

Mira Magnusson

Sjuksköterskeprogrammet, 180 hp, Institutionen för vårdvetenskap

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Handledare: Agneta Cronqvist

Examinator: Elisabeth Winnberg

## **Nurses' experiences of involving family members in home-based care**

A qualitative study with nurses working in home-based care provided out of consultorios in Havana, Cuba

## **Sjuksköterskors erfarenheter av att involvera familjemedlemmar i hemsjukvård**

En kvalitativ studie med sjuksköterskor arbetandes inom hemsjukvård bedriven utifrån consultorios i Havanna, Kuba

## Sammanfattning

**Bakgrund:** I Havanna, Kuba, har de upprättat en stor tillgänglighet av sjukvårdsinstanser och hälsocenter som arbetar nära patienterna och deras familjer, både geografiskt och socialt, så kallade consultorios. Familjecentrerad omvårdnad är något som eftersträvas inom sjukvård i västvärlden. Ett flertal studier har visat att familjecentrerad omvårdnad ökat patientsäkerheten och patientens tillfredställelse av vården och att psykologiskt stöd för anhöriga bidrar till en bättre hälsa både för dem och patienten.

**Syfte:** Att beskriva sjuksköterskors erfarenheter av att involvera familjemedlemmar i hemsjukvård som bedrivs utifrån consultorios i Havanna, Kuba.

**Metod:** En kvalitativ studie med semistrukturerade intervjuer genomfördes och fem sjuksköterskor som arbetade eller har arbetat på consultorios i Havanna, Kuba, deltog. Resultatet bearbetades utifrån kvalitativ innehållsanalys baserad på den strategi som beskrivits av Graneheim och Lundman.

**Resultat:** I resultatet framkom två huvudteman: *Betydelsen av familjemedlemmar i hemsjukvård* och *Betydelsen av sjuksköterskans involverande av familjemedlemmar i hemsjukvård*. Det första temat beskrev familjemedlemmar som en resurs i sjuksköterskans arbete i hemsjukvården. Familjemedlemmarna presenterades dels som informanter men också som en tillgång i sjuksköterskans arbete samt som ett psykologiskt stöd till patienterna. Det andra huvudtemat berörde sjuksköterskans roll kring hur hen engagerar familjemedlemmarna i hemsjukvården. Sjuksköterskorna uttryckte vikten av att se hela bilden av deras patienters situation, hur de utbildar familjemedlemmar i omvårdnaden och hur de stödjer familjemedlemmar psykologiskt.

**Diskussion:** Resultatet diskuterades utifrån den valda teoretiska utgångspunkten: konceptet om *Familjecentrerad omvårdnad*. Sjuksköterskornas upplevelse av familjemedlemmars roll och deras arbete med att involvera dessa diskuterades i relation till tidigare forskning och begreppet familjecentrerad omvårdnad.

**Nyckelord:** Familjemedlemmar, familjecentrerad omvårdnad, hemsjukvård, Kuba

## **Abstract**

**Background:** In Havana, Cuba, they have established a great availability of health centers that work close to the patients and their families, both geographically and socially. Family-centered nursing is something that is sought within the health care in the Western world. Numerous studies have shown that family-centered nursing increases patient safety and patient satisfaction and to provide psychological support to family members has shown to contribute to a better well-being to both them and the patient.

**Aim:** To describe nurses' experiences of involving family members in home-based care provided through consultorios in Havana, Cuba.

**Method:** A qualitative study was completed with semi-structured interviews with five nurses that was currently working or had been working at consultorios in Havana, Cuba. Analysis was done according to qualitative content analysis based on the approach presented by Graneheim and Lundman.

**Results:** The data resulted in two main-themes: *The significance of family members in home-based care* and *The significance of the nurse's involvement of family members in home-based care*. The first theme describes the family members as an asset to the nurse in the home-based care. The family members were presented as informants to the nurses, psychological support to the patients and about family members being an asset to the nurse. The second main-theme concerns the nurse's role in involving family members in home-based care. The nurses expressed the importance of seeing the whole picture of their patient's situation, how they educate family members to be involved in the care and how they support the family members psychologically.

**Discussion:** The results were discussed based on the selected theoretical framework: the concept of family-centered care. The nurses' experience of family members' role and their work to involve them was discussed in relation to previous research and the concept of family-centered care.

**Keywords:** Family members, family-centered care, home-based care, Cuba

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## 1 Introduction

Cuba is a country well known for its highly developed health care system. Their health care is free for the Cuban population and they have a great number of educated nurses and physicians. In Havana, they have established a great availability of health centers that work close to the families, both geographically and socially. The discussion about how nurses can make patients and their family members participants of the care provided is constantly ongoing in health care. In our education we have read and studied a lot about how we as nurses can make patients and their families participants of the care provided. I therefore wished to explore the Cuban nurses' experience of family members' role in the home-based care that is provided out of consultorios in Havana.

## 2 Background

### 2.1 Demographics of Cuba

Cuba is a country in the Caribbean with a population of approximately 11 million people in 2012 (Globalis, 2014; Landguiden, 2013). The Island measures almost 111 km<sup>2</sup>, which is about one fourth of the size of Sweden. Out of the whole population, 75% lives in Urban Areas. The Capital is Havana, situated in the northwest part of the island, and has approximately 2 million inhabitants. The government has always been the mayor employee in Cuba, but in recent years, economic reforms carried out, which led to that many government employees lost their jobs and unemployment has risen. After the fall of the Soviet Union in the 1990's, Cuba's economy collapsed radically, since they had been the country's major partner for import and export (<http://www.svensk-kubanska.se>, Landguiden, 2013). This led to huge sanctions of all goods such as food, housing and work opportunities and other important imported necessities, and the country's supplies ran very low. Therefore, the government started to give monthly rations of a basic food supply to every Cuban. Cuba's current main export is work labor, mostly medical staff, but also teachers and sport-coaches amongst others (<http://www.svensk-kubanska.se>).

