

## **Reading between the lines**

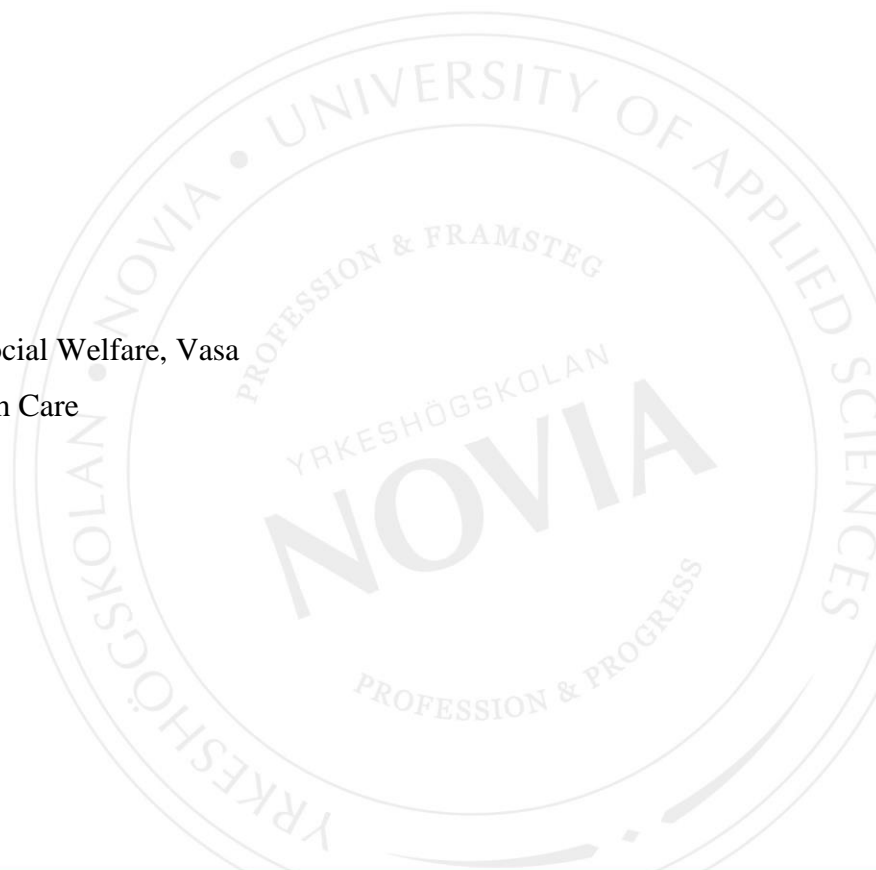
- An interview study on nurses' experiences when caring for patients with developmental disabilities

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## **BACHELOR'S THESIS**

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### **Abstract**

The aim of this study is to identify and describe the challenges nurses experience when caring for patients with developmental disabilities and how these challenges affect the quality of care. The study focuses on nurses' experiences on challenges when caring for patients with developmental disabilities as well as the strategies nurses use to overcome challenges and ensure high quality care to their patients. The background of the study describes previously identified challenges and how they can be coped with. The concepts of "caring" and "uncaring" based on Halldórsdóttir (1996) were used as theoretical framework for the study. These concepts describe how the connection between the nurse and the patient affects the patients' experience of the care encounter as positive or negative, or as "caring" or "uncaring".

The data collection method used in the study was theme interviews. A total of five interviews were used in the study. The interviews were transcribed and analysed using content analysis. Four main themes were identified; nurses' attitudes, challenges in establishing rapport, overcoming challenges and ensuring quality of care. It was found that nurses generally have a positive attitude toward caring for patients with developmental disabilities, that there are challenges in establishing rapport including challenges in communication, understanding, connection and own knowledge. To overcome challenges nurses use various strategies including help from others, most often the patient's caregivers, and by using pictures to aid in communication and understanding. Participants shared some advice on how they ensure quality of care when caring for patients with developmental disabilities, including thinking mentalities and practical arrangements. Additionally, nurses' opinions on what is necessary in order to better be able to meet and care for patients with developmental disabilities was discussed.

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Language: English

Key words: Caring, Uncaring, Challenges, Developmental disabilities

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## 1. Introduction

Developmental disabilities are described by the Centres for Disease Control and Prevention as “a group of conditions due to an impairment in physical, learning, language or behaviour areas”. The conditions begin during the developmental stage and affects the everyday activities of the individual throughout his or her life. These conditions are common and affect all racial, ethnic and socioeconomic groups equally. Some examples of common developmental disabilities include ADHD, Autism Spectrum Disorder, Cerebral Palsy, Hearing loss, intellectual disability, learning disability, vision impairment and other developmental delays. (CDC, 2015)

The cause of developmental disabilities is mostly idiopathic, meaning that it is not known why certain individuals get affected and others do not. It is known that most developmental disabilities begin before birth, such as Down’s syndrome, but they can also begin after birth following an early infection or injury, for example Cerebral Palsy. It is believed that developmental disabilities are caused by a mixture of factors including genetics, health and behaviour of the parents during pregnancy, being born prematurely, or exposure of the mother or baby to environmental toxins. (CDC, 2015)

Individuals that are affected by developmental disabilities get sick the same way as unaffected individuals but may require the nurse to have special knowledge to provide quality care and fulfil the special needs of the patients. Health problems such as asthma, skin conditions, migraine and gastrointestinal problems are more common in individuals with developmental disabilities (CDC, 2015), but these patients can be found in all kinds of wards at the hospitals, which is why all nurses in primary care would need training on how to care for these individuals and what tools can be used to successfully care for special needs patients. Such training is currently not included in the nurse education.

My personal interest in the topic of challenges affecting the care of patients with developmental disabilities started during my first practice period, when I was practicing in a home for young individuals with developmental disabilities, both mental and physical of varying severity. During an evening shift one of the clients living there was getting ill, and had to be sent by an ambulance to the hospital. However, we were understaffed that day so there was no one that could go with her, and she was not able to communicate on her own. The hospital sent her back

the same night with extremely elevated CRP, pneumonia, and they had not even bothered to change her diapers while she was there

Although challenges occur when caring for special needs patients, these should be overlooked, and nurses should have guidelines on how to provide equally good care to developmentally disabled as they do to unaffected patients.

## **2. Aim and Problem Definition**

The aim of this study is to identify and describe the challenges nurses working in somatic care settings experience when caring for patients with developmental disabilities and how these challenges affect the quality of care. The assumption is that there are certain factors that influence the quality of care provided. The study will also bring up strategies that can be applied in dealing with the challenges that arise, and in turn improve the care quality.

The following questions will be answered:

1. What challenges do nurses experience when caring for patients with developmental disabilities?
2. How do these challenges affect the quality of care provided?
3. What strategies can be used to improve the quality of care?

## **3. Background**

The term developmental disabilities refer in this study to chronic conditions that the individual is born with, that affects his or her mental and physical development. Developmental disabilities such as ADHD, Autism spectrum disorder, Cerebral Palsy, hearing loss, intellectual disability, learning disability, vision impairments and other developmental delays cause difficulties in providing care of good quality to the individuals during states of illnesses, as it may be difficult to communicate and establish rapport and caring nurse-patient relationships with them. Learning disabilities such as dyslexia are not considered in this study.

Oehrtman and Lessick (2014) conclude that as the life expectancy of individuals with different forms of developmental disorders has increased, these individuals will be found in all types of

wards, for all types of treatments, not just in the paediatric unit as before. According to the researchers the prevalence of DD's has increased and continues to increase, which is why nurses need education and training in special need caring. (Oehrtman & Lessick, 2014)

### **3.1. Nursing Challenges**

Sowney and Barr (2006) conducted a study with the aim to explore the experiences of nurses in accident and emergency units caring for people with intellectual disabilities. The study was conducted in Northern Ireland and consisted of 27 nurses from 5 different hospitals divided into 5 focus groups. The participating nurses were interviewed and after analysing the interviews the researchers identified six challenging themes in caring for intellectually disabled patients: existing good practice, respect of individuals, communication difficulties, difficulties gaining consent, lack of knowledge and dependence on carers. (Sowney and Barr, 2006)

Goshman & Nikoloff, created a practical experience in order for nursing students to gain insight and experience into caring for developmentally disabled children. The students were assigned a DD child, and they got an overview about the child and previous history. The students were then supposed to make a treatment goal for the child, and work towards it through regular meetings. At first the students felt uncomfortable due to difficulty establishing rapport. In the end the experience proved beneficial for both parents of the children and for the students: the parents felt satisfied for helping in training, and hope that the future professionals would have a greater understanding and sensitivity to DD children. The students benefit later in their work life, as they had gained experience and learned that these patients were "children first and handicapped second". (Goshman & Nikoloff, 1984)

Davies (2008) explored some of the difficulties faced by nurses providing health care to older patients with learning disabilities. By comparing previous studies Davies identifies "recognising illnesses" and "communication" as challenges for nurses caring for adults with learning disabilities. Recognising illnesses is difficult because patients with learning disabilities may express atypical symptoms, such as shouting, which may be misinterpreted and dismissed as a bad habit by inexperienced nurses. Communication is a challenge in nursing for adults with learning disability as the patient may not be able to express themselves verbally, making it difficult for the nurse to help them. Another barrier in communication is that the patient may

not be able to understand the healthcare procedures which can cause distress and un-cooperative behaviour making necessary procedures more difficult or impossible to carry on with. (Davies, 2008)

