



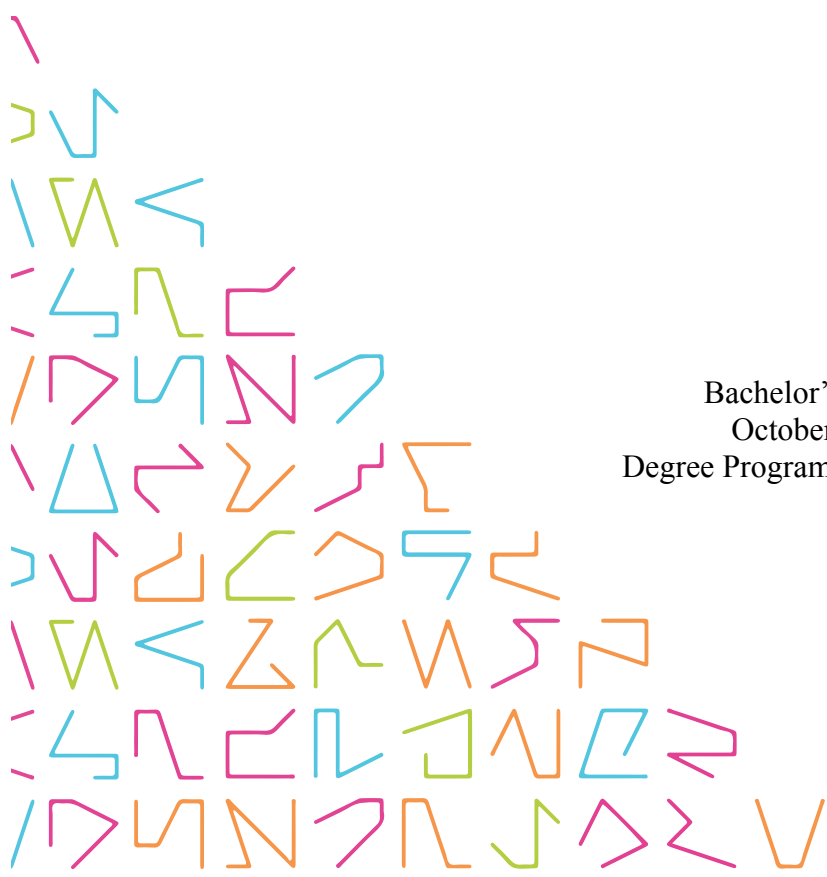
TAMPEREEN
AMMATTIKORKEAKOULU

MEETING A PROFOUNDLY DISABLED PERSON IN NURSING

Teaching Material for Tampere University of Applied
Sciences

Sointu Laaksonen

Bachelor's Thesis
October 2016
Degree Programme in Nursing



ABSTRACT

Tampereen ammattikorkeakoulu
Tampere University of Applied Sciences
Degree Programme in Nursing

LAAKSONEN SOINTU:
Meeting a Profoundly Disabled Person in Nursing
Teaching Material for Tampere University of Applied Sciences

Bachelor's thesis 31 pages, appendices 12 pages
October 2016

There are around 50 000 individuals with disabilities in Finland. Disabilities are such a narrow field of specialisation. Most nursing studies do not have any teaching about the subject, even though most nurses will come across with disabled individuals during their career. The ultimate goal of this study was to produce teaching material to fill this gap and give information about profound disability.

The aim of the study was to gather information about profound disability and how to meet profoundly disabled patients in nursing. The purpose of the study was to produce teaching material for Tampere University of Applied Sciences nursing teachers. The product was conducted keeping in mind that the target group was nursing students and the objective of the study was to enhance nursing students' abilities to meet a disabled patient. The study was limited to consider adults who have a profound disability. Working life connection was Tampere University of Applied Sciences.

The study was functional in nature. The data were collected from literature. Main concepts were nursing, meeting a patient in nursing, profound disability and most common health problems associated with profound disability. These main concepts were the theoretical starting points of the study and they are also the base for the product. The product developed throughout the whole process. The thought in the beginning was to give suggestions about what should be asked from the carers of the disabled person when the disabled person is coming to the hospital. During the literature review it was detected that these suggestions were not found from the literature. The ultimate form of the product was clear, structured, overall information about profound disability and meeting patients from this group. The product is available for teachers to use in their lectures.