Cuba has, even though unemployment has increased the latest years, according to the statistics available at Globalis (2014), a poverty of 0% and the same statistics for malnutrition. They have mandatory education up until 9<sup>th</sup> grade and all the education, even college, is free for the whole population. They have an almost nonexistent illiteracy (99,8% of the population can read). The Cuban government has worked hard to sustain a high level of gender equality

in the labor market which in 2010 was around 47%, which is almost as high as it was in Sweden at the same time (50%).

## **2.2 The Cuban Health care system**

Cuba is a socialistic one-party state and the country has been in political conflict with the United States of America (USA) for almost 50 years (Globalis, 2014; Landguiden, 2013). The conflict has made Cuba limited in their economic relations and commercial trade with the rest of the world since the USA enforced a trade embargo towards Cuba in the 1960's. This has made the country forced to be independent and self-sufficient in several areas. One example of what the blockade from the USA caused, is that Cuba had to develop their own pharmaceutical industry. It has also made the country develop a well organized and widespread health care system, which is well-known internationally.

Cuba has a GDP (Gross Domestic Product) of approximately 6000 USD per capita, which is almost ten times less than Sweden (Globalis, 2014). The country has, although their third world economic status, a health care comparable with the western world (Offredy, 2008). The Cuban health care system consists of consultorios, policlinics and hospitals. The country has 14 provinces and in each province there are 169 municipalities, which each has approximately six policlinics. Adjacent to the policlinics are the consultorios; these are the cores of the primary care. The doctors and nurses live in the same area as the consultorios, and sometimes even in the same facility as the clinic, and they work together as a team. Their main job is health- prevention, promotion, home-based care and rehabilitation. The doctors and nurses has usually lived and worked in their neighborhood for a long period of time and it's not unusual that they get to know their patients well (Globalis, 2014).

Life expectancy in Cuba is 76 years for males and 81 years for women, the equivalent numbers in Sweden are 80 years for men and 84 for women (World Health Organization {WHO}, 2014). The most common death causes in Cuba are non-communicable diseases with 82%, compared to death caused but communicable diseases that are 7%. The most common causes of deaths are cardio-vascular diseases (39%) and cancer (29%). In Cuba they have almost eradicated communicable diseases with vaccination programs, but it is also due to the fact that the immigration is almost 0%, which prevents diseases to spread as widely as to other countries. Compared to regions nearby that has a higher level of poverty and immigration, the comparable figures show that the communicable diseases are much more common. The national system in Cuba has a strategy or action plan, together with the primary

care, to reduce both the burden of tobacco use and injurious alcohol consumption (Wiley, 2012). They also have a policy that the health care should work to promote physical activity.

The Ministry of Public Health's National Nursing Division coordinates the nurses that work out of the consultorios (Gorry, 2013). They set up the framework and the protocols that determine what the nurses should achieve and how to do it. The work includes administration of vaccinations, health promotion, preventive educational talks, finding risk factors and support psychosocial problems. The Cuban nurses work out of a bio-psychosocial approach to health and well-being, which is an approach where it is not just lack of sickness but even your psychosocial status, which determines quality of life.

### **2.3 Professional nursing and patient- and family-centered care**

The International Council of Nurses (ICN, 2012) has put together a guideline of ethical codes and principals that is supposed to serve as standard for nurses working worldwide. The principals suggest that nurses should work according to the aim of doing no harm, doing good and advocate justice. Another important ethical consideration, that is included in the ethical code, is to respect every person's autonomy and provide support to both patients and families. The focus of professional nursing has for a long time been on activating patients and family members in the health care provided (Pelletier & Stichler, 2014). This approach is called patient and family-centered care. There has been an interest from both governments and professional providers in United States to increase the engagement of patients and family members in belief that this improves the quality of the care. Pelletier and Stichler (2014) presents different approaches from different agencies and organizations. Some examples of how to include patients and family members are to educate nurses into being more particular when informing about the care and how they can help to improve health and quality of life. Another approach is to educate the patients and the family members to be inquisitive to the health care provided which would make them attain more influence on the decisions and treatment options proposed. Another study describes some necessary conditions that must be taken into consideration to make family-centered care possible (Mastro, Flynn & Preuster, 2014). It emphasizes that nurses need to create a caring and trusting relationship that eliminates power differences between the professionals and the family members or patient. This will thus create an equal relationship that will encourage empowerment, shared decision-making and increase patient and family engagement.

Patient- and family-centered care has shown increased patient satisfaction and patient safety in many areas of health care (Ahmann & Dokken, 2012). In a study by Brooke-Nolen & Warren (2014) the importance of nurses having knowledge on giving family members enough support in intensive care units (ICU) were investigated. The authors explain the importance of nurses being able to recognize the need for physiological support, both for the families who are having a sick family member but also the patients, to increase the healing process and well-being of everyone included. This study was made in an ICU; however, one can consider this knowledge to be applicable to nursing in all types of care units. Panicker (2013) found that parents with sick children, valued the nurses abilities in relational communication more than technical skills. To be met with compassion and respect and to be included in the care was highlighted as an important part to feel empowered as a family member. The study suggests furthermore that an environment based on support, mutual trust and shared decision-making will lead to a better well-being in the family.

#### **2.4 The problem statement**

Since Havana has an extensive work closely with their patients through consultorios, there could be of great value to enlighten this area of knowledge in hope of helping to improve patient safety and satisfaction both in the actual location but also in our own country. The nurses at consultorios work with home-based care, which unavoidably means meeting family members daily. Since the focus on nursing has been on activating family members in the care (Pelletier and Stichler, 2014), this study might enlighten a new way of approaching family members in the health care provided in other countries. As to my knowledge no studies about nursing through consultorios have been performed in Cuba. Therefore there is a need for a study that compiles information and explores nurses' experiences of involving family members in the home-based care provided through consultorios.

### **3 Aim**

The aim of this study was to describe nurses' experiences of involving family members in home-based care provided through consultorios in Havana, Cuba.

