holm & Angelsen, 2014). The nurses have to remember to take all of the required equipment and pharmaceuticals for each day, because they do not have time to go back and get them.

Every day is different, and a routine visit to a patient can become an acute setting; the nurses do not know what scenario they will meet. Many elderly caregivers live alone and the care providers mostly travel alone without direct support from the rest of the team, other than over the phone. Furthermore, there are sometimes problems with patients smoking, pets, and potential risks of threats from the environment (Robyn et al., 2008). While the nurses interviewed did not report any threats, the risk of threats from family or perhaps neighbors should not be neglected.

7.2 METHODOLOGICAL LIMITATIONS AND CONSIDERATIONS

Focus group interviews are useful for obtaining perceptions and needs at the group level. The discussion should be an interaction between the group members, and the ideal situation is for the members of group to inspire each other, when profoundly discussing matters of importance to the participants. The weakness of focus groups could be that some group members avoid discussing sensitive topics in a group. Furthermore, the moderator has to see to that every member of the group is heard. Another matter discussed between the authors was my personal experience of AHC. This could cause some bias, since I have knowledge of the nurses' work, and also may take some issues for granted. However, one of the co-authors was always present at the interviews, and if something was unclear, they had the opportunity

to raise a question in order to clarify statements. I am also a trained nursing counselor, and I am familiar with the dynamics of a group.

There are some advantages of analyzing documents. Since data are already documented, the risk of influencing the data is small. However, the quality of documentation in Study 2 varied. Information of nursing care was difficult to categorize since nurses had interpreted the standardized terminology differently. Hence, the same sort of information could be found under different headings in the records. Data and information in nursing documentation was often fragmented, patients' statuses were frequently repeated, and follow ups and evaluations were sporadic. The documentation frequently implied complex situations involving both interprofessional contacts and family members, but the whole event was rarely documented. The data provided in the documentation is not necessarily the truth, only what has been documented (Appleton & Cowly, 1997; Abbot et al., 2004).

8 CONCLUSION

Society, technology, and medicine has developed and is continuing to develop even further, therefore educators and policymakers need to consider developing nursing home health care training and education (Al-Mazrooa, 2011; Benner, 2004). Nursing care in AHC is perceived as joyful and challenging by the nurses. However, challenges may prove to be complex and difficult when dealing with several different diagnoses and advanced technology. Patients' families are often perceived as assets in daily care but complications can arise when dealing with the family. AHC nurses need advanced knowledge and skills in advanced nursing, pathophysiology, advanced technology, medical techniques, psychology and communication, pain, and pain relief. Furthermore, they need knowledge in PCC and FPCC. Making accurate assessments by telephone is another high priority. To deliver safe care, team work is considered essential to the nurses interviewed, but team work also includes other parts of the health care system, which means possessing substantial knowledge of the rules and regulations. To improve quality in care, nurses need to improve their knowledge of how to retrieve best practice information. The documentation analyzed showed substantial flaws in readability and care evaluation. Obtaining accurate information for all team members and for patient safety is an area that requires further scrutiny.

9 IMPLICATIONS FOR NURSING PRACTICE

The two studies in this thesis illustrate part of the contents and meaning of nursing care within AHC and implications for nursing competence and nursing education. The two studies gain an insight into the variety and complexity of the nurses' work and indicate the competencies needed for nurses working in AHC. The intention of this thesis was to contribute to further discussions and studies related to the educational needs of nurses working within AHC. It is necessary to discuss what is most important and what is less important when educating future nurses (Benner, 2010). However, this thesis only shows a small piece of nursing in AHC. To get an overall picture of nursing care in AHC, additional studies with various foci and different angles are needed.

10 FUTURE RESEARCH

Further research concerning nurses' use of EBP in AHC, observational studies of nurses' interactions with patients and family caregivers, nursing documentation, and studies concerning patient and family satisfaction with home health care within AHC are needed.

11 SVENSK SAMMANFATTNING

I början av förra seklet föddes och dog många i hemmet, men i och med industrialiseringen har förutsättningarna för sjukvården ändrats. Utveckling av teknik och medicin gjorde att vi under 1900-talet vande oss mer och mer vid att olika institutioner tog över delar av våra liv. Samma utveckling som gjorde att vården institutionaliserades har fortsatt och från och med slutet av förra seklet har det blivit möjligt att få mycket avancerad vård i hemmet.

Många sjuka och äldre föredrar att kunna vara kvar i sina hem också när de blivit svårt sjuka. Inom den avancerade hemsjukvården är de flesta patienter i ett palliativt skede, men också detta har förändrats de sista åren. Nu kan man behandla till exempel kronisk hjärtinsufficiens, svåra infektioner, njurinsufficiens med hemdialys samt ge stöd och viss medicinsk hjälp till cancerpatienter i ett kurativt stadium. Det har dock visat sig att önskan att vara kvar i hemmet kan ändras och försvagas mot slutet av livet. Med detta i åtanke, så är det så att i samma takt som hemsjukvården utvecklats och expanderat så har också antalet vårdplatser på sjukhus minskat. Det är följaktligen svårare att få plats på sjukhus om det skulle behövas.