In 2009, Hemsley, Balandin and Worrall conducted a study with the aim to investigate nurses' expressed concepts of 'time' in stories about communicating with patients with developmental disability and complex communication needs in hospital. The researchers used purposive sampling and interviewed 15 nurses from 6 different kinds of wards about barriers to and strategies for successful communication when caring for patients with developmental disabilities and complex communication needs in hospital. The participating nurses identified time as both a barrier and a facilitator to successful communication. Time as a barrier was explained by nurses being busy and communication with patients with developmental disability as being time consuming. Other nurses described time as a facilitator in communication. Taking more time communicating with the patient with a developmental disability will make the patient more co-operative in procedures, saving time in the end. (Hemsley et al., 2012)

### **3.2. Coping with challenges**

In 2012 Drake et al conducted a study in which they evaluated the use of a coping kit for children with challenging behaviours associated with DD's. Participants were found through convenience sampling and the nurses needed to have previous experience with DD children. The kit contained communication and picture cards, pen and paper and toys that the child could keep, as well as toys to use only while at the hospital. Both nurses and parents received written instructions on how to use the kit. The nurses then filled in surveys and the results showed that the nurses thought the kits were useful, as they reduced the children's anxiety prior to and during procedures, as well as they made the children more co-operative. (Drake et al. 2012)

### **3.3. Quality of Care**

Ndengeyingoma and Ruel conducted a study with the aim to explore nurses' representations of caring for people with an intellectual disability, intervention strategies they currently use, and to identify needs to ensure quality care. The study was conducted in Quebec, Canada. The researchers conducted semi/structured interviews with 18 participating nurses with various

levels of experience. The researchers found that the participating nurses were concerned with their lack of knowledge about caring for patients with intellectual disabilities. The participating nurses identified challenges in organising care and managing the patients' different behaviour and communication difficulties. Time was identified as a factor limiting the quality of care. Nurses tried to speak more slowly using simple words when communicating with this patient group. Several nurses suggested that they would need training in meeting patients with intellectual disabilities either when beginning at the workplace, as a training day or as part of the nursing education in order to provide higher quality care to these patients. (Ndengeyingoma and Ruel, 2016)

## 4. Theoretical Framework

In this section the theoretical framework will be discussed. The theoretical framework of this study is the concepts of "caring" and "uncaring" encounters between the nurse and the patient, based on Halldórsdóttir's theory "Caring and Uncaring Encounters in Nursing and Health Care" which was published in 1996.

Halldórsdóttir's theory focuses on the encounter between the patient and the nurse from the patient's perspective. The theory describes how the *connection* between the nurse and the patient affects the patient's perception of the care as caring or uncaring. The major concepts in the theory "Caring" and "Uncaring" will be discussed in more detail below.

### 4.1. Caring

Professional caring is defined by Halldórsdóttir as competence administered with compassion. A nurse is viewed by the patient as caring only if she delivers care with compassion. The subcomponents of the concept of professional caring are *competence, caring and connection*. The combination of these components results in the formation of "The Bridge" between the nurse and the patient.

*Competence* in nursing is according to Halldórsdóttir a set of skills including *competence in empowering patients, competence in building relationships, competence in educating patients, competence in making clinical judgements, and competence in doing tasks and taking action on behalf of people*. (1996, 31)



*Caring* in nursing, involves openness and perceptiveness of others, genuine concern and interest in patients, moral responsibility, dedication, courage to be involved and being truly present for the patient. (1996,31)

*Connection* in nursing means that the nurse can develop professional intimacy with the patient, while simultaneously maintaining professional distance.

*The Bridge* is what forms between the nurse and the patient when there is a professional connection between the two, including professional competence and genuine caring. In this scenario the patient perceives the encounter as caring, trusts the nurse, and experiences an increase in the sense of health and well-being.

## 4.2. Uncaring

Lack of Professional Caring, or Uncaring, is when the bridge, or the connection between the nurse and the patient fails to form. The patient then perceives the encounter as uncaring, and the nurse being incompetent. Factors that contribute to the patient perceiving the nurse and patient encounter as uncaring are *indifference and incompetence*. The presence of these factors results in the formation of “*The wall*” between the nurse and the patient.

*Indifference to the patient as a person*, states Halldórsdóttir, is one of the *fundamental characteristics of an uncaring approach by a nurse*. The main difference between a caring and uncaring approach is based on Halldórsdóttir’s study whether the nurse acknowledges the patient as a person or not. (1996,49)

The patient may perceive the nurse as being *incompetent* in situations when the nurse does not communicate effectively, when the nurse does not respect the patient’s need for information and instruction, and when the nurse does not give the patient enough time. (1996,32)

*The Wall* is what is formed when the patient and the nurse do not connect. In this scenario the patient perceives the nurse as being uncaring and there is lack of trust between the two. The patient experiences a decrease in wellbeing and health.

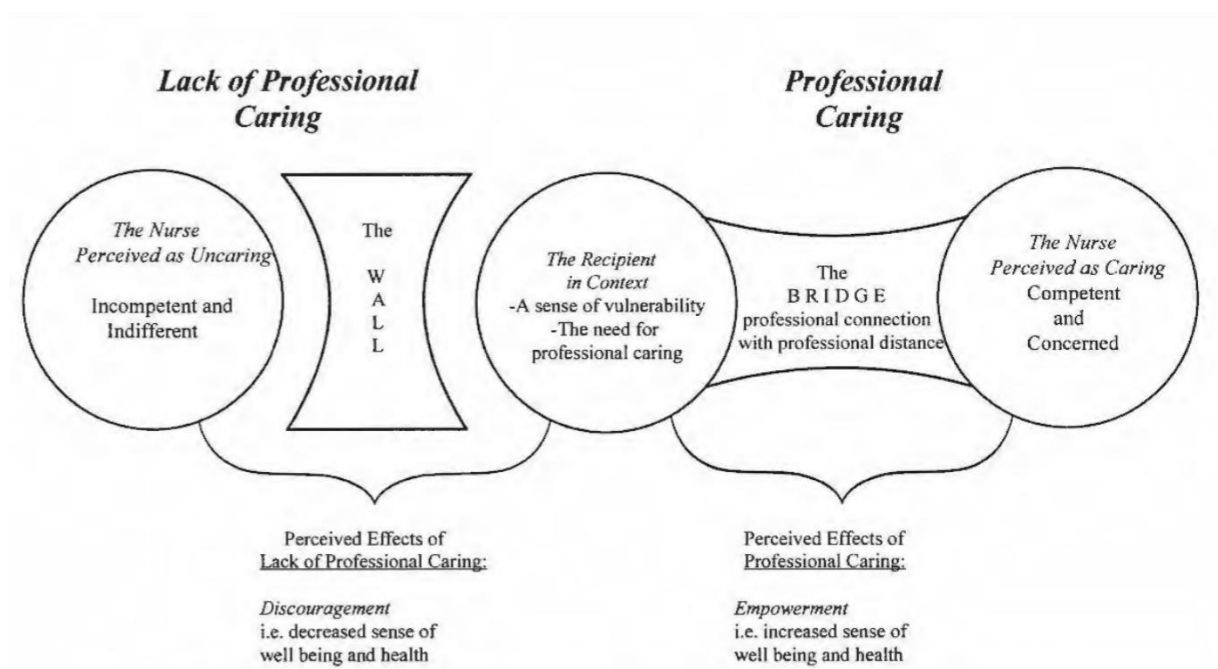


Image 1: A schematic model of Halldórsdóttir's "Caring and Uncaring Encounters in Nursing and Healthcare" theory. (Halldórsdóttir, 1996)

## 5. Research Method

In this section the choice of the qualitative research method will be motivated. The data collection process will be described, including a description and motivation for the Theme interview as data collection method, how participants were found and an outline of the criteria for participation. A description of the qualitative data analysis will be provided, and Ethical considerations will be discussed.

### 5.1. Qualitative research method

A qualitative research method was selected for this study as the previous research on the topic "Nurses' experiences on challenges in caring for patients with developmental disabilities" is limited. With the qualitative approach the author hopes to gain new information and knowledge about the topic, so that challenges can be limited or overcome more easily in the future.

## **5.2. Data Collection**

In the data collection section, the Theme interview will be discussed. The section also includes a description on the process of finding participants, as well as an outline of the participation criteria for the study.

### **5.2.1. Theme interview**

The selected data collection method for this study is through Theme interviews, described by Hirsjärvi and Hurme (2008) as a type of semi-structured interview, in which certain, predetermined themes are discussed. The themes are the same for all participants, but their answers determine which direction the interview takes. In the theme interview the voice of the participant is brought up higher, as it is the participant that chooses how deep into the topics they want to go and what they want to tell the researcher.

The motivation for the choice of theme interview as the form of data collection is that the topic of the study is a poorly researched area within nursing, and the theme interview approach gives possibility to complex answers and new knowledge. Since it is the participants that guide where the discussion is going it is likely that new ideas, that the researcher could have missed, are brought up. The theme interview also gives the researcher the possibility to ask follow-up questions, which the structured interview would not. The theme interview is also a good method from the ethical perspective, as the participant chooses what to share with the researcher and can avoid talking about difficult or upsetting topics if so desired.

The pre-set themes to be discussed during the theme interviews are the participants experiences on caring for patients with developmental disabilities, the participants experiences on challenges when caring for patients with developmental disabilities, how the participants deal with the challenges they meet, and how the participants think that the care for patients with developmental disabilities could be improved.

### **5.2.2: Finding participants**

According to Henricson (2012) participants for qualitative studies should be found through purposive sampling. The researcher should look for individuals that have experienced the

phenomena that is being studied and ask these individuals to participate in the study. By finding participants through purposive sampling the researcher can achieve results that accurately describe the phenomena. To get further variation and broader image of the phenomena, the researcher can look for participants that are from different age groups, have different amount of experience, different gender, or different settings. As there are fewer participants in qualitative studies it is important that the participants can provide rich and accurate information. (Henricson, 2012).