## 4 Theoretical framework

To clarify what family-centered care means when it is mentioned in this study, the concept of *family-centered care* as described by Benzein, Hagberg and Saveman (2012a) will serve as theoretical framework. This concept emerged in Sweden in the early 1990s at Linnéuniversitetet in Kalmar after visiting other parts of the world where this concept already was established. The theoretical framework of family-centered care is based on a systemic orientation (Benzein et al., 2012b). This orientation is an approach that argue that all contexts, interactions and relationships a person belongs to, affects the whole of how we live our lives and how we perceive reality. The authors describe the concept of family-centered care as a theory with the perception that the patient and the family members should be seen in a perspective where all parts of their living context should be taken into consideration. They explain it as if one person in the family gets sick or are in need of health care, it does not only affect the patient but the family as a whole.

In this theory, the authors explain the concept of family as a self-defined group of persons that together creates the family (Benzein et al., 2012b, 2012c). It could be persons related by blood or legal bounds, or a person that is not related at all but still to be seen as essential in their life. The important part is that it is the family itself who states who is a part of it. This theory makes it possible to distinct one important issue: if a member of the family for example has been abusive, it can be excluded from the group. This also makes it possible for close friends to be seen as a part of a family. The authors advocate that the concept of family-centered care should be used in nursing both to gain better knowledge about the patient, but also to prevent family members from unnecessary suffering (Benzein et al., 2012b, 2012d). To invest time in creating a good relationship with the family members also creates an opportunity to obtain useful information about the patient, but it is also valuable to create a relationship of trust between the family members and nurses, which can lead to an improved and more secure health care. The authors emphasize that family-centered care is necessary also to be able to gain knowledge about possible dysfunctions in a family. This is crucial to facilitate in creating a safe and healing environment for the patient and to help the family as a whole (Benzein et al., 2012b, 2012d).

The concept of involving family members in health care is emerging more frequently (Benzein et al., 2012b, 2012d). One of the dangers with making family members participate a lot is that they sometimes are used as a source to unburden the nurses in their work. The concept of family-centered care is trying to define how to include family members in the

health care to ease the burden of having a sick family member, and highlights that it is of great importance that they should not be seen as assets to economical benefits for the health provider, but as a part of the patients' well-being. It is important that as nurse be aware of that, having a sick family member can be a great burden and that not everyone is able to take part in the health care without getting enough psychological support (Benzein et al., 2012b, 2012d).

Family-centered care can be related to the concept of caring as described in nursing science. Hence, the concept of caring will pervade this study.

## **5. Method**

### **5.1 Design**

The aim of this study was approached with a qualitative method with qualitative content analysis. This method was chosen since the intention was to extract themes with meaning units and subjective experiences with considerations of each participator's diverse contexts and consequences of different experiences they have encountered in their work (Graneheim & Lundman, 2003).

### **5.2 Participants**

The inclusion criteria for participating were to be a registered nurse that had worked, or was currently working, at a consultorio that provided home-based care in Havana. Consultorios was chosen over other health care-institutions, since the health care provided out of this particular establishment involves a great deal of contact with the families of the patients.

The recruiting was proceeded by snowball sampling (Kristensson, 2014). The nurses were recruited by a local mentor which the author had established contact with prior to the arrival in Havana, Cuba. A first nurse was recruited and she in her turn asked other nurses if they would consider participating. All of the recruited nurses was handed an information sheet with more detailed information of the study when asked upon (see Appendix 1 & 2). The participants where also, prior to the date of the interview, given oral information of the timeframe of the interview and it was also assured that the participants were aware of that the conversation would be recorded and that their involvement was voluntary and confidential (Kristensson, 2014).

Five nurses participated in the study and all participants were female. The age of the participants varied between 30 to 49 years old with an average age of 37.5. They had worked between eight to 22 years as a nurse, with the median of 14 years in the profession.

### **5.3 Data collection**

The study was based on an interview guide with semi-structured questions (see Appendix 3), this to enable the nurses to speak about their subjective experiences on the topic that was relevant for the aim of the study (Kristensson, 2014).

Open questions were asked and opportunity for reflection was given the participant with guidance by the interviewer. The interview guide sustained of two scientific aims regarding nursing. It contained the aim that was constructed for this study and another aim that was used in a second study written by two other authors from Sweden. Five individual interviews were recorded and they were each approximately 30-40 minutes long.

To ensure a situation where the participants could be comfortable, emphasis was put on that the nurses got to choose the location of the interview to enable a safe environment (Kristensson, 2014). For example one was held at a consultorio during work hours and another at one of the nurses' apartment. All of the interviews were held in a place where privacy was allowed. The first four interviews were conducted in Spanish with help of an interpreter that translated into Swedish, and the fifth was held in Swedish with a Cuban-Swedish nurse. Present during the first four interviews was the participant, the interpreter, one of the authors from the second study and the author of this study. During the fifth interview the individuals present was only the participant, one of the authors from the second study and this study's author.

To ensure a strong interview guide and to practice the authors experience on taking the role as interviewer, the first interview served as a pilot-interview and was transcribed and analyzed before continuing with the following four interviews (Kristensson, 2014). The first interview guide was modified and one question was excluded.

### **5.4 Data analysis**

The interviews were transcribed and analyzed with a qualitative content analysis as described by Graneheim & Lundman (2003). The recordings were transcribed into Swedish, word by word, including pauses, laugh and other emotional aspects that were recorded during the interview (Kristensson, 2014). The transcriptions were encoded with numbers where the

nurses were labeled with numbers 1-5 to ensure anonymity. In the presentation of the results, the nurses are referred to these numbers to ensure anonymity of the participants. The recorded data was deleted as soon as it had been transcribed.

First step of the analysis was to emerge units of meaning from the transcriptions that related to the aim of the study (Graneheim & Lundman, 2003). These units of meaning would later on be condensed and coded. The codes were later abstracted into main themes and sub-themes that described the topic of the study (see Appendix 4), this to be able to compile the interviews to find similarities and differences and then used to simplify the description of the phenomenon. The result in this study is based solely on data gathered from the interview guide mentioned in this study (see Appendix 3). Thus, none of the information regarding the second study, written by two other authors, were included in the results in this study.