När en familjemedlem insjuknar i en svår sjukdom så påverkas hela familjen och deras livskvalitet på olika sätt. Man ska också komma ihåg att familjer kan se ut på många olika sätt, vara i olika stadier av livet och det är den enskilda personen som avgör vem som är dennes familj. Familjen kan bestå av till exempel en äldre make/maka, barn, men det kan också vara en vän eller till och med en granne. När vården blir avancerad ingår ofta teknik i hemmet relaterad till sjukdomen och den vård som ska utföras, vilket ställer höga krav på både patient och familj.

Sjuksköterskor som arbetar med svårt sjuka personer i deras hem är dedikerade sitt arbete, känner stort ansvar och anser att teamarbetet är mycket viktigt, Men de möts också av stora utmaningar i arbetet.

Kompetens är ett svårdefinierat begrepp, men det innehåller en persons kunskap, färdigheter, attityder och mognad. Kompetensen är också relaterad till kontext. Quality and safety competencies for nurses (QSEN) har utvecklat ett system för utveckling av sjuksköterskeprofessionen. De föreslagna områdena är; patientcentrerad vård, teamarbete och samordning, evidensbaserad vård kvalitetsutveckling, säkerhet och informatik. Samma system har antagits av Svensk sjuksköterskeförening med det undantaget att man valt begreppet personcentrerad i stället för patientcentrerad.

I den första studien i denna avhandling intervjuades fyra fokusgrupper bestående av sammanlagt 21 sjuksköterskor från fyra olika enheter för avancerad hemsjukvård. Syftet med studien var att fånga sjuksköterskornas uppfattningar om arbetet inom den avancerade hemsjukvården. Data analyserades med en kvalitativ innehållsanalys.

Resultaten från den första studien visade på att sjuksköterskor var djupt engagerade i sitt arbete som innehöll både glädje och utmaningar. Sjuksköterskorna beskrev att det var lättare att se ”människan” när man vårdade patienten i hemmet. Sjuksköterskor värderade patientens autonomi högt och såg familjen som samarbetspartners i detta arbete. Utmaningarna bestod oftast i att tekniken var väldigt avancerad och att patienterna hade varierande diagnoser. Det kunde också uppstå kommunikationsproblem, ofta relaterat till språkförbistringar. Sjuksköterskor beskrev att de också behövde beväpna sig med en hel del tålamod då en del patienter rökte, hygienen inte tillfredställande eller att det fanns husdjur. I den andra studien gjordes en dokumentanalys av sjuksköterskors omvårdnadsdokumentation. Sextio omvårdnadsjournaler från två olika enheter för avancerad hemsjukvård insamlades. Data analyserades med en kvalitativ innehållsanalys. Utifrån dokumentationen kunde man identifiera att arbetet bestod av både planerad och akut vård. Den planerade vården utgick ifrån en upprättad vårdplan eller läkarordination. De vanligaste utförda åtgärderna var läkemedelsadministration, ofta intravenöst, infusioner, blodtransfusioner, provtagning, omläggningar. Kontakten mellan sjuksköterska och patient verkade ofta vara per telefon. Dokumentationen beskrev också utbildning och råd till både patienter och deras familj. Dokumentationen beskrev dessutom teamarbete och samarbete med andra delar av hälso- och sjukvården. Kvaliteten på dokumentationen varierade kraftigt och informationen var ofta svår att finna. Avancerade vårdbehov fanns ofta beskrivna, men det fattades ofta utvärderingar av utförda åtgärder.

Denna avhandling avser att vara ett bidrag till en vidare diskussion avseende utbildningsbehov hos sjuksköterskor som arbetar inom den avancerade hemsjukvården. Av de intervjuade sjuksköterskorna hade de flesta inte någon specialistutbildning. Utvecklingen har gått snabbt och vi behöver resonera om vad utbildningar ska innehålla, vad som är viktigt och mindre viktigt. Sjuksköterskor som arbetar inom den avancerade hemsjukvården behöver kunskap på avancerad nivå avseende personcentrerad vård, familjecentrerad vård, patofysiologi, medicinsk teknik, psykologi, kommunikation samt smärta och smärtlindring. Att göra korrekta bedömningar på telefon är ett annat angeläget område. Sjuksköterskor behöver också få mer kunskap i sökning av vetenskaplig litteratur och evidensbaserad vård. De två studierna ger en inblick i vad arbetet som sjuksköterska inom den avancerade

hemsjukvården innebär och innehåller, däremot kan man inte dra några generella slutsatser av två kvalitativa studier.

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