### **5.2.3: Participation criteria**

To ensure that the participants are suitable for the study and able to contribute with relevant information to the study, the researcher should decide on certain criteria that should be fulfilled by the participant in order for him or her to participate in the study. (Henricson, 2012)

## **5.3. Qualitative Data Analysis**

According to Elo and Kyngäs (2009) content analysis can be described as “a method for analysing written, verbal or visual communication messages”. The content analysis process is made up of three phases; preparation, organizing and reporting. When conducting content analysis, the researcher first transcribes the interview verbatim and then groups what has been said into subcategories, categories and themes. Based on the identified patterns either new knowledge is generated, which is called inductive content analysis, or previous knowledge based on a theory is tested, which is called deductive content analysis. (Elo & Kyngäs, 2008)

According to Wibeck, in Henricson (2012) interviews should be transcribed, and the transcribed text should be read through several times by the researcher. Once this has been done, the researcher should start to pick out recurring themes from the text, by picking out quotations. Quotations that contain similar phrases or have the same meaning are grouped together to form subcategories. Subcategories with similar meanings are grouped into categories, and categories that are somehow related to each other are grouped together into larger, more abstract themes. For clarity this process can be made with the help of a table with columns. The larger themes

that are found should be discussed and reflected upon in relation to theory and background. (Henricson 2012)

## **5.4. Ethical Considerations**

Based on the National Advisory Board on Research Ethics paper "*Ethical Principles for Research in the Humanities and Social and Behavioral Sciences and proposals for Ethical Review*" (2009) there are three groups of ethical principles to take into consideration when conducting research within the humanities and social and behavioural sciences. These groups are "Respecting the Autonomy of the Research Subjects", "Avoiding Harm", and "Privacy and Data Protection". These ethical principles and how they are ensured in this study will be discussed below.

### **5.4.1. Respecting the autonomy of the research subjects**

"Participation in research should be voluntary and based on informed consent." is stated in the National Advisory Board on Research Ethics paper.

In this study the participants were given information regarding the study prior to deciding on participation. The participants were informed about the aim and purpose of the study, about the interviews being recorded on a mobile device, transcribed and later destroyed. Additionally, the participants were informed about their rights; that participation is voluntary and that they can withdraw from the study at any point without consequences. The participants signed a consent letter to confirm their participation in the study.

### **5.4.2. Avoiding Harm**

The author took measures to not cause any mental, social or financial harm to the participants throughout the study; during the data collection phase, in the storage of data, and in the publication phase. (National Advisory Board on Research Ethics, 2009)

### **5.4.3. Privacy and Data Protection**

Privacy and data protection consists of “protecting research data and confidentiality”, “storing or destroying research data” and “protecting privacy in research publications”. (National Advisory Board on Research Ethics, 2009)

The author took measures to protect the participants privacy and data through collecting the data in such a way that no personal information such as names was recorded. The interviews and what were said in them cannot be traced back to the participant. Additionally, once the data analysis has been completed the author destroys all recordings, transcriptions and consent letters so that the collected data and the participants information will not get revealed.

The participants were given the possibility to choose in which language they want the interviews to be conducted based on personal preference. Participants chose to be interviewed in Swedish as that was their mother tongue and they felt more comfortable speaking Swedish. Quotations were translated into English for the research paper, but the Swedish original quotation is also provided to give an accurate image of what was said during the interviews.

### **5.5. Conduction of the study**

As the aim of this study is to identify and describe challenges that nurses experience when caring for patients with developmental disabilities there are certain criteria that the participants need to fulfil in order to participate. In the data collection stage of the study the author searched for participants that fulfilled the participation criteria. The criteria for participating in this study are as follows:

- The participants should be educated nurses.
- The participants should not be specialized or extensively experienced with caring for patients with developmental disabilities.
- The participants should have encountered patients with developmental disabilities in their work settings, but the majority of their patients should not have developmental disabilities.
- The participants should not have worked in a home for developmentally disabled.

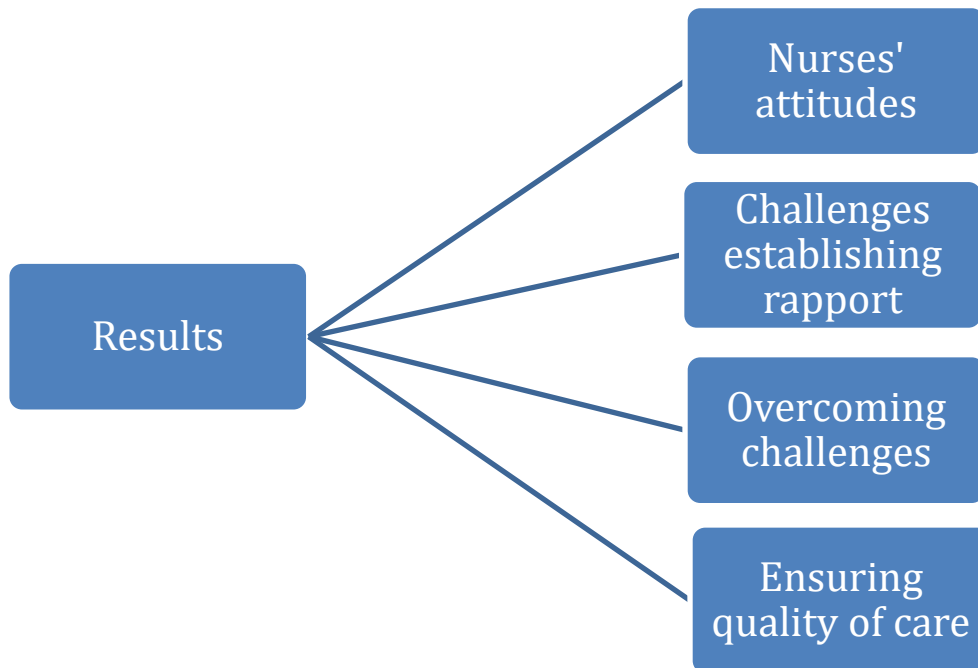
The participants were found by asking nurses volunteering in the local Red Cross units if they wanted to participate. A total of six nurses agreed to be interviewed. Before starting the interviews, the participants were informed about the study and about their rights as participants. The participants were informed that the interviews would be recorded for transcribing purpose and later deleted. The nurses that agreed to participate were informed that they represent themselves and their own opinions and experiences, not their workplace nor the Red Cross Organization. They were given a consent letter (appendix 1) beforehand which they signed if they wanted to participate. The participants could choose the location and time of the interview according to their respective preference. Six interviews were conducted and recorded, but due to technical issues one recording was lost, and could not be used in the study. A total of five interviews were used. The average length of the interviews was from ten to fifteen minutes. Theme interviews were used, so that the participants could decide what experiences and thoughts they wanted to share, and the author could ask questions based on what the participants were discussing.

When the interviews had been conducted, they were transcribed and analysed using content analysis. The interviews resulted in a total of 17 pages of transcribed data. The transcribed texts were read through carefully several times, after which quotations that were relevant for the study were picked out and copied into a different document. A table was created with four columns; quotations, subcategories, categories and themes. Quotations that were made by the participants were grouped together according to their content. Quotations that contained the same phrasing or had the same meaning were grouped together to form subcategories. Subcategories that had similar contents and meanings were grouped together to form categories. Categories that were relevant to each other were grouped together to form themes. A total of four larger themes were identified in this study. These themes will be presented and described in more detail in the result section below.

## **6. Results**

In this section the results of the analysis will be described and discussed in more detail. After analysing the obtained data four themes were identified; Nurses attitudes, Challenges in

establishing rapport, Strategies to Overcome challenges, and Ensuring Quality of Care. An image showing the themes is provided below.



*Image 1: A schematic image showing the themes resulting from the data analysis.*

### **6.1. Nurses' attitudes**

Under the theme Nurses' Attitudes the participating nurses' own experiences and attitudes toward caring for patients with developmental disabilities were discussed. A schematic image demonstrating the data analysis for this theme can be found in appendix 2/6.

The participants in this study described their own experience with caring for patients with developmental disabilities, as well as their opinions to whether it is more challenging to care for this group of patients. Three categories were identified. These were: Not a challenge, A motivating challenge, and A mental challenge.

#### ***Not a challenge***

Some of the participants were of the opinion that caring for a patient with a developmental disability is not a challenge, and that the patient's disability does not affect the nurse's ability to provide good care to the patient. However, they valued the presence of a relative or caregiver of the patient at the hospital.



*“I cannot say that it is more difficult to care for a patient with developmental disability. But it feels safe when they have their own caregiver with them.” (“Inte kan jag säga att det är svårare att ta hand om en patient med utvecklingsstörning. Men det känns tryggt när de har sin egenvårdare med”)*

### ***A motivating challenge***

Several of the participating nurses believed that it is more challenging to provide quality care to the patient with a developmental disability. However, all of the participants agreed that they do not let the challenges affect the care that they provide to their patients. If something, the challenges they face make them more motivated to work hard to provide their patients with the best care possible.

*“I would not think that it’s a challenge we cannot manage, but actually a challenge that we will manage.” (“Inte skulle jag tänka att det är en utmaning vi inte klarar av, utan egentligen en utmaning som vi ska klara av”)*

### ***A mental challenge***

One of the participants connected caring for the patient with a developmental disability with something that is mentally challenging for the nurse. She explained that she thinks it is unfair to the patient and that it is difficult for her to watch the patient and the family, knowing that the patient will have to deal with the disability for the rest of his or her life, he or she will not be able to live a normal life, and will probably die young.