## **6 Ethical considerations**

The participant's anonymity was maintained and confidentiality was assured (Kristensson, 2014). The participants were informed that they were voluntarily participating in the interviews, knowing that they could withdraw their involvement at any time. The importance of informing the participants that participation was entirely voluntary was highlighted while directing the local mentor before the recruitment began. To ensure that the information had been obtained, there was both an oral and written consent conducted in the beginning of every interview (see Appendix 1 & 2) (Kristensson, 2014). The author also took into consideration that the participants could hold back on account of the political situation in the country where there could be a danger for them to question their health care system and the way they work. The study was approved by the Research Ethical Committee at Department of Health care Sciences, Ersta Sköndal University College in Stockholm, Sweden 2015 (Dnr 1503/B).

## **7 Results**

Through the analyses of this study, two main-themes occurred, the first main-theme has two sub-themes and the second has three (see Table 1). These two main-themes with their sub-themes will be presented in parallel with information and examples on the basis of the recorded interviews, and they will also be enhanced with relevant quotes.

Table 1. Including main-themes and sub-themes as presented in the result

Main-themes	Sub-themes
The significance of family members in home-based care	<ul style="list-style-type: none"> <li>• Family members as informants to the nurses and psychological support to the patients</li> <li>• Cuban family members as an asset in home-based care</li> </ul>
The significance of the nurse's involvement of family members in home-based care	<ul style="list-style-type: none"> <li>• The nurses' function in home-based care: how to see the whole picture</li> <li>• The nurse as an educator of family members</li> <li>• The nurse as psychological support to family members</li> </ul>

## 7.1 The significance of family members in home-based care

In this theme, two sub-themes emerged: *Family members as informants to the nurses and psychological support to the patients* and *The Cuban family members as an asset in home-based care*. They are both describing the family member's role in nursing in home-based care and the nurses' experience of the importance of this involvement relation to their work. The second sub-theme also includes a cultural aspect of the family member's role in home-based care. Each sub-theme will be reviewed separately in the following paragraphs.

### 7.1.1 *Family members as informants to the nurses and psychological support to the patients*

This sub-theme describes nurses' experiences of the positive facts on family members serving as a source to information regarding their patients. They described experiences of having family members and neighbors around them as a valuable asset to gain more knowledge about the state of the patient and its surroundings. In this sub-theme it also appeared that the family members served as a great psychological support for the patients. They described that they often came with the patient to visit the consultorio and also that they usually knows a lot about their family members health and psychological well-being. One nurse said: "If you for example have a patient with asthma the family is a great support who helps the patient and helps us with information, they give a lot of psychological support" (3).

Most of the nurses described that they often gained more information when talking with the family members than if they would only have the patient itself as informant. They would tell the nurses about how they managed the medication and how the state of the patient's well-being improved or declined. The nurses explained that the families members also support the

patients psychologically by being close to them and often serve as company during home-based visits as well as during appointments to the consultorios. Some nurses further explained that the family members had an advantage in getting information about the patient since they live together and see them all the time. They often use the family members as a source to information and to obtain knowledge about their patient by talking to them. One nurse expressed it like the following quote:

*Yes sometimes you have the family to give you information... if I for example have a patient who won't take their pills the family members tells me... they see more than we do and helps us that way... we talk a lot with them...(3)*

One of the nurses explained that just by walking in the streets, she could gather information about the patient, which resulted in the benefit of not needing to go visit the patient.

All this was expressed as to be an asset to ease the workload to the nurses. Since they often got information from the surrounding environment, both family members and neighbors, the nurses expressed it as they were easily, and often accurately, informed if anyone was in need of extra assistance or if something new had occurred recently.

### **7.1.2 The cuban family members as an asset in home-based care**

Throughout most of the interviews the nurses expressed that family members were a great support in their work and that the home-based care were a significant part to enable the nurses to provide accurate care to their patients. They expressed that the co-operation with the family members usually was good and that they often were there to contribute to prevent further complications in the patients' situation. When explaining to family members what they could do to help, the nurses all expressed that they often listened cautiously and took their advice with sincerity. One verbalized it like below:

*Yes, most of the families helps out in taking care of the patients that we have... they are often very good at helping out in our work. When you explain how they can do they listen carefully and they really do as we tell them. The home-based care is very important part in this, to do follow-ups on the patients (2)*

It was further explained that including family members in the care is of great importance to ensure that they know what they can do and why they need to do it. The nurses expressed that most of the family members are very willing to be engaged in the care of the patient and that

they usually make their work easier by supporting them in basic treatments and handlings. The nurse that had worked at a consultorio previously explained: "They help out to do some things that aren't too difficult... for example we teach them how to give injections with insulin and when to do it, how you check the glucose-levels in the blood." (5).

One nurse explained that the family members' willingness to help simplified their work since they had a lot of other administrative work to do at the consultorio. Another nurse expressed that the patients that doesn't have the benefit of family members to help you at home, have a greater risk of getting worse and to develop further complicated states. She explained that a lot of diseases and complications could be prevented with accurate support, and that is why the family members' are such a good asset in the home-based care since they help to work preventative.

Another matter that was brought up by one nurse was that when delivering bad news to the patient, nurses informed the family members first. This to ensure that the patient has enough support while receiving new sensitive information about their health, where one nurse expressed it like this:

*It's common that when you are about to leave difficult news you talk to the family members first... you meet with them to tell them what has happened with the patient and then you gather everyone to go in together to talk to the patient... it's because it should get enough support while receiving difficult news. Because you can't know how they'll take it or how they will react, so it's better to talk to the family members first to have kind of like a preparation before you tell them something heavy. So that support already exists... (5)*

The nurses described that family members serve as an important asset in unloading the nurses' work in these situations. They assist by ensuring that the patient had enough psychological support nearby and that they in that way could be prepared in unpredicted and strong reactions. Two of the nurses further emphasized the experience of how the Cuban culture automatically involves family members in the nursing provided through the home-based care. They expressed that it is in the Cubans nature to be a part of the nursing of their families and one of the nurses explained it like this:

*... It is very natural that the family helps. It is just how it is. Here in Cuba it's perfectly natural that you help each other... especially a lot psychologically. The family is always there if you are sick, everybody, and the neighbors too... (3)*

The nurses further explained that they get educated in how to involve family members in home-based care, but that it is usually not necessary because it is in the Cubans culture to

assist the nurses and the patients. One of the nurses expressed that the family members strive to be involved in the care, since being an active part in taking care of your family members is a great pride in Cuba.