The literature review revealed that epilepsy and psychiatric disorders were the most common comorbidities associated with the profoundly disabled. It was also found out that challenging behaviour is common within profoundly disabled individuals. Profoundly disabled individuals express indisposition in exceptional ways, the most common way was self-harm. Clear and simple communication were noted to be in a key role when interacting with a disabled patient.

Key words: intellectual disability, nursing, profound disability

TIIVISTELMÄ

Tampereen Ammattikorkeakoulu
Degree Programme in Nursing

LAAKSONEN SOINTU:

Syvästi kehitysvammaisen kohtaaminen hoitotyössä
Opetusmateriaalia Tampereen Ammattikorkeakoululle

Opinnäytetyö 31 sivua, joista liitteitä 12 sivua
Lokakuu 2016

Suomessa on arviolta 50 000 kehitysvammaista henkilöä. Kehitysvammaisten kanssa toimimisessa on paljon erityispiirteitä, mutta sairaanhoitajien koulutuksessa asiasta kerrotaan vain vähän, vaikka sairaanhoitajat tulevat joskus tapaamaan kehitysvammaisia työhönsään. Opinnäytetyön tarkoituksena oli helpottaa opettajia ottamaan asia puheeksi sairaanhoitajaopiskelijoiden kanssa.

Opinnäytetyön tarkoituksena oli tuottaa opetusmateriaalia Tampereen ammattikorkeakoulun hoitotyön opettajille. Opetusmateriaali kuvaa kehitysvammojen luokittelua, syvästi kehitysvammaisen piirteitä sekä syvän kehitysvammaisuuden yleisimpiä liitännäissairauksia. Tavoitteena oli muodostaa selkeä opetusmateriaali, joka ohjaa hoitotyön opiskelijoita kehitysvammaisten potilaiden kohtaamisessa.

Toiminnallisen opinnäytetyön aineisto kerättiin kirjallisuuskatsauksen avulla. Opinnäytetyön tehtävänä oli selvittää, mitä hoitajan tulee huomioida hoitaessaan syvästi kehitysvammaista potilasta ja mitkä ovat syvän kehitysvamman yleisimmät liitännäissairaudet. Opinnäytetyö rajattiin koskemaan aikuisia, syvästi kehitysvammaisia ihmisiä. Opinnäytetyön tuotos kehittyi koko prosessin ajan. Prosessin alussa ajatuksena oli antaa ideoita asioista, joita syvästi kehitysvammaista jatkuvasti hoitavilta kannattaa kysyä potilaan tullessa sairaalaan. Kirjallisuuskatsauksessa kävi ilmi, ettei kyseisiä asioita löydy kirjallisuudesta. Tuotoksen lopullinen versio oli selkeä, strukturoitu ja kokonaisvaltainen tietopaketti syvästä kehitysvammaisuudesta ja siitä, kuinka kohdata potilaita tästä ryhmästä.

Kirjallisuuskatsauksessa kävi ilmi, että syvän kehitysvamman yleisimmät liitännäissairaudet ovat epilepsia ja mielenterveyden ongelmat. Opinnäytetyön perusteella voidaan myös todeta, että haastava käyttäytyminen on hyvin yleistä syvästi kehitysvammaisilla ihmisillä ja että he ilmentävät pahaa oloaan poikkeuksellisin tavoin. Näistä tavoista yleisimmäksi osoittautui itsensä vahingoittaminen. Selkeä ja yksinkertainen kommunikointi on avainasemassa kehitysvammaisten kanssa työskennellessä.

Asiasanat: kehitysvammaisuus, hoitotyö, syvä kehitysvammaisuus

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ABBREVIATIONS AND TERMS

AAC	Augmentative and alternative communication
ID	Intellectual Disability
IDD	Intellectual and developmental disability
ICD-10	International Statistical Classification of Diseases and Related Health Problems
IQ	Intelligent quotient
SPID	Severe and Profound Intellectual Disability
TAMK	Tampere University of Applied Sciences
WHO	World Health Organization

1 INTRODUCTION

It is estimated that in Finland there are 40 000 disabled people, which means that one out of 100 Finnish citizens is disabled (Kehitysvammaliitto 2012). However, Kaski, Manninen & Pihko (2012, 21) mention in their book, that with epidemiologic studies done in Finland, it has been found that there are around 50 000 people with mental disabilities. They also point out that the prevalence of severe disabilities, which means IQ lower than 50, is internationally quite average, which indicates that 0,4% of school age children in Finland are severely disabled (Kaski et al 2012, 21–22). In the year 2014, there was 5 390 people living in the institutions for severely disabled people (Sotkanet.fi 2015), so the percentage of severely and profoundly disabled people is quite low.