*“I think it is more challenging mentally. I feel bad for the patient and for the parents.” (“Jag tycker det är mera psykiskt utmanande. Jag tycker synd om patienten och föräldrarna”)*

## **6.2. Challenges in establishing rapport**

Under the theme challenges in establishing rapport when caring for patients with developmental disabilities four main categories were identified. These categories were: communication, understanding, connection and knowledge. A schematic image demonstrating the data analysis process for this theme can be found in appendix 3/6.

### ***Communication***

The participants in this study identified communication as one of the main challenges when caring for a patient that has a developmental disability. Language and Body Language were identified and described as important tools in the care of all, but especially in the care of developmentally disabled. These subcategories will be described below.

### ***Language***

Language was identified by most of the participants as an important factor affecting their ability to provide patients with developmental disabilities with good nursing care. The participants suggested that in cases where their patients had severe forms of disabilities and were unable to speak normal language it was more difficult for them as nurses to fulfil their patients' needs.

*“It becomes quite challenging since my main work tool is my language. I need to make myself understood and I need to understand the patient, and if there is no language this becomes more challenging.” (“Det blir ganska svårt eftersom mitt största arbetsredskap är språket. Jag måste kunna göra mig förstådd och jag måste förstå patienten, och om det inte finns ett språk så blir det mer utmanande”)*

Another participant commented on the challenge in situations where their patients can communicate orally to limited extent and rely on the use of support signs:

*“It can be difficult if they have sign language, some communicate unclearly and have their own signs.” (“Det kan vara svårt om de har teckenspråk, vissa kommunicerar otydligt och har egna tecken.”)*

All participants agreed that although some patients with developmental disabilities may not be able to, or have limited ability to express themselves using oral language:

*“They can always express themselves in some way.” (“De kan nog alltid uttrycka sig på nåt sätt”)*

### ***Body Language***

The use of body language when caring for a patient with a developmental disability was brought up by all participants. Body language was mentioned both in the sense of reading and interpreting the patients' body language, but also in the sense of the participants considering their own body language while caring for the patient.

According to the participants the patients' use of body language can make it easier for the nurses to understand how they are feeling and based on that adapt their own behaviour to make their patient feel safer. One of the participants suggested that the stiffness of a patient's body shows that the patient is uncomfortable in the situation. Another participant discussed the patient's eyes as an indicator of how he or she is feeling:

*“Eye contact is important. You can see on the eyes how a person is feeling. You can see on their eyes if they are afraid.” (“Ögonkontakten är viktig. Man kan se på ögonen hur någon mår. Man kan se på ögonen om de är rädda.”)*

A third participant stated her appreciation of patients with developmental disabilities showing their emotions clearly. If the patient is unable to communicate verbally emotional display aides the nurses in understanding their patient;

*“Aggression and anger are also ways of communication” (“Aggression och ilska är också en form av kommunikation”)*

Participants also discussed their own body language and how they use it to get their message through to the patient. One participant talked about using her hands to calm the anxious patient down and send the patient the message that she only wants her well. Another participant stated that when caring for patients with developmental disabilities:

*“I use my body language and consider how I stand and hold my body, so I don’t provoke anything unnecessary.” (“Jag använder mitt kroppsspråk och tänker på hur jag står och håller min kropp så att jag inte provocerar något onödigt”)*

## ***Understanding***

The participants identified Understanding as an important challenge and factor that could affect the quality of the care when caring for patients with developmental disabilities. If the nurse and the patient cannot understand each other there is a risk that the care quality suffers. The participants discussed understanding from two perspectives; the patient understanding the nurse, and the nurse understanding the patient.

### ***The patient understanding the nurse***

The main challenge in understanding was according to the participants the patient understanding the nurse. The participating nurses felt that it was sometimes difficult to get the patient with a developmental disability to understand them, and even more difficult to know whether the patient had understood them or not.

*“You do not always know how good contact you get with them. Do they understand what you mean?” (“Man vet inte alltid hur bra kontakt man får med dem. Förstår de vad man menar?”)*

Another participant suggested that people often underestimate patients that have developmental disabilities ability to understand saying that:

*“Many times they understand more than one would think” (“Många gånger förstår de mer än man skulle tro”)*

All participants in the study admitted to making extra effort to make sure the developmentally disabled patient could understand them. Several participants discussed the importance of bringing things down to the patient's level, talking slowly and explaining well with simple words. One nurse stated that she sometimes uses pictures when explaining things, and other times tries to use support sign. The participants were all of the opinion that if they could get their patient to understand what was being done to them and why, he or she would co-operate better and the care experience would be better for both the patient and the nurse.

### ***The nurse understanding the patient***

The participants also identified the nurse understanding the patient as a challenge that could affect the care outcome when caring for the developmentally disabled patient. However, all participants agreed that they could always understand the patient in one way or another. One participant stated that:

*“You have to read between the lines.” (“Man måste läsa mellan raderna”)*

The participants also agreed that it is good to include the patient's own caregiver; a parent or someone working with the patient on a daily basis, in the care of the patient, as they know the patient and what he or she wants and can help the nurse understand. The participants said that it is better to bring the caregiver in at an early stage, than to let the patient become too anxious since the latter would leave the patient with a bad care experience and could lead to less co-operation in the future.

### ***Connection***

Connection between the nurse and the patient was another challenge identified by the participants. In the connection category the participants identified patients being afraid, and gaining patients' trust as two factors affecting the care.

### ***Patients being afraid***

Several of the participants made the comment that a patient with developmental disabilities can be difficult to connect with, since they are often scared when they come to the care situations both because they come to a new place, but also because the nurses are new, unfamiliar people.

*“They are a bit anxious when they come to a new place, it does not feel safe to them” (“De är lite oroliga när de kommer till ett nytt ställe. Det känns inte tryggt för dem”)*

*“When they come to us, they are scared, they are anxious, because we are people they are not used to.” (“Då de kommer till oss är de rädda, de är oroliga, för vi är människor de inte är vana med”)*

One participant pointed out that how the nurse acts in different situations, for example under stress, affects the patient’s level of fear.

*“If it becomes stressful and people start to yell they become scared” (“Om det blir bråttom och folk börjar ropa blir de rädda”)*

The participants agreed that if the patient is afraid he or she will not trust the nurse, and will not co-operate with the nurse, affecting the care experience from the patient’s perspective in a negative way.

### ***Gaining patients’ trust***

The participants suggested that gaining patients’ trust is a central part of nursing for the patient with a developmental disability. If the patient is uncomfortable in the situation, afraid of the new surroundings and people, the patient will not trust the nurse and it will be more difficult to establish the connection between the nurse and the patient that is needed for the care to be successful. The participants agreed that they need to work to gain the trust of their patients:

*“As a nurse you have to make them feel safe, so they don’t become anxious.” (“Som skötare måste du få de matt känna sig trygga, så att de inte blir oroliga”)*

The participants had different ways of making the patients feel safe and gaining their trust, including staying calm, moving forward slowly and paying attention to details. One participant stated that her way of gaining the developmentally disabled patient’s trust and establishing connection is that:

*“I try to show them that I am on their side.” (“Jag försöker visa dem att jag är på deras sida”)*

### ***Knowledge***

The participants identified their own knowledge about developmental disabilities as an important factor challenging their ability to care for patients with developmental disabilities. The participants brought up concern about themselves having insufficient knowledge on the topic.

### ***Insufficient knowledge***

Several of the participants in the study said that they feel that their own knowledge about developmental disabilities and how to care for affected patients was limited. Some were concerned that their own lack of knowledge affected their ability to care for this group of patients, and they often rely on relatives. Even a participant that had been working in acute care settings for nearly 40 years stated that:

*“Although I have been working for a long time I don’t know much about developmental disabilities.” (“Fast jag har jobbat länge så vet jag inte så mycket om utvecklingsstörningar”)*

Participants were also saying that even if they had some knowledge about a developmental disability each patient case is unique and patients with the same diagnosis can still be very different to care for. One participant was saying that:

*“There is such a big variation between developmental disabilities.” (“Det är så stor skillnad mellan utvecklingsstörningar”)*

Continuing to explain that in her opinion it is more challenging to care for a patient with a severe disability that you do not know much about, than to care for another patient with a mild disability that you know equally little about.

## **6.3. Nurses’ strategies to overcome challenges**

Under the theme Nurses’ strategies to overcome challenges the participants discussed what strategies they use to overcome the challenges described above. Topics discussed were getting help from others, the participants own strategies, as well as the participants’ identified needs to make dealing with challenges in caring for patients with developmental disabilities easier. A schematic image demonstrating the data analysis process for this theme can be found under appendix 4/6.

### ***Help from others***

All of the participants admitted to relying on help from others when caring for patients with developmental disabilities. In this category Help from the relative or caregiver, The relative or caregiver as a burden, and Help from co-workers were discussed.

### ***Help from relative or caregiver***

All of the participants discussed getting help from the patient's own relative or caregiver as a great support when nursing for this group of patients. The participants were appreciative of the help they got from the relative or caregiver especially in communicating with the patients and in interpreting the patients' needs. Older and more experienced participants were describing the change in the relatives or caregiver's presence at the hospital over the years, saying that this aspect has improved a lot over time. One participant was explaining that in the beginning of her career the relatives of patients with developmental disabilities were not included in the care almost at all, but that nowadays they are even encouraged to be at the hospital with the patient. The participant said that:

*“Having their own caregiver or relative there makes our job so much easier. They know the patient and know exactly what they mean or how they want things.” (“Har de sin egenvårdare eller anhörig med gör vårt jobb mycket lättare. De känner patienten och vet exakt vad de menar och hur de vill ha saker”)*

The other participants also discussed the positive effects of having the patient's relative or caregiver at the hospital. Not only did they help in communication and understanding, but their presence also had a calming effect on the patient, making them more co-operative in care situations.