## **7.2 The significance of the nurse's involvement of family members in home-based care**

This theme consists of three sub-themes: *The nurse's function in home-based care: how to see the whole picture*, *The nurse as an educator of family members* and *The nurse as psychological support to family members*. Together they describe the nurses' experiences of how they enable involvement of family members in the home-based care provided through consultorios. The themes consist of the nurses' articulated knowledge of how they co-operate with other professionals, how the nurse should think to enable involvement of family members and how they educate family members and why.

### *7.2.1 The nurse's function in home-based care: how to see the whole picture*

This theme contains the nurses' experiences of how they work with home-based care according to a perspective where they strive to see more than just the patients' disease or physical problems, but to include their living situation and whole context of existence. The sub-theme also sustains of nurses' portrays of how they work together with other professionals.

Throughout all of the interviews the nurses explained the importance of getting to know the whole family and the whole situation in the households visited, to enable provision of an efficient health care. One of the nurses said:

*When they don't come to the consultorio you have to go visit them at home... then you do an analysis of how the family situation is in the home... if someone smokes inside or if someone is an alcoholic... if there are newborns or under aged... if there's disoriented people or yeah kind of like that, what it looks like in their home... an analysis of the family situation... people live together here in a different way... that is the biggest different... you have to take into consideration when you form a national health-program that people here live together, often very many maybe ten persons fifteen persons in an apartment, a lot of different... everyone have their different problems... a lot of things that you have to take into consideration... it can be difficult sometimes... (4)*

Even though some of the nurses thought that to take in a whole family and keep track of many situations sometimes could be contributing to a heavy workload, the majority of the nurses

expressed the work close to the families and the people as a positive factor. They described that to enable a health care that can provide what is required, a close relationship and a broad perspective is desirable. One of the nurses articulated it like this:

*The most important to me, and what makes consultorio better than any other health care is that you get to know your people better, you know more about the, you meet a lot of different groups for example kids, pregnant women, elderly... it is not just kids if you are in pediatrics... it is a huge advantage to get to be close to ones people... (1)*

It was expressed that the work close to the families and in the homes created a special relationship that made you, as a nurse, closer to your patients. The nurses explained through most of the interviews that they usually met with the patient's family members and talked about the situation at home, how they felt and about the patient's well-being.

The co-operation between professionals was described by all the nurses, and was considered as a valuable asset in the home-based health care. Most of the nurses explained that they had experience of including social workers to families in need of extra support and that this was a good asset to ensure a better situation for the whole family, and one of them said:

*For example there can be an old person that is in need of help, that's when you contact the social workers and you can get a permit that says that you don't have to work and that you instead can stay at home to take care of your family member... (1)*

The nurses further expressed that they often contacted psychologists, therapists or social workers if needed, and since they work closely with the doctor they could easily get them to make an extra visit if desired.

### **7.2.2 The nurse as an educator of family members**

This sub-theme reviews the nurses' experiences of educating family members in the nursing in home-based care. Several of the nurses expressed how they enabled the family members to be contributing to the patients' well-being and how they could use the family members as an asset in the nursing, and one explained: "depending on what disease it is that the patient have, we teach the family members and educate them in how they should do" (1). The involvement and education of family members was experienced as a common way of working in the home-based care. Throughout all the interviews the nurses explained in different ways how they

educated the family members in giving injections, helping with physical therapy or taking vital controls.

One of the nurses explained that they teach the family members about basic preventative nursing that they can accomplish to enable an improved environment for the patient:

*We also teach the families about hygiene, that they have to wash their hands before eating, about how they do with the insulin, and if the patient is lying down in the bed a lot we'll teach them how to turn them in the bed and also a lot about diets... (1)*

### **7.2.3 The nurse as psychological support to family members**

This sub-theme is illuminating the nurses' experiences of being a psychological support to the family members of the patients. Most of the nurses expressed that working with home-based care helps to create a relation to the families, which enables a more informal way of supporting them when needed. One nurse said:

*It is also usual that family members come in to talk. They are often worried about how the situation with the patient is and what is happening with it... then you try to explain and ease and explain as much as you can. That's when I think it is very good that you have a personal relationship... that you know each other. Because then you understand more about how it is in that particular family (5)*

It was further explained in several of the interviews, that family members often needed psychological support and that the nurses usually had the opportunity to talk to them when they needed to, since they worked in the same area as their patients and also since they visit them in their homes. It was expressed by some of the nurses, that the possibility to spontaneously get in contact with the nurses often relieved stress of the family members and that it was seen as a strength of the home-based care.

One of the nurses expressed that the fact that they work in the same area as their patients and the families, makes their support more efficient. She explained further that the nurses' work provided out of consultorios incorporates more psychological support than in other health care services:

*... I'm also educated in therapy and I am qualified to work in a hospital... but I work here because I like it so much... there is a greater need for psychological support and therapy here than what it is in hospitals (3)*

## 8 Discussion

The aim of this study was to explain nurses' experiences of involving family members in home-based care provided out of consultorios in Havana, Cuba. The section that follows is a discussion of the choice of method and the results presented above in correlation with the theoretical framework presented earlier in the study.

### 8.1 Methodological considerations

My first meeting with the participating nurses was at the time of the interviews. The first contact they had had with this study, was through my local mentor who recruited the nurses. The contact with this local mentor was established while in Sweden, and the recruitment criteria and information about the study was sent to him to ensure that the respondents would be aware of the purpose of the study and that the conditions of the participation was communicated properly. The recruiting was proceeded by snowball-sampling, which means that one nurse was asked to participate and she asked her colleagues if they would like to participate and they in their turn, asked their colleagues. The risk with this way of recruiting is that the possibility that the information about the study and the participation not would be given correctly, and it could have been wise to have the author present in the recruitment process (Kristensson, 2014). To eliminate this risk, the author ensured that the information regarding the conditions for participation had been communicated and understood correctly at the first meeting with the informants, with both oral information and written consent. This method of recruiting was also chosen as an appropriate and effective approach, considering the conditions that prevailed for this study. Since it was difficult to gather nurses to participate without having a direct contact with the health care facilities in the city of Havana, and also with the limited timeframe and restricted possibilities of communication that Cuba suffers from. There was a sufficient mixture of age and years of experience of the participating nurses, which gives a broad and diverse perspective on how the Cuban nurses perceive their way of working and is therefore considered as a strength in this study.