Disabilities are such a narrow field of specialisation that not many nurses know how to interact or what to take into consideration when facing a disabled person. Because disabled people are living and treated in their own facilities, nurses who haven't worked with them, does not know what to do when facing one. In the nursing education in Tampere University of Applied Sciences (TAMK), there is not any teaching about disabled people even though most of nurses will meet a disabled people at some point in their career.

In a bachelor's thesis written by Kokkonen (2012) in Pirkanmaan Ammattikorkeakoulu (PIRAMK) a few years ago, the author interviewed nurses working in the emergency room in Tampere. He asked what they would like to know more about disabled people. One of the interviewees had answered that a course in nursing school about disabled people would be good. Also a few had said that they haven't been interacting with disabled people before, so they are uncertain of how to communicate with them. (Kokkonen 2012, 25–29.) This confirmed the writer's idea of the need for this kind of teaching material.

2 THEORETICAL STARTING POINTS

In this chapter the writer is going to introduce all the key concepts of this bachelor's thesis. The main concept in this thesis is on meeting the disabled patient. Nurses and nursing students need enhancing on that field because lack of information causes insecurity and meeting the patient is where enhancing is needed, the diseases are the same as non-disabled people have. The final product is going to be teaching material for TAMK to use, because that is an efficient way of giving the information for the future nurses.

2.1 Nursing

The basic thought of nursing is promoting health and well-being (Tingle & Cribb 2013, 24). Nursing performed by a professional is based on nursing science. These professionals can be for example registered nurses, public health nurses or licenced practical nurses. Nursing is a multiprofessional field and its purpose is to promote the patient's health with the patient and guide them how to maintain it. (Leino-Kilpi & Välimäki 2008, 23–26.) Nursing is a holistic practice and nurses should be patient oriented, instead of disease oriented. In health care field individuality has a big role. Every patient should be treated individually and each patient's individuality should be respected. Patients life, their living environment, physical and social one, should be taken into consideration while taking care of them. (Rumbold 1999, 7–8.)

Burhans and Alligood (2010, 1694) interviewed nurses for their study and found out that most of their interviewees brought up following themes for quality nursing: caring, empathy, respectful interaction, responsibility, intentionality and advocacy. Some interviewees also brought up clinical skills, but they were not valued as important as earlier mentioned themes. Those six themes were described as the essence of quality nursing care. (Burhans & Alligood 2010, 1694–1695.)

Caring is considered as the first characteristic of nursing. It has the biggest role in enhancing human life and is considered as key role in nursing team. Caring includes professional knowledge and skills, respecting others, positive communication and noticing the experiences of other people. (Ara, Somibala & Urmila 2015, 87). Dahlberg & Drew

(1997, 306) present other various characteristics that nurses should have. One of these is openness, which in holistic nursing means that the nurse should not have any expectations of the patient, but they should let the patient tell them about themselves. They also mention open-heartedness. Open-heartedness means being compatible and available for others. It requires awareness and caution not to share too much of personal details as a professional. (Dahlberg & Drew 1997, 306.)

According to Lillrank (2015, 362) there are three different quality types in nursing, which are patient safety, clinical decision making and patient experience. Clinical decision making is about making the diagnosis, doing the needed examinations, such as anamnesis and tests, and making the care plan. Patient safety includes for example procedures, waiting times and information that is provided for the patient. It has to be noted that the nurse is not the only one who can endanger patient safety, the patient themselves can also cause danger to their own safety by their own actions. Patient experience however, is difficult to determine because every patient has their own perceptions. Some patients might want to know everything there is to tell about their diagnosis, when some patients want to know as little as possible. (Lillrank 2015, 362–364.)

2.2 Meeting a patient in nursing

In quality nursing, the nurse should see the patient as a human, a person and not just as the disease or illness they might have. Showing empathy and noticing their feelings rather than ignoring them is something a nurse should do in order to meet the patient as a person. Earning the patients trust and building a bond between the nurse and the patient is shown to be beneficial for their relationship. With special featured patients, e.g. demented or disabled people, there might be only one nurse they trust and that one nurse gets the most “out” of the patient. (Meeting the patient as a person... 2014, 15.)