### ***The relative or caregiver as a burden***

Although the participants were all saying that the patient's relative or caregiver is a great support in the care of the patient with a developmental disability one participant pointed out that the relative or caregiver can also be a burden in the care:

*“If something happens, we have two to take care of.” (“Händer det någonting, så har vi två att ta hand om”)*

Usually, she explained, nothing happens, but in a scenario that the patient for example stops breathing they have to simultaneously help the patient, while trying to calm the panicked relative. In another scenario, she explains, something could happen to the relative, and then they suddenly have two patients to take care of.

### ***Help from co-workers***

One of the participants discussed situations in which the patient with a developmental disability arrives to the hospital alone, without a relative or caregiver to help in the care. The relative or caregiver might not always have the possibility to come to the hospital with the patient, so then

the nurses must manage without their help. The participant pointed out that if a patient or situation becomes too challenging to manage on your own, you should not hesitate to ask your co-workers for help, saying that:

*“You’re not alone, you have others in the team with you that can help.” (“Man är inte ensam, man har andra i teamet som kan hjälpa”)*

### ***Own strategies***

The participants had various own strategies that they used when caring for patients with developmental disabilities. The strategies involved thinking creatively and outside the norms. One participant explained that she had tried to use support sign language at some point, with low success, since she had limited knowledge. The same participant said that she often uses pictures to help when explaining procedures:

*“Many times it helps to be creative, find a computer, show them images when explaining.” (“Många gånger hjälper det med att vara kreativ, hitta en dator, visa bilder medan man förklarar”)*

Another participant got creative in a situation where the developmentally disabled patient was at the hospital without a relative or caregiver. The participant explained that the patient became anxious and noisy if left alone, and they did not have enough staff to place one nurse with the patient, so she brought the patient with her into the office, where the patient calmed down in her company, and she could go on doing her paperwork.

*“Once I had a patient in my office with me for a long time while I was doing paperwork.” (“En gång hade jag med mig en patient i mitt kansli en lång stund medan jag gjorde pappersarbete”)*

### ***Identified needs***

The participants thought that overall they could overcome challenges arising in the care of patients with developmental disabilities quite successfully. However, they identified some factors needed in order to better deal with the challenges, or even to avoid some of the challenges in the first place. These needs were Learning more, and Good information prior to care.

### ***Learning more***

As the participating nurses thought that their own knowledge about developmental disabilities was limited and affecting their ability to provide good care several of them said that they would



like to learn more about the disabilities. As most of the participants said that they did not have so much experience caring for patients with developmental disabilities and their specific caring needs one participant concluded that:

*“It would be good to know a bit more about different developmental disabilities.” (“Det skulle vara bra att veta lite mera om olika utvecklingsjukdomar”)*

Another participant was thinking about the challenge in communication between the nurse and the patient and concluded that to be able to better care for this patient group:

*“It would be good to learn some kind of communicative aid.” (“Det skulle vara bra att kära sig något slags kommunikativt hjälpmedel”)*

More specifically the participant wanted to learn sign language, as in her experience support sign language is commonly used as an aid in communication within this patient group.

### ***Good information prior to care***

Four of the participants mentioned the quality and content of the report they get about the patient before meeting him or her plays an important role in caring for patients with developmental disabilities. One participant stated that:

*“It is very important that we get a good report about what the patient is like, what he or she reacts on, and how he or she wants to be treated.” (“Det är jätteviktigt att vi får en bra information om hurudan patienten är, vad han eller hon reagerar på, och hur han eller hon vill bli behandlad”)*

Other participants made similar comments. The participants were explaining that if the report they get before meeting the patient is good the care experience is improved for both the patient and the nurse. The older participants were saying that the reporting prior to care has improved much during the years, but they still wanted to emphasize the need for good information about the patient and his or her individual characteristics and needs prior to care.

## **6.4. Ensuring Quality of Care**

Under the theme “Ensuring Quality of Care” the participants discussed and described their own ways of ensuring that the developmentally disabled patient gets care that is of good quality. The participants described and gave advice on both thinking mentalities and practical arrangements

they make when caring for a patient with a developmental disability. A schematic image of the data analysis process for this theme can be found under appendix 5/6.

### ***Thinking mentalities***

One of the participants was explaining that to give good care, one needs to go into each situation with an open mind. If one has positive expectations and no prejudice the care experience is better for both the nurse and the patient. Another participant was saying that her way of ensuring good quality care not only for patients with developmental disabilities, but for any patient is remembering that:

*“I care for everyone equally. They get the same care as a police officer or doctor in the other bed.” (“Jag vårdar alla lika. De får samma vård som en polis eller läkare i den andra sängen.”)*

### ***Practical arrangements***

One of the participants working in a recovery room explained that they make certain practical arrangements when they have a patient with a developmental disability. Such arrangements include the number of patients per nurse. The participant stated that normally each nurse at the shift has around four patients, but:

*“When you have a patient with a developmental disability you have only that patient, especially if it is a child you have only one.” (“Har man en patient med utvecklingsstörning så har man bara den patienten, speciellt om det är nåt barn så har man bara en.”)*

The same participant said that if she knows in advance that there is a patient with a developmental disability coming in for a planned surgery, she tries to make it routine to go meet the patient before the procedure, simply to make the patient feel more comfortable in the recovery room afterwards.

*“If they have someone they know there, they feel a lot safer. Sometimes I’ve met them before the operation, and then when they wake up they see you again, then it is almost like they know you.” (“Har de någon de känner där känner de sig mycket tryggare. Ibland har jag mött dem före operation, och sen då de vaknar ser de en på nytt, så då är det ju nästan som de skulle känna en”)*

The participant explained that in her experience patients often believe that if the nurse knows them from before, the nurse will make sure they are safe and well.

## **7. Discussion**

This chapter is divided into three parts; “Result Discussion”, “Method Discussion and Critical Review” and “Conclusion”. In the “Results Discussion” part the findings of the study will be discussed in relation to the theoretical framework and in relation to the background research. In the “Method Discussion and Critical Review” part the selection of method and its’ relevance will be discussed and reviewed critically. The trustworthiness of the study will also be discussed in this chapter. In the conclusion the study will be tied together and suggestions for further research will be made.

### **7.1. Result Discussion**

In this section the research findings and their connection to the theoretical framework, to the aim and to the background of the study will be discussed. The aim of the study is to identify and describe challenges that nurses experience when caring for patients with developmental disabilities and how these challenges affect the quality of care.

Four themes were identified after analysing the interviews. These themes were “Nurses’ attitudes”, “Challenges in establishing rapport”, “Overcoming Challenges” and “Ensuring Quality of Care”. These themes will be discussed in more detail below.

#### ***Nurses’ attitudes***

The theme “Nurses’ attitudes” was an unexpected, additional finding that was not mentioned in the background nor in the theoretical framework. The participants identified caring for patients with developmental disabilities as “not a challenge”, as “a motivating challenge” and as “a mental challenge”. The way nurses feel about caring for patients with developmental disabilities may affect how they actually care for them.

The findings suggest that if the nurse does not feel that caring for a patient with a developmental disability is a challenge, the nurse will care for the patient the same way as he or she would care for a patient without a developmental disability and would not let their own attitudes affect their ability to provide good care to the patient.

Based on the findings it can be suggested that the nurses that describe caring for patients with developmental disabilities as “a motivating challenge” are the nurses that work hardest to improve quality of care in this patient group. These nurses work extra hard to make sure they do not let the challenges affect their ability to provide good care to their patients.

The nurses that view taking care of patients with developmental disabilities as a mental challenge may or may not let their own emotions affect their ability to provide good care for patients with developmental disabilities, depending on the situation.

The findings suggest that the attitudes of nurses play an important role in the quality of care of patients with developmental disabilities. When nurses have positive attitudes he or she open-mindedly goes into the care situation and tries his or her best to provide good care to the patient. When nurses have positive attitudes, they express genuine concern and interest in their patients, investing both time and effort into the care they are viewed as caring. If the nurses are caring, the care encounter between the nurse and the patient also has potential to be experienced as “caring” if competence and connection between the nurse and the patient can also be established. (Halldórsdóttir, 1996)

### ***Challenges in establishing rapport***

The second theme identified; “Challenges in establishing rapport” when caring for patients with developmental disabilities was mostly supported and backed up both by the background and by the theoretical framework used in this study. Within this theme four categories were identified. These categories were “communication”, “understanding”, “connection” and “knowledge”.

“Communication”, or ineffective communication, was mentioned in the theoretical framework as a factor that affects the care experience for the patient under the concept of an “uncaring” experience. This suggests that if the nurse and the patient are unable to communicate effectively the care encounter is experienced in a more negative way by both the nurse and the patient. (Halldórsdóttir, 1996)

“Communication” was described as one of the main challenging factors when caring for patients with developmental disabilities by most of the participants in the study. The category “communication” was identified as a challenging factor in the background, where Sowney and

Barr (2006) found communication challenges to be one of the important challenges when caring for intellectually disabled patients. Davies (2008) also identified communication as a factor affecting the nursing care of developmentally disabled patients, as interpreting their communication may be difficult and signs of illness might be missed due to this factor.