The number of participating nurses was chosen in relation to the timeframe of the work and also according to the aim of the study. Kristensson (2014) states that it is almost impossible to beforehand state which number of participants you need to conduct enough information for a qualitative study. It depends on how well the participators express themselves and what you can gather from each interview. The use of a minimum of four participants was decided as satisfactory in relation to the relevance and size of this study. Five

participants were eventually chosen to be included in the results. This was considered enough, since they spoke freely and provided the author with enough relevant information. Another factor contributing to the decision that five interviews were enough was that the participants described the same phenomenon but in different ways, and that more interviews would most certainly only confirm the facts that was already conducted. Despite the fact that a larger amount of participants almost always would contribute to a stronger analysis, it was considered enough as bearing for this particular study.

The interview guide comprised of two scientific aims regarding nursing, to conduct information for two different studies. This was carefully considered and discussed before deciding, since it may have impact on the results and not give accurate answers concerning each topic (Kristensson, 2014). One can assume that it might not let the participant focus enough on the aim for this study and that a deeper understanding might not be reached. However, the authors from both studies agreed on using the same participants and the same interviews since there was a difficulty in finding nurses to participate in the study. And since the aims were closely related to each other it was considered as a possible way of working, this would later appear to be a strength to this study since the different aims opened up for a broader perspective in the answers. Both aims were explained beforehand and the interview-guide was modified to work for both studies. A pilot-interview ensured that the questions in the guide would serve its purpose and conduct information for both aims in the different studies. A pilot-interview is a good way of ensuring a well formed guide with relevant questions, and it served its purpose well since it enlightened the need of structure and clarified the importance of how to precise the questions in the coming four interviews (Kristensson, 2014). The fact that the two aims were included in the interview guide even turned out to be profitable for both studies, since they complemented each other in some parts and guided the nurses in advantage to both studies. A limitation recognized during the analysis was that there were no questions asked about nurses' experience on how involving family members could have impact on the families' well-being. This would on the other hand be more relevant in a second study.

The interviews were conducted in Spanish with an interpreter translating into Swedish. This made the nurses able to speak freely and to use their own words. Even though Kristensson (2014) argue that it might be distracting having an interpreter present, the author decided to choose to let the nurses speak in their mother tongue instead of finding nurses who spoke English. This since it is not very common that Cubans are fluent in English, but also concerning the risk that it might make their statements less accurate and prevent them from

speaking freely. During the transcriptions, focus was on the interpreter's translation, but since the author has basic knowledge in Spanish, it ensured and enabled a more thoroughly understanding of that what was said in the interviews actually got translated and included into the results. Graneheim and Lundman (2003) enlighten the fact that a lot of the communication during interviews is non-verbal, such as laughs, pauses and posture. But since there was an interpreter translating, there is a limitation in the results since the non-verbal communication might not have been completely accurate.

The interviews were constructed with open questions to enable the participants to express their subjective experiences on the topics (Kristensson, 2014). This served its purpose well and made the participants able to speak freely and without too much guiding. Since there was no opportunity to meet with the participants in beforehand, there was no possibility to get to know each other beforehand. It could have been fruitful to set up a first meeting to be able to create a relationship before conducting interviews, and this might be considered a weakness in this study.

The analysis was completed out of Graneheim and Lundman's (2003) qualitative content analysis method. A table attached as an appendix (see Appendix 4) was made to make the analyzing process clear for the reader. The coding of the data helped to make the sorting of the results into themes and subthemes easier for the author and was considered a strong tool in the analyzing process. To let participants recognize the findings is a good way of gaining trustworthiness (Graneheim & Lundman, 2003). All participants were offered to take part of the results during the writing process, but no-one was interested in doing so before the whole study was completed. With that in consideration, the participants got information about how to find the study electronically and how they could contact the author if they had any questions.

It is also important that the author of a qualitative study is aware of the preconceptions that might exist (Graneheim & Lundman, 2003). The author therefore went back to the raw data several times to ensure that the analysis was accurate and that existing preconceptions did not influence the reflection on the transcribed data.

## **8.2 Discussion of results**

The results in this study show that nurses working out of Consultorios in Havana, co-operates and involves family members a lot in the care they provide. The nurses participating in this study described that the family members serve as a valuable asset in getting information

regarding their patients and that the fact that they work close to the families was a positive factor in their job. The nurses expressed that when they spoke to family members, their experiences were that you often gained information about the patient that the patient itself would not tell them. Benzein et al., (2012d) mean that the conflict regarding involving family members is that it is of great value to be able to get to know more about the patient with help from the family members. They also emphasize that it might be considered a danger since it creates a risk in forgetting that the patient is, and should always be, the main focus and the main source too information about its own state of well-being. None of the nurses articulated any problems with the fact that they used the family members as informants, since they mean that they are the ones closest to the patient and that they of course knows a great deal about the state of the patient. With this knowledge, a need to consider more education about family-centered nursing could be fruitful for Cuban nursing. Most of all to enlighten the fact about the disadvantages and weaknesses that can occur when too much focus is put on involving and using family members.

The nurses in the study also emphasized the fact that the family members often serve as a great psychological support to the patients and the results also showed that the nurses see themselves as a valuable psychological support to the family members. Most of the nurses expressed closeness and familiarity to the family members and patients as a strength, as it made it easier for them to provide psychological support and to get closer to them privately. To create such a private relationship was a natural part of their work and something they saw as a natural part of being a nurse. In a study by Brooke-Nolen & Warren (2014) it was investigated how family members often are in need for psychological support while facing disease in the family. They emphasize that it is not only the patient that is in need for support but the nurses also need to take the family members well-being in consideration. If a nurse can recognize the need for psychological support to not only the patient but also the family members, the authors of the study mean that the healing-process and well-being will increase with quite small means. Bhalla, Suri, Kaur, & Kaur (2014) examined the family members needs while taking care of relatives in an acute setting. This showed that the need for emotional support, well communicated information and a caring attitude from the health care staff was important to feel safe and comfortable. This might be considered to also be applicable in a home-based care environment since the relatives often are present there.