Effective communication and positive relationship between the patient and health care professional are essential to successful medical encounters. Patients who have had effective communication with their health care provider are noticed to be more satisfied with their care. Communication is important in every medical interaction, but it plays especially big role when the patient is disabled. Studies have shown that people with disabilities are less likely to receive preventative or primary care, even though they are more

likely to have conditions that need health interventions compared non-disabled people. (Morris, Dudgeon & Yorkston 2013, 472.) Ziviani et al (2004, 213) also stated that effective communication between the health care provider and the patient is in a key role in a good relationship.

2.2.1 Meeting a disabled patient

Ziviani et al interviewed health care providers, disabled individuals and health care advocates. The importance of the advocate, for example a paid carer or family member, of the disabled patient was pointed out. The role of the advocate is to facilitate effective communication between the disabled individual and the health care provider. From health care providers' point of view was mentioned that they expect the advocate to know the patient and be able to give information about the patient. They also thought that having an advocate would ensure the information's passing to the home setting. Disabled individuals were asked about issues that they have when interacting with a health care provider. It was noted that disabled individuals would prefer to be talked directly to them, not just about them, and that they would want to be informed and talked in age-appropriate way. It was also stated that the health care providers tend to interact more with the patient's advocate than the patient. From the advocates' point of view was stated that health care providers should explain the health issues to the disabled patient in simple and clear terms and according to the patient's level of understanding. (Ziviani et al 2004, 213, 216–218.)

Blair (2011) has given instructions about how to improve the care of disabled patients. As also mentioned before, the health care provider should speak directly to the patient. If the patient has impairments with communication, augmentative and alternative communication (AAC) can be helpful. AAC can be anything from pictures to photos, symbols and signs. Non-verbal cues, such as facial expressions and sounds can express pain, discomfort or anxiety that the patient is experiencing. If the health care provider cannot understand what might be wrong, they can turn to the people who know the patient well, they usually can read the patient and tell what is wrong. Behaviour changes can allude illness or change in the condition, but assessing the patient beforehand is important, so that those changes are not interpreted as signs of the disability. (Blair 2011, 24.)

2.3 Profound disability

According to WHO, disability is a hypernym for activity limitations, impairments and restrictions in participating. Activity limitation means that the person has difficulties executing a task or action, impairment is a problem in body structure or body function and participation restrictions means the person is having problems while involving in life situations. (WHO 2015.) There are several different terms, such as mental retardation, learning disability and intellectual disability, in literature that are used for disability. All of them emphasise different things. Mental retardation emphasises the neurological dysfunction, learning disability highlights the learning difficulties and intellectual disability emphasises the primary dysfunction. Learning disability is used in British literature when intellectual disability is more used in American literature. (Patja 2001, 13.)

In order for the doctor to diagnose a person with intellectual disability (ID), there has to be three criteria that the person fills. These criteria are: IQ lower than 70, significant limitations in at least two adaptive skill areas and onset before the age of 18. Adaptive skills areas are for example communication, self-direction, self-care and social skills. Classification of different stage disabilities are presented in figure 1. Intellectually disabled people are commonly known to have difficulty in interacting with environment. (Fisher 2004, 48–49.) People with ID are usually known to have other behavioural problems, such as smearing with feces, aggression that is directed towards others and self-injurious behaviour (VanderSchie-Bezyak 2003, 54). There are many causes to intellectual disabilities, such as brain injury, brain malformation and other genetic or acquired syndromes. In half of ID cases, the cause is clear, but in the other half the underlying reason cannot be determined even when investigated. (Arvio & Sillanpää 2003, 108.)