“Understanding” was described by the participants as another important factor affecting their ability to care for patients with developmental disabilities. The participants identified that it might be difficult for them as nurses to understand their patients but were more concerned about the patients not understanding the nurses. Similar findings were found by Davies (2008) who concluded that if the patient with a developmental disability does not understand a procedure the patient will be less likely to co-operate in said procedure, something that was also mentioned by some of the participants in this study.

In the theoretical framework understanding, or rather lack of understanding can be interpreted as being part of ineffective communication, which results in the care encounter being interpreted as “uncaring” by both the patient and the nurse in question. (Halldórsdóttir, 1996) “Connection” was mentioned in the theoretical framework as one of the key aspects in the encounter between the nurse and the patient. If there is a successful connection between the nurse and the patient the care encounter is considered “caring”, and if there is not a successful connection between the parts the encounter is considered “uncaring”. The findings of this study support the framework, as the participants expressed that if they could not connect it was difficult to get the patients calm and co-operative, which made their care worse although they were trying to give good care. (Halldórsdóttir, 1996)

Challenges in “connection” between the nurse and the patient were identified as an important factor when caring for developmentally disabled patients. The participants stated that patients are afraid, and they need to connect with them in order to achieve a successful care relation. Goshman & Nikoloff (1984) found similar results, saying that nurses found it difficult to establish rapport with these patients in the beginning of the care period.

Nurses’ knowledge was described in the theoretical framework using the word “competence”. If the nurse has knowledge, he or she is considered competent by the patient, and if there is lack of knowledge from the nurse’s side he or she may or may not be viewed as incompetent by the patient. The nurse may also consider him-/herself to be incompetent in situations where his or

her lack of knowledge affects his or her ability to give the patient good care. (Halldórsdóttir, 1996)

Nurses' own "knowledge" about developmental disabilities and how to care for this patient groups special needs was identified by the participants as the final challenging factor when caring for patients with developmental disabilities. This finding supports the findings of Sowney and Barr (2006) and of Ndengeyingoma and Ruel (2016), who both found that nurses identify their own lack of knowledge about developmental disabilities as a critical challenging factor when caring for this patient group.

### ***Overcoming Challenges***

The third theme identified "Overcoming challenges" when caring for patients with developmental disabilities showed partly similar findings as previous studies, and partly some new input on the topic. Three categories were found under this theme; "help from others", "own strategies" and "identified needs".

"Help from others" included getting help from the patient's relative or caregiver, the caregiver or relative as a burden, and getting help from co-workers. Getting help from the patients' relatives or caregivers was an expected finding, that agrees with the findings of Sowney and Barr (2006) who identified dependence on caregivers as a central theme in caring for patients with intellectual disabilities. The relative or caregiver as a burden and getting help from co-workers were not mentioned in the background, and not as frequently by the participants as help from relatives or caregivers was. This indicates that nurses value the experience and help they get from the relatives or caregivers more highly when caring for patients with developmental disabilities.

"Help from others" is not mentioned in the theoretical framework, but it is important to consider this as a means of reaching the competences, such as connection, which is necessary for achieving a "caring" nurse and patient encounter.

"Own strategies" that nurses used for overcoming challenges when caring for patients with developmental disabilities included being creative in their work. It was found that for example using pictures when explaining procedures was a method used by nurses to overcome to overcome the challenge of patients not understanding the nurse or the procedure. These findings

are similar to Drake et al. (2012) who found that using pictures reduce anxiety and make patients with developmental disabilities more co-operative.

As for the theoretical framework, “Own strategies” to overcome challenges in caring for patients with developmental disabilities are important when trying to establish connection, which is essential in a “caring” encounter between the nurse and the patient. (Halldórsdóttir, 1996)

“Identified needs” for being able to provide better care for the patients with developmental disabilities include learning more and good information prior to care. The need to learn more agrees with the findings of Ndengeyingoma and Ruel (2016) who similarly found that nurses would be interested in participating in training days to learn more about caring for patients with developmental disabilities. Good information prior to care was not mentioned in the background but plays an important role when trying to give good nursing care to patients.

Learning more and receiving good information prior to care can both be said to be related to the aspect of competence under the concept of a “caring” encounter between the nurse and the patient. As the nurse learns more and receives good information, he or she may feel more competent when providing care. If the nurse acts with confidence the patient may also experience the nurse to be competent, which leads to the interpretation of the care encounter as “caring” from both parts involved. (Halldórsdóttir, 1996)

The nurses’ will to learn more can also be interpreted as the nurse being caring, and showing interest in the patient, which is also a necessary characteristic of the nurse in a “caring” nurse and patient relationship. (Halldórsdóttir, 1996)

### ***Ensuring Quality of Care***

The fourth and final theme identified in this study was “ensuring quality of care” in which nurses described their individual ways of ensuring quality of care when caring for patients with developmental disabilities. This theme was not brought up in the background as it is based on information that the nurses participating in this study provided as advice to other and future nurses. Two categories were found “thinking mentalities” and “practical arrangement”.

“Thinking mentalities” included having a positive attitude, and caring for all patients equally, regardless of their background and whether they had a developmental disability or not. Being open minded is described in the theoretical framework as one of the characteristics of a “caring” nurse. By following positive thinking patterns in the nurse and patient encounter and going into care situations with patients that have developmental disabilities with an open mind improves the chances of the encounter to be experienced as “caring”. (Halldórsdóttir, 1996)

“Practical arrangements” that the participants made when caring for patients with developmental disabilities included reducing the nurse to patient ratio and keeping the patient close to them at all time. Making practical arrangements like these show that the nurse is giving compassionate care by giving the patient time and making him or her feel safe. Compassion in nursing care is stated as essential in a “caring” encounter, which suggests that by making simple practical arrangements to be there for the patient, ensures that the care is in fact of “caring” nature. (Halldórsdóttir, 1996)

By making a point of caring for everyone equally and by making practical arrangements to better be able to manage the challenges that come with caring for a patient with developmental disability in the hospital setting the nurse is showing dedication in their work, and showing that they are there for the patient. Dedication and presence for the patient is described in the theoretical framework as part of the caring characteristic of a nurse. (Halldórsdóttir, 1996)

The findings in the study suggest when caring for patients with developmental disabilities in the hospital setting nurses work hard to overcome associated challenges and generally achieve what is described in the theoretical framework as a “caring” encounter between the nurse and the patient, including competence, caring and connection.

## **7.2. Method Discussion and Critical Review**

In this section the method used in the study will be discussed and reviewed critically based on recommendations from literature.

According to Wallengren and Henricson (2012) qualitative studies should be reviewed by looking at the sample, the data collection, and the data analysis in relation to the terms



credibility, reliability, confirmability and transferability. Additionally, the author should point out limitations and strengths in the study and make suggestions about what could have been done differently to generate more trustworthy results. (Henricson, 2012)

### **7.2.1. The sample**

The sample of participants consisted of six nurses, out of which the interview data provided by five could be used for the analysis. Having only five subjects could be considered a weakness of the study, as it gives limited amount of data and important knowledge could be missed due to this. However, as the participants were nurses working in various settings, and had various experience in nursing, and in caring for patients with developmental disabilities, it could still be argued that this low number of participants provided rich and reliable data through their interviews. To make sample data more reliable it could have been good to include participants from different cities or even different countries to get a broader image. Increasing the sample size would have made the study more trustworthy by giving more data to either support or contradict the findings obtained using this sample size.

### **7.2.2. The data collection**

The data collection method used in this study was theme interviews, which provided rich and relevant data for the study. Ethically theme interview was a good data collection method, as the direction of the interview was steered by the participants and what they thought was relevant. Little input was made by the author, and follow-up questions were asked in a neutral way, to avoid researcher-bias in the participants stories. Although the participants were choosing the direction of the interviews the pre-selected theme guide helped the interviewer and interviewees to go back to the topic, and thus ensure credibility. The selection of theme interviews as data collection method was suitable for this study, as the data provides an accurate and reliable reflection on how the participating nurses feel about caring for patients with developmental disabilities. The fact that the different participants expressed similar feelings support the reliability of the study.

### 7.2.3. The data analysis

According to Wallengren and Henricson (2012) the data analysis and the data obtained in a qualitative study should be reviewed in relation to credibility, reliability, confirmability and transferability. Strengths and weaknesses should be brought up and discussed. (Wallengren and Henricson, 2012)

Elo et al. (according to Polit & Beck, 2012) suggest that credibility deals with the extent to which the data addresses the intended focus of the study. (Elo et al., 2014). Credibility has been achieved in this study as the data presented is relevant to the focus of the study and answers the research questions posed in the beginning.

“Reliability” is defined by the Merriam-Webster dictionary as “the extent to which an experiment, test, or measuring procedure yields the same results on repeated trials.” (Merriam-Webster, 2018). As the study was based on the qualitative method interviews it is quite unlikely that repeating the study will yield the exact same results. However, as certain themes came up in all interviews that were conducted in the study it could be argued that the findings are in fact reliable to some extent.

Elo et al. (according to Polit & Beck, 2012) suggest that confirmability refers to how similar understandings of the data and its’ meaning, relevance and accuracy two or more independent people could have after reading the data. (Elo et al 2014). This means that it should be possible for different individuals to understand the data in the study the same way. The author has striven to achieve confirmability in this study by carefully documenting direct citations from participants into the text, in order to give the reader room for own interpretations.

Transferability, according to Elo et al. (based on Polit & Beck, 2012) refers to how well the findings of a study can be transferred or generalized to other groups or settings. (Elo et al., 2014). As the focus of the study was specific to nurses caring for patients with developmental disabilities, it is difficult to generalize the findings to other groups than this. However, as the participants were nurses working in different units and provided similar opinions, it could be argued that findings of the study could be generalized to the similar groups of participants, in different settings.