The fact that nurses in Havana instinctively serve as a psychological support to family members is an interesting fact. As described earlier, they explained it as a natural part of being a nurse since they know all the patients and the family members on a more private

platform. The psychological support occurs natural to them more so than to nurses in, for example, Sweden where the relationship towards patients and their family members are based on a much more professional level (Dahlberg & Segesten, 2010). One can presume that a more private relationship between nurse, patient and family members can become a danger to the nurse. Benzein et al. (2012d) emphasizes the importance of creating a trusting relationship and they further believes that it is important that the nurse dares to get close to the family and be authentic in the meeting. This, they argue, requires self-awareness and self-reflection in order to behave professionally, since the risk of getting psychologically drained and emotionally vulnerable increases the closer you get to the family. Despite these presumptions and reports, none of the participating nurses mentioned this as a problem.

Almost all nurses described that involving family members is a natural part of their work in Cuba and that the families often considered it as an assumed way of how nursing is provided. It was explained as a part of the Cuban culture and they didn't seem to reflect too much on the dangers of putting too much weight on the family members and to use them too much as assets in the care. The nurses described that they often taught the family members how to perform different standard procedures and nursing measures. According to Benzein et al., (2012b, 2012d) there is a common problem among nurses and health care staff that they take for granted that family members should serve as an assistant in the nursing. They argue that putting too much pressure and burden on a family member ultimately can result in negative impacts such as stress, lack of sleep, depression, anxiety and exhaustion. However, they also emphasizes that being a part of taking care of your own family members is a source to contentment and joy. They mean that there is of great importance that the nurse makes a conscious estimation, in each specific situation, about how much the family members should be involved in the care of their patients and where the nurse needs to step in more. They also emphasize that it is crucial that a family member or relative never are to be seen as a source of financial savings and cost effectiveness. This is also reviewed in a study by da Costa Melo, dos Santos Rua, and de Brito Santos (2014) where they emphasize the importance of nurses being close to the family members and serving as a support to the whole family. They further discuss the problem with nurses having trouble distributing their work and that this might end up with putting too much pressure on the family member. They mean that it is of great importance that the nurse is well educated in how to encounter every different situation and be able to adapt the care along existing conditions. The problem I discovered with the Cuban nurses' experiences, is that they see the family members as an expected resource and asset in the care for their patients. If one starts from a notion that it is assumed as natural that family

members should be involved in the care, you might put a burden on a person that is not ready to commit to what is expected of them.

Another aspect the nurses enlightened is that working close to the family members was perceived a good way of working preventative. Since the family members usually informed the nurse when sudden changes in the patients' well-being occurred, the right treatment could be provided faster. This way of working has previously been studied and several scientific reports and in literature (i.e. Ahmann & Dokken, 2012; Pelletier and Stichler, 2014; Benzein et al., 2012d) explain that involving family members increases patient safety and satisfaction. On the other hand, relying too much on the family members in the home-based care could jeopardize patient safety as they may not have sufficient medical knowledge and the risk that something could be missed increases. This could also contribute in putting too much pressure on the family member and one can assume that their well-being then would be put aside. Da Costa Melo et al. (2014) found that family members that were provided with adequate knowledge, adapted to allow an effective understanding, gained an increased self-esteem and a strengthened personal identity. The earlier presented studies (Ahmann & Dokken, 2012; Pelletier & Stichler, 2014) were focused on other health care settings. Therefore one can argue that the fact that patient safety and satisfaction increases with family participation in those settings, can stand as even stronger argument to prioritize education for nurses in how to involve and educate family members in the home-based health care. The argument is even clearer while examining the results from the study by da Costa Melo et al., (2014) since educating nurses was shown to contribute to a better well-being of the family members involved. This knowledge might contribute even more to a further developed pedagogy and also to strengthen nurses' knowledge on *how* they can educate family members in the most efficient way in the home-based health care.

The results of this study show a generally positive attitude towards family members' participation in the care. The nurses barely mentioned anything negative with the care they provided. From the perspective of that Cuba is a politically oppressed country, one can discuss whether the results are entirely credible. It is questionable whether the nurses actually mean what they say, or if they have been taught how they should present their work and how they feel strained to talk about the systems of Cuba's with a positive attitude, not to be put at risk in any way.

One can further assume that the results from this study not entirely are applicable to Sweden and the health care system that is established here. The nurses in this study expressed that the geographical aspect of being close to their patients and their family members,

increased prospects for getting to know both parts well and made it possible to gain an additional overview of their situation in life. This might question the opportunities to be able to implement family participation the same way in Sweden. Especially if you look at the bigger cities, where acute care hospitals and larger primary care centers dominate the health care and establishments like Consultorios are not yet established. In Stockholm, healthcare is organized differently compared to Havana, since a nurse rarely knows their patients and their family members personally in the same way as the consultorio nurses.

## **9 Clinical implications**

The results of this study reveals possibilities to learn from another country and another culture in developing health care systems in other parts of the world. The cultural aspect, which constitutes the main differences in how the Cuban nurses treat family members in comparison with nurses in Sweden, can be useful to implement new ways of working in the Swedish health care. The Cuban nurses see the involvement of family members as a great asset to get closer to the families and to unburden their workload while it also prevails a more effective care and deeper knowledge about the patient. The downside with their way of nursing can be the heavy workload that might burden the family members. But with that in mind, the results of this study can be used as guideline to learn more about how to involve family members by creating a more private relationship in the health care provided in other contexts and cultures.

## **10 Further research**

Since this study only focused on the nurses' perspective on how to involve family members in the care provided in home-based care in Havana, there is a suggestion for further research. The nurses' experiences in this study showed a positive attitude towards involving family members and since reports have shown that it creates more well-being and increases patient safety and satisfaction, the subject is of great importance. Also due to the fact that the involvement of family members and patients has an increasing significant role in the health care, there could be of interest to investigate both the family member's perspective on being involved in the health care, but also the patient's perspective on involving family members in their care.