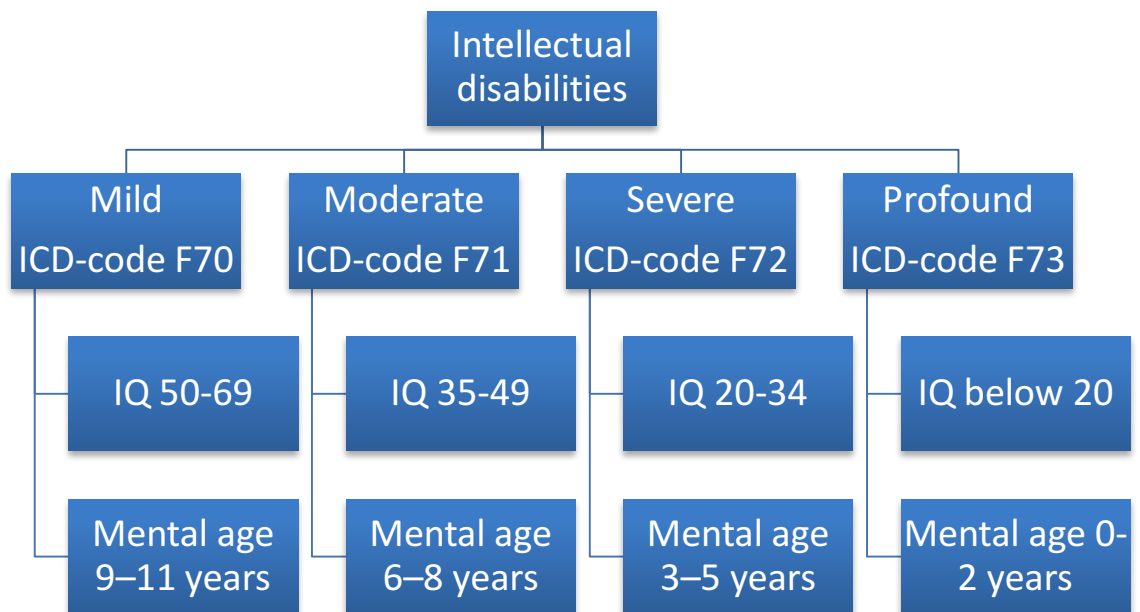


FIGURE 1. Classification of intellectual disabilities (Modified from Kaski et al 2012, 18).

Profoundly disabled people are completely dependent of other people's help, day and night. They have severe deficiency in communication and movement and they are unable to take care of personal actions and control their bladder and bowel. People with profound mental disability have IQ below 20 and their mental age is from zero to two years. A study made in Finland found out that 60% of severely and profoundly disabled people have restricted ability to express themselves or understanding speech and 50% of them have epilepsy, 35% have different stage physical restrictions and 22% have some type of psychiatric disorders. (Arvio & Aaltonen 2011, 15–16.) Most common associated impairments with severe and profound intellectual disability (SPID) are speech defects, epilepsy and motor handicaps (Arvio & Sillanpää 2003, 109).

In the 1960's ID individual's life expectancy was around 18 years (Patja 2001, 18). During the past years it has increased and especially younger disabled individuals are expected to live as long as their non-disabled peers (Fisher 2004, 50). Patja (2001,18) states in her study that more severely disabled individuals still have poorer life expectancy, but low intelligence necessarily does not mean the person has a shorter life. Because of the increase of life expectancy, disabled people are more likely to have same chronic illnesses

as non-disabled people, such as diabetes, cardiovascular diseases and cancers. People with disabilities have more physical and chronic health problems than non-disabled people, but they are still more likely to receive inadequate care for their problems. This derives from lack of resources, inadequately trained health care professionals and the stigma associated with disabilities. (Fisher 2004, 50–51.)

2.4 Most common health problems associated with profound disability

Van Schrojenstein Lantman-De Valk, Metsemakers, Haveman and Crebolder (2000, 405–406) learned in their study that people with ID have 2.5 times more health problems than people without ID. The most common problems were neurological and psychological problems. Eye and ear problems were listed as third and fourth common health problems. They also noticed that prevalence of sensory impairments is much higher with intellectually disabled people than people without ID. The authors came to the conclusion that ID people's problems with communication might be because of sensory impairments. (Van Schrojenstein Lantman-De Valk et al 2000, 406.) Because of these findings the writer of this thesis decided to choose the following two topics to be concentrated on.

2.4.1 Epilepsy

Epilepsy is a group of neurological conditions that appears as recurrent seizures. Epileptic syndromes are classified by the type of seizures, age of onset and electroencephalograph characteristics, sometimes a brain scan is also needed. (Flower 2011, 332.) Epileptic seizures can be divided into two groups, depending on how they begin: generalised seizures and focal seizures. Generalised seizures begin in some network of the brain and the rapidly generalise to the whole brain, not showing any focal signs. Focal seizures begin in networks in one hemisphere and may (or may not) generalise. (Alvarez 2015, 493.)