The data obtained in the theme interviews was analysed using content analysis. Citations that were relevant in the authors opinion were picked out from the transcriptions and made into groups based on their contents. While conducting the content analysis it is possible that the interpretation of the data becomes biased by the authors own background. To avoid this the author has tried to be objective while conducting the analysis, and strictly grouping citations by content. Researcher bias could have been reduced or avoided by having several authors and doing the analysis together. To improve confirmability in the data analysis and presentation of results the author has made sure to include citations in the text, so that the reader can follow and understand the research in a similar way as the author.

As the interviews were conducted in Swedish and the quotations were translated into English errors in translation may occur. To avoid translation errors from affecting the readers interpretation of the results, the original Swedish quotations are also provided in the text. By doing so, the author has attempted to improve the confirmability of the study.

On basis of the data analysis it can be stated that nurses working in different settings of primary care experience similar challenges when caring for patients with developmental disabilities and have somewhat similar ways of dealing with them to improve the care. This indicates that the findings of the study could be generalized to nurses that work in different settings, and occasionally receive patients with developmental disabilities.

The study was conducted on a relatively small scale with limited resources. If the study had been broader, with more informants and more time, it is likely that additional interesting findings would have come up, as already now the study answers a question that had not been asked in the aim, that is “what attitudes do nurses have toward caring for patients with developmental disabilities?”. However, for a small-scale study the method used was appropriate and the results obtained were relevant and interesting.

### 7.3. Conclusion

The aim of this study is to identify and describe challenges that nurses face when caring for patients with developmental disabilities and how these challenges affect the quality of care. By interviewing five nurses and analysing the data they provided four themes relevant to the aim were identified, and the research questions were answered. It was found that challenges in caring for patients with developmental disabilities are challenges in establishing rapport, including challenges in communication, understanding, connection and knowledge.

Challenges in caring for patients with developmental disabilities affect the quality of care in the way that nurses work harder to be able to give their patients more time and make them feel safe. Nurses generally do not let the challenges affect the care in a negative way, but rather ask others for help more frequently to manage and keep the care of high standard.

Strategies used to ensure the quality of care and ways of overcoming challenges differed slightly depending on the setting and nature of the encounter, but generally included help from others, such as patients' relatives or caregivers, or co-workers as well as learning more about the disabilities and the patients and getting a good report prior to care. When possible, nurses make practical arrangements that give them the chance to give their patients time and safety.

Based on the findings of this study it can be stated that when caring for patients with developmental disabilities nurses strive to achieve a "caring" relationship with their patients, where they express competence in their work, compassion and caring toward their patient, and establish connection with the patient. Nurses put their patients' feelings first and often succeed in establishing what Halldórsdóttir describes as a "caring" nurse and patient encounter.

An interesting result was that the nurses generally had a positive attitude towards caring for patients with developmental disabilities and that it was more important for them to make sure their patients understood them and felt safe, than it was for them to understand their patients. As the participants showed interest in and expressed a need to learn more about developmental disabilities and how to care for these patients it would be useful to conduct follow-up studies with the aim to develop training programs or workshops to familiarize nurses with caring for patients with developmental disabilities.

Another interesting finding was how well integrated and appreciated the presence of a relative or caregiver was in the nursing care of patients with developmental disabilities. Further research could be conducted with caregivers of individuals with developmental disabilities as participants, asking the questions *“how do relatives or caregivers experience the quality of care when their close one is hospitalized?”* and *“what could nurses do differently when caring for patients with developmental disabilities?”*.

Based on the findings of this study it would be essential to develop a training program for nurses and nursing students to become familiarized with developmental disabilities and their specific characteristics and needs, as well as some basic communicative aids, so that patients with developmental disabilities can feel safe and be taken better care of when hospitalized in the future.

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# Appendix 1/6

## Letter of Consent

My name is Sofia Blomqvist and I am writing my bachelor's thesis about nurses' experiences on challenges in caring for developmentally disabled patients.

The aim of the study is to identify and describe the challenges nurses experience when caring for patients with developmental disabilities and how these challenges affect the quality of care.

The study will also bring up strategies that can be applied in dealing with the challenges that arise, and in turn improve the quality of care.

For the study I am looking for nurses and I am asking you to participate. Interviews will be conducted during the winter 2018 at a calm place of your choice. The interviews will be recorded and transcribed into text. After the study is completed the recordings will be destroyed.

Everything you say during the interview will be kept confidential

In the interview you will represent yourself and not your workplace nor the Red Cross organization.

Participation is voluntary, and you can withdraw at any time.

If you have any questions, feel free to contact:

Sofia Blomqvist

Eva Matintupa

Student

Supervising Teacher

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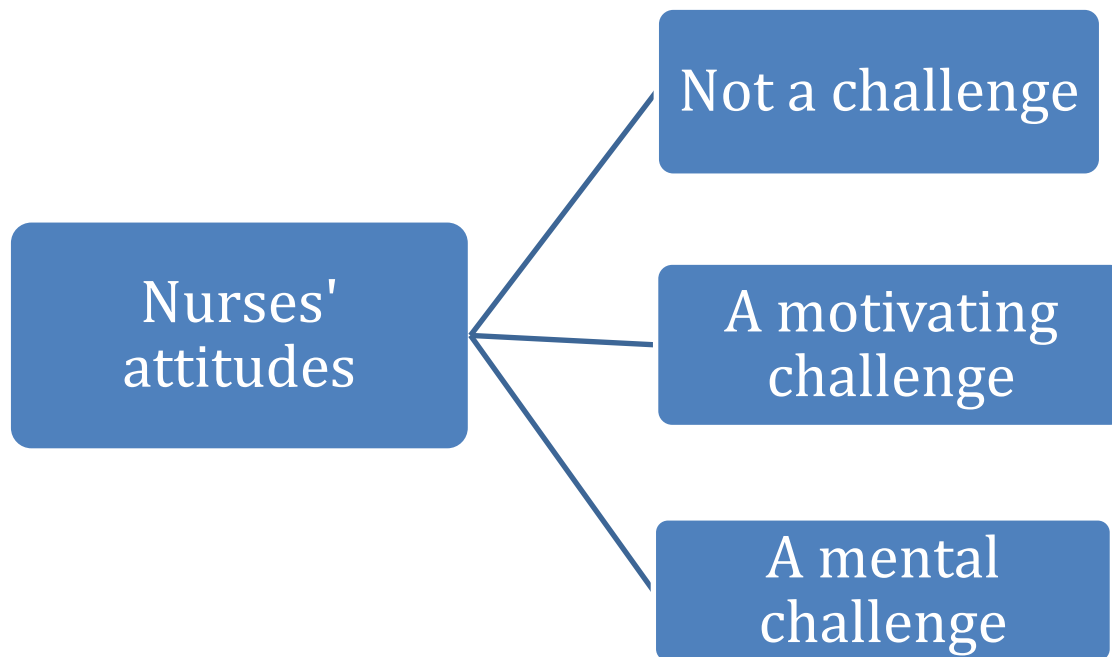
I, \_\_\_\_\_, agree to participate in the study and to the conditions mentioned above.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Place and Date