## **11 Conclusion**

The aim of this study was to investigate nurses' experiences of involving family members in home-based care provided out of consultorios in Havana, Cuba. The results showed both the nurses' perspective on how family members were involved in the care and how the nurses served as a psychological support to them. The results implicated that a big part of the involvement of family members was seen as a positive factor and that the family members was considered an asset in the care. The risk of putting too much pressure on the family members was not articulated as a problem among the nurses.

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## **Appendix 1 – Letter of information: English**

### **Application for participation in study**

This study is aimed at registered nurses and intends to investigate their work. The aim of the study is to describe nurses' experiences of involving family members in home-based care.

With this letter of information, you are asked if you would consider participating in this study.

If you would choose to participate you will be interviewed. The interview will be a normal conversation during about one hour, and it will be recorded with your consent. The interview will then be transcribed to simplify the analysis. There will not be any names or other personal data printed that could reveal the participant.

It will be a nurse student from Sweden, Mira Magnusson that will be interviewing.

The recorded data will be saved at a data memory (USB) and kept under lock. A report will be written and when all the interviews are done the data memory will be destroyed. The report will be available both on print and electronically via the Ersta Sköndal University's library.

Your participation in this interview is voluntary and you can withdraw your participation at any point without explanation. If you have any questions about the study or the interview, do not hesitate to contact one of the following persons listed below.

If you are interested in participating in this study, please contact Mira Magnusson on the telephone number listed below in order to agree on time and place for the interview.

Number: +5378328587

Research Ethics Committee of the Department of Health Sciences at Ersta Sköndal University College has approved the survey, Stockholm, Sweden 2015, Dnr 1503/B

Agneta Cronqvist, reg. nurse. PhD.

Nr: +468-555 050 23

E-post: agneta.cronqvist@esh.se

Mira Magnusson, Bachelor candidate.

Nr. +46735737535

Epost mira.magnusson@student.esh.se

## **Appendix 2 – Letter of information: Spanish**

### **Solicitud de participación en este estudio para cualquier persona que trabaja como enfermera en La Habana, Cuba**

Este estudio esta dirigido a personal.

Y tiene la intención de investigar la trabajo de las enfermeras. El objetivo del estudio es describir las experiencias de enfermeras incluyendo miembros de la familia en el cuidado de la salud de sus pacientes. Con este formulario se te informa si deseas participar en el estudio.

Si usted desea participar será entrevistado. La entrevista es como una conversación que durara cerca de una hora y seria grabada si usted da su permiso. La entrevista se imprimirá para facilitar el desarrollo del estudio.

No se escribirán nombres o ningún dato personal que revele quien es la persona que esta siendo entrevistada. Es Mira Magnusson la que hará la entrevista. Los datos de la entrevista de la entrevista se guardaran una memoria datos (USB). Los datos obtenidos se guardaran bajo llave. Se escribirá un reporte cuando todos los participantes se hayan entrevistado después se destruirá la USB.

El reporte estará a disposición en formato de papel y de forma electrónica a través de la biblioteca de Ersta Skondal högskola.

La participación en este estudio es voluntaria y cuando así se quiera podrá suspenderla sin dar explicaciones. Si usted tiene preguntas sobre este estudio puede contactar a alguna de las que relacionamos a continuación ee esta pagina.

Estas interesado en participar entonces contáctanos para acordar el día y el lugar de la entrevista en este numero: +5378328587

El comité investigativo de la institución para la ciencia del cuidado del paciente, Universidad de Ersta Skondal, ha aprobado esta investigación. Suecia, Estocolmo, 2015, Dnr 1503/B

Agneta Cronqvist, leg. sjuksköt., fil. dr.

Tel. 08-555 050 23

E-post: agneta.cronqvist@esh.se

Mira Magnusson, fil. kand.

Epost mira.magnusson@student.esh.se

## **Appendix 3 – Interview Guide**

### Introductory questions

1. For how long have you worked at the consultorio that you work on today?
2. For how long have you been a nurse?
3. How old are you?
4. Do you live in the same area as the consultorio?
5. Can you describe a regular day at work, from when you start in the morning until you go home?

### Interview questions

6. Can you describe how you involve family members in the nursing around your patients?
7. Can you describe a special situation you have participated in, when family members have been involved?

### Termination question

8. Is there anything else you would like to add or describe?

## Appendix 4 – Matrix with samples from the table of analysis

Main themes	Sub-themes	Coded units	Condensed units of meaning	Units of meaning
The significance of family members in home-based care	<b><i>Family members as informants to the nurses and psychological support to the patients</i></b>	Family members as informants	The family is a great psychological support and a good source to information about the patient	<i>”If you for example have a patient with asthma the family is a great support who helps the patient and helps us with information, de give a lot of psychological support” (3)</i>
	<b><i>The Cuban family members as a asset in home-based care</i></b>	Family members as an asset	There is a good cooperation with the family and most want to help	<i>”I really think it’s good when you can co-operate with the family. Many families are very engaged about being involved in their family members situation” (2)</i>
The significance of the nurse’s involvement of family members in home-based care	<b><i>The nurses’ function in home-based care: how to see the whole picture</i></b>	A holistic perspective / Co-operation with other professionals	We cooperate with other professionals so they can be sure that the family gets the right help and support	<i>”For example there can be an old person that is in need of help, that’s when you contact the social workers and you can get a permit that says that you don’t have to work and that you instead can stay at home to take care of your family member...” (1)</i>
	<b><i>The nurse as an educator of family members</i></b>	Educating family members	We teach family members how they can manage and control the disease in the home	<i>“Here in Cuba we for example have a lot of diabetes, we teach them how to check the glucose levels in the blood, how to use the needle and to get the blood out to control it in the measure-tool, that is one example of what we do...” (1)</i>
	<b><i>The nurse as psychological support to family members</i></b>	The nurse as psychological support to family members	It is good that you are close to the family members, both geographically and socially since you then can give great support to them too	<i>”Family members often call the consultorio or come to find the nurse there to talk about the patient. It is mostly spontaneous, I think that is good. Because family members can be worried and in need of support to and then it is god that they can stop by to talk...” (5)</i>