Generalised seizure's symptoms are loss of consciousness and powerful convulsions in limbs and torso. The patient might bite their tongue during the seizure and pass secretions. In a focal seizure the patient can have advanced symptoms, such as sight-, taste-, hearing- or smell delusions. After these, the consciousness descends and the patient can not react

to stimulus. They usually do not remember these seizures afterwards. Focal seizures can also include twitching and abnormal behaviour. (Terveyskirjasto 2015.) If the seizure lasts over five minutes or repeats before the patients has returned conscious, emergency number should be called in order to get more help. There can also be a certain time limit that is agreed with the patient's treating doctor, that if the seizure lasts longer than the agreed time, emergency number should be called. (Käypä hoito 2016.)

Alvarez (2015, 496) states that older studies, that were done in institutions for intellectually and developmentally disabled (IDD) people, showed that 35–60 % of these people had epilepsy. The prevalence of epilepsy has a relation with the degree of IDD. With mild intellectual disability the prevalence of epilepsy is around 20%, when in severe and profound disability it can be as high as 50%. (Alvarez 2015, 496.) Compared to non-disabled people, the prevalence rate of epilepsy is 20 times higher with people with IDD (Hanson 2008, 474). Epileptic disorders are also more severe with severely to profoundly disabled individuals. Epilepsy with IDD people is complex, they usually have more than one seizure type and treatment is more difficult than with general people. (Alvarez 2015, 496.) Hanson (2008, 476) agrees with Alvarez in her paper. She mentions a study done in the United Kingdom, in which the authors claimed that 75% of epileptic seizures remain refractory to treatment and epilepsy with people with IDD is difficult to control (Hanson 2008, 476).

Choice of anti-epileptic drugs depends on the type of epilepsy, since not all medication works for all types of seizures. Patients are always supposed to take into the decision making progress when thinking about medication. Though with disabled people, the doctor has to consider if the patient has enough of understanding to participate, if not, doctor can discuss with patient's family. Emergency medication is used when an epileptic seizure lasts more than five minutes, usually the medication is rectal diazepam or buccal midazolam. Most epileptic seizures pass on their own and lasts less than five minutes, but can also last for longer times than that. The longer the seizure lasts, the more difficult it is to stop. (Flower 2011, 332, 339.)

If a seizure continues more than 30 minutes, it is described as status epilepticus, convulsive or non-convulsive. Convulsive status epilepticus is always a medical emergency, so it is important to try to stop the seizure before that stage. (Flower 2011, 340.) Status epilepticus occurs when the mechanisms, that usually are responsible of ending the seizure,

fails or when abnormal mechanisms start which causes the seizure to continue. If the seizure lasts more than five minutes, it is supposed to be treated as threatening status epilepticus, which means that it is treated as it was status epilepticus. If the epilepsy with a certain individual is difficult to treat, doctors can agree on other criteria according to which the situation can be classified and threatening status epilepticus. There are several different types ways of how status epilepticus appears. (Käypä hoito 2016).

2.4.2 Psychiatric disorders

Individuals with disabilities have greater possibility of developing psychiatric disorders. Diagnosing these problems with disabled individuals is much more difficult than with regular people since people with disabilities have restricted cognitive and communicative competences. (Janssen & Maes 2013, 689–690.) The actual prevalence of psychiatric disorders among IDD individuals is difficult to determine. There have been several studies about it and the results have varied very much. Some of the reasons for wide variation can be because the diagnostic criteria, cohort sizes and selective nature of study populations that have been set for the studies. (Felce, Kerr & Hastings 2009, 244.)

A survey was done in United Kingdom about antipsychotic medication that were prescribed to adults with ID. The most common indications for medication were psychotic illness, anxiety, aggression, threatening behaviour and self-harm. (Eady, Courtenay & Strydom 2015, 97.) Deb, Thomas and Bright (2001, 506) learned in their study that rate of self-harm was substantially associated with the degree of disability, impaired communication skills and female gender. On the contrary, Hemmings, Gravestock, Pickard and Bouras (2006, 274) found out in their study that self-harm was associated with younger age, but not with degree of disability or gender.

Bhaumik, Tyrer, McGrother and Ganghadaran (2008) state in their study that behavioural problems and autism spectrum disorders tend to be more common with male individuals who have severe or profound disability. The prevalence of behavioural problems might even be under-estimated, because of the communicational problems with the patient with severe to profound ID. Also ID individuals often present with unremarkable symptoms, therefore noticing and estimating their symptoms can be difficult. (Bhaumik et al 2008, 986, 992.) Various factors, such as use of antipsychotic medication, degree of ID and

attendance to any kind of day activity, were associated with different types of behavioural problems (Deb et al 2001, 511).