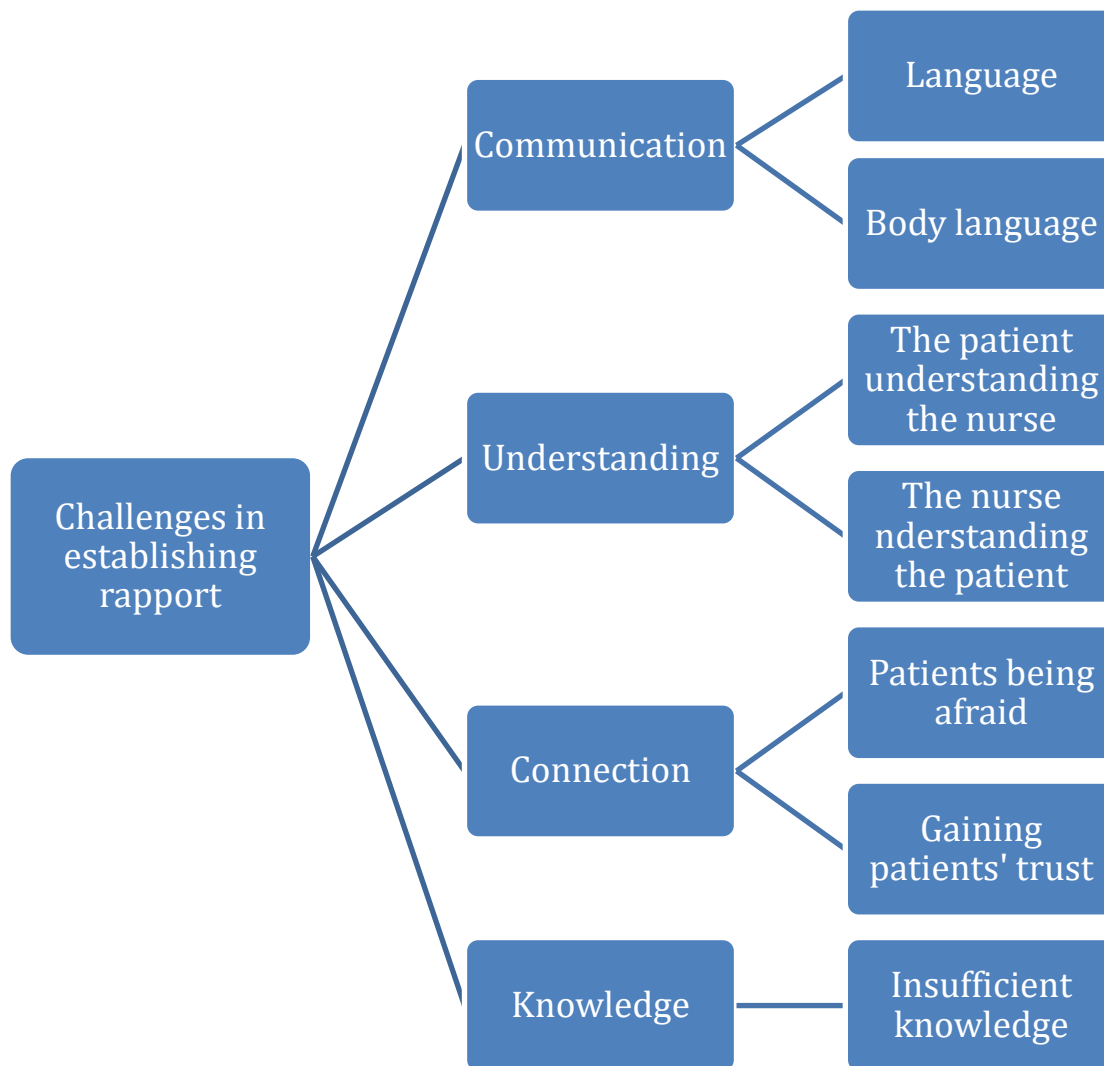


## Appendix 2/6



*Appendix 2, a schematic image showing how the 1<sup>st</sup> theme; Nurses' attitudes was formed using content analysis.*

## Appendix 3/6



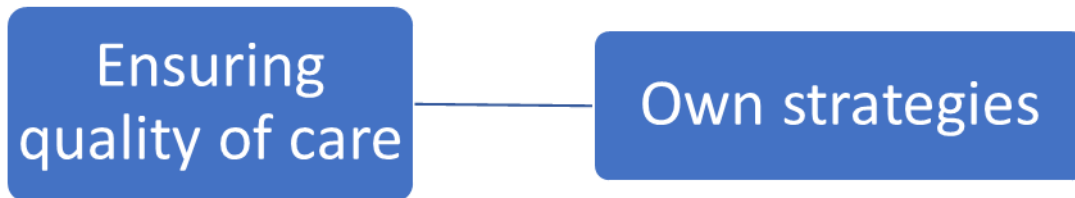
*Appendix 3; a schematic image showing how the 2<sup>nd</sup> theme “Challenges in establishing rapport” was formed using content analysis*

## Appendix 4/6



*Appendix 4; A schematic image showing how the 3<sup>rd</sup> theme “Overcoming Challenges” was formed using content analysis.*

## Appendix 5/6



*Appendix 5; a schematic image showing how the 4<sup>th</sup> theme “Ensuring Quality of Care” was formed using content analysis*

## Appendix 6/6

Themes	Categories	Subcategories	Quotations
Nurses' Attitudes	Not a challenge		<ul style="list-style-type: none"> <li>-Actually it is not that different with them than with other patients.</li> <li>- In my opinion it is not more difficult to care for a patient with developmental disability. But it feels safe when they have their own caregiver with them.</li> <li>-I do not think it is a challenge to care for a patient with developmental disability.</li> </ul>
	A motivating challenge		<ul style="list-style-type: none"> <li>- It is actually quite fun with them, but it is always a challenge.</li> <li>- I would not think that it's a challenge we cannot manage, I would rather say that it is a challenge that we will manage.</li> <li>- It is always a challenge when they come</li> <li>- It's always a bit extra when they come.</li> </ul>
	A mental challenge		<ul style="list-style-type: none"> <li>- I think it is more challenging mentally. I feel bad for the patient and for his or her parents.</li> </ul>
Challenges in establishing rapport	Communication	Language	<ul style="list-style-type: none"> <li>- They can always express themselves in some way.</li> <li>- Challenges can be the communication.</li> <li>- It can be difficult if they have sign language, some speak unclearly and have their own signs.</li> <li>- It becomes quite challenging since my main work tool is my language. I need to make myself understood and I need to understand the patient, and if there is no language this becomes more challenging.</li> </ul>

	<p>Understanding</p>	<p>Body language</p>	<ul style="list-style-type: none"> <li>- You need to bring it down to a level that the patient can understand.</li> <li>- Eye contact is important. You can see on the eyes how a person is feeling. You can see on their eyes if they are afraid.</li> <li>- Aggression and anger are also ways of communication</li> <li>- It is a challenge to get them to co-operate with us.</li> </ul>
		<p>The patient understanding the nurse</p>	<ul style="list-style-type: none"> <li>- You never know how good contact you get with them. Do they understand what you mean?</li> <li>- That they understand what you mean and that they understand what they have been through</li> <li>- Many times they understand more than one would think.</li> <li>- The patient might not cognitively understand why he or she needs the care that I am offering.</li> </ul>
		<p>The nurse understanding the patient</p>	<ul style="list-style-type: none"> <li>- You have to read between the lines.</li> </ul>
	<p>Connection between nurse and patient</p>	<p>Patients being afraid</p>	<ul style="list-style-type: none"> <li>- They can be aggressive, or they can be very happy and nice.</li> <li>- They can be anxious.</li> <li>- They are a bit anxious when they come to a new place, it does not feel safe to them</li> <li>- When they come to us, they are scared, they are anxious, because we are people they are not used to.</li> <li>- If it becomes stressful and people start to yell they become scared.</li> </ul>
		<p>Gaining patients' trust</p>	<ul style="list-style-type: none"> <li>- As a nurse you have to make them feel safe, so they don't become anxious.</li> </ul>

Overcoming challenges	<p>Knowledge about developmental disabilities</p> <p>Help from others</p>	<p>Insufficient knowledge</p> <p>Help from the relative</p>	<ul style="list-style-type: none"> <li>-Just try to act as natural as possible. Explain everything you do.</li> <li>-Try to be and talk as calmly as possible.</li> <li>-Try to find a way to communicate.</li> <li>-Talk calmly, try not to get stressed.</li> <li>-Get down to their level.</li> <li>- I try to show them that I am on their side.</li> <li>-Move forwards slowly and try to find the right way</li> <li>-It is all about the small details.</li> <li>-Use your hands to make them feel relaxed.</li> <li>-Stay calm and try to get the patient to communicate with you.</li> <li>-Just start all over again.</li> <li>-You want them to co-operate and to trust you.</li> </ul> <ul style="list-style-type: none"> <li>- There is such a big variation between developmental disabilities.</li> <li>- Although I have been working for a long time I don't know much about developmental disabilities.</li> </ul> <ul style="list-style-type: none"> <li>- Having their own caregiver or relative there makes our job so much easier. They know the patient and know exactly what they mean or how they want things.</li> <li>- We always try to make it possible for them to have a caregiver or relative with them.</li> <li>- Their own caregiver can help.</li> <li>- We try to manage without the relatives as far as possible, but they are often there.</li> <li>- Nowadays the caregiver can come all the way into the operation theatre.</li> </ul>
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	<p data-bbox="437 741 632 775">Own strategies</p> <p data-bbox="437 1294 655 1328">Identified Needs</p>	<p data-bbox="703 450 919 517">The relative as a burden</p> <p data-bbox="703 600 887 667">Help from co-workers</p> <p data-bbox="703 1294 895 1328">Learning more</p> <p data-bbox="703 1697 863 1809">Good information prior to care</p>	<ul style="list-style-type: none"> <li data-bbox="951 197 1390 409">- Bring their caregiver quite fast so they can help with communicating. Often the patient with developmental disability becomes more anxious if you stand there talking as a stranger.</li> <li data-bbox="951 454 1366 521">- If something happens we have two to take care of.</li> <li data-bbox="951 600 1366 701">- You're not alone, you have others in the team with you that can help.</li> <li data-bbox="951 745 1342 857">- Once I had a patient in my office with me for a long time while I was doing paperwork.</li> <li data-bbox="951 857 1342 992">- I use my body language and consider how I stand and hold my body so I don't provoke anything unnecessary.</li> <li data-bbox="951 1003 1358 1037">- Sometimes I use support sign.</li> <li data-bbox="951 1037 1334 1104">- Sometimes I use pictures to explain a scenario.</li> <li data-bbox="951 1115 1358 1216">- Many times it helps to be creative, find a computer, show them images when explaining.</li> <li data-bbox="951 1294 1374 1361">- It would be good to learn some kind of communicative aid.</li> <li data-bbox="951 1373 1390 1440">- Sign language would be good to know.</li> <li data-bbox="951 1451 1374 1552">- It would be good to know a bit more about different developmental disabilities.</li> <li data-bbox="951 1563 1382 1664">- Regular schoolings and good information before a patient with developmental disability comes.</li> <li data-bbox="951 1697 1374 1877">- It is very important that we get a good report about what the patient is like, what he or she reacts on, and how he or she wants to be treated.</li> <li data-bbox="951 1888 1318 1955">- The information from their caregivers is important.</li> <li data-bbox="951 1966 1366 2022">- Talk with the patient's caregiver or relative about what</li> </ul>
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Ensuring quality of care	Own strategies		<p>the patient likes or reacts to, so that you know how to handle the situation.</p> <ul style="list-style-type: none"><li>- I care for everyone equally. They get the same care as a police officer or doctor in the other bed.</li><li>- Go into each situation with an open mind.</li><li>- When you have a patient with a developmental disability you have only that patient, especially if it is a child you have only one.</li><li>- If they have someone they know there, they feel a lot safer. Sometimes I've met them before the operation, and then when they wake up they see you again, then it is almost like they know you.</li></ul>
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