Challenging behaviour is common with ID individuals, prevalence varies from 2 to 60 % according to different studies (Pruijssers, Meijel, Maaskant, Nijssen, & Achterberg 2014, 162). The most common forms of challenging behaviour are self-harm, aggression and destructive behaviour (de Winter, Jansen & Evenhuis 2011, 676). Pruijssers et al (2014, 169) state in their study that according to their research, all studies about anxiety and challenging behaviour show an association between them. The relationship between anxiety and challenging behaviour is complex, probably bidirectional therefore no causal relationship can be concluded. Hayes et al (2011, 187) found out in their study that in some cases, challenging behaviour can indicate underlying mood problems, mostly low mood, with SPID individuals living in institutions. Ross & Oliver (2002, 195) have stated the same finding as Hayes et al, there is a link between challenging behaviour and mood problems with SPID individuals.

Challenging behaviour is believed to lead from stress the person is experiencing. Individuals use challenging behaviour when they are trying to stop the stress and getting away from the element that causes stress. Challenging behaviour can also be something that gives them pleasant stimulation and that way the stress fades away. If their behaviour is something that may cause disruption in other people's safety, the nursing staff should consider the possibility of restraining actions, such as chemical, physical or seclusion. If the nursing staff decides to go with the restraining actions, they have to make sure that they are still obeying the law. (Frankova 2015, 109.) Some disabled individuals use AAC to help them communicate with other people. There is a link between challenging behaviour and communication difficulties, when a person with impaired verbal communication is not understood, they might turn to challenging behaviour to let people know, there's something wrong. (Hagan & Thompson 2014, 69.)

3 PURPOSE, TASKS AND OBJECTIVE

The purpose of this thesis is to produce teaching material for TAMK nursing teachers about meeting profoundly disabled people. The objective is to provide information about disabilities for nursing students. The final product will give a brief introduction about profound disabilities and the special features they usually have. The ultimate goal of the thesis is to provide information and tools for future nurses when meeting a disabled patient and also increase the safety of disabled patients, when the nurses know what they're supposed to take into consideration in disabled people's care.

Research questions are the following:

- What needs to be taken into consideration when meeting a profoundly disabled person in a hospital?
- What are the most common health problems associated with disabilities?

4 METHODOLOGICAL STARTING POINTS

The methodology chapter describes the process of conducting the bachelor's thesis. The writing process, data collection and the product conduction are discussed in a detailed manner.

4.1 Functional bachelor's thesis

Functional thesis is a form of thesis that aims for example guiding someone's actions or organizing activities. The product of a functional thesis can be a booklet, an event, a seminar, video or a portfolio or anything the writer wants it to be. It is good if the idea for the topic comes from working life, because then it is known, that there is need for the thesis. In this thesis, the working life connection is TAMK.

The thesis should be pragmatic and executed with investigational attitude. (Vilkka & Airaksinen 2003, 9–10.) Functional thesis is always targeted to a certain group. Therefore, it is important that the thesis writer defines the target group in the beginning of the process. The content of the thesis defined according to the target group. Accurate defining of the target group helps the writer to limit the thesis topic so that it is not too wide or too narrow. (Vilkka & Airaksinen 2003, 38, 40.)

Functional thesis consists of two parts, the report and the product. The report explains what the writer has done, why and how has it been done and what are the results and conclusions that the writer found. The report also describes the work process. (Vilkka & Airaksinen 2003, 65.) The product is directed to the target group. When working on the product, the writer has to keep in mind the target group, what they already know about the topic and where and how the product is going to be used. (Vilkka & Airaksinen 2003, 129.)

A functional thesis includes a literature review. Literature review is a thorough research about the topic which is going to be studied. Before beginning the literature review, the research questions have to be conducted. When research questions have been conducted, data gathering can begin. After all the data is collected the data should be analysed. (Polit

& Beck 2012, 94–96.) When conducting instructions or information booklets, source criticism is in a key role. The writer has to consider where the information has been gathered, is it for example from literature, journals or studies. The writer has to describe how the information is evaluated to be trustworthy and correct. (Vilkkä & Airaksinen 2003, 53.) In this thesis the writer used the guidelines from *Nursing Research: Generating and Assessing Evidence for Nursing Practice* (Polit & Beck 2012).

4.2 The process of this bachelor's thesis

The process of this bachelor's thesis began in the autumn of 2015 by choosing the topic. After choosing the topic, the plan was made. The study plan already includes the purpose, tasks and objective, a concise introduction about the topic and the schedule of the thesis project. Data collection and literature review were done during the spring, summer and autumn of 2016 and simultaneously this report was written. The final product was done after the written report was finished, in the autumn of 2016. Final presentation at the University of Applied Sciences was in November 2016.

A high-quality literature review is designated with several qualities. It must be thorough, up-to-date and the writer has to become an expert of the topic. Another feature of high-quality is that it is systematic, the writer has clear criteria for including or excluding resources. A good literature review is also reproductive, which means that another reviewer should be able to come to the same conclusions with the same criteria and decision rules as the person who made the original study. Primary sources are recommended to be used the most since they provide more accurate than secondary sources. Also secondary sources are rarely completely objective. (Polit & Beck 2012, 95–97.) The thesis writer decided to use a few secondary sources even though it is not recommended. The writer reviewed the information presented in the secondary sources and the reliability of the source. Thesis writer came to the conclusion after doing searches on the internet databases that the information will not be found anywhere else and decided to use the secondary source.

If the topic is studied before, there are many types of research material available for the thesis writer. It is good to review the possible resources before using them. There are a few good criteria for reviewing the resources: when and where has it been published and

is it a reliable and known publisher. If there is a certain author that is cited in several different resources, she or he is probably quite known and reliable author in their own field. (Vilkka & Airaksinen 2003, 72.) The writer of this thesis aimed to review the found resources according to these criteria. The journals where the articles were published, were reviewed by the writer of this thesis. The writer also tried to find the original sources from that were cited in the articles and seemed like they would be suitable for this thesis. The writer mostly used articles published in different journals, such as *Journal of Intellectual Disability Research* and *British Journal of Learning Disabilities*, which the writer had evaluated as trustworthy and reliable sources.

For this thesis the writer searched for resources for the literature review mostly from Cumulative Index for Nursing and Allied Health Literature (CINAHL) and TAMK Finna, which is an internet library that provides e-books, e-articles and such for TAMK students to use. In the beginning of the process the writer used also PubMed, but it did not provide any relevant results, when the writer made the searches. The writer searched from CINAHL using search words such as: disability, profound disability, profound retardation, mental retardation, nursing care, epilepsy, communication, challenging behaviour, nursing, augmentative and alternative communication and psychiatric disorders. The research results varied very much depending of the search words. Most of the found results were eventually excluded, because they did not have the profound/severe disability aspect in them. The writer excluded all studies that had children because the thesis is about adult patients. The writer limited the topic to consider profoundly disabled individuals, because they need the most help and are the most difficult to communicate with. If the future nurses know how to meet the most difficult types of patients, they also know how to meet the less severe individuals who possibly are able to communicate by themselves.

Limitations of the search are used to ensure that the results are accurate. Limitations such as full text only, English language and peer-reviewed articles were used in the search. Even though the writer is a native Finnish speaker, she decided to not search for studies in Finnish language, since she did a search in CINAHL for Finnish resources, but did not find any. Some Finnish books about disabilities and methodology were used as resources. The writer did a few searches in the beginning of the process with limiting the years from 2006 to 2016, but the results were too narrow. The writer then decided not to use any

limitations with the publishing year. Also trustworthy websites such as WHO and Kehitysvammaliitto were used. Inclusion and exclusion criteria are presented in table 1.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> ○ Profound & severe disability ○ Adult ○ Full text ○ Peer reviewed 	<ul style="list-style-type: none"> ○ Mild & moderate disability ○ Children ○ Languages other than English & Finnish

TABLE 1. Inclusion and exclusion criteria

4.3 Teaching material

Teaching material can be almost anything, for example a book, picture, slide-show, recording, internet page or learning game. From pedagogical point of view, a good teaching material is not aiming for brief and shallow learning experiences, but the ambitious goal should be enriching the student's cognitive knowledge. (Uusikylä & Atjonen 2005, 164–165.) Tuononen and Pelkonen (2004) described teaching material as high-quality, flexible and goal-directed. In quality teaching material, the focus should be in the elements that support the study process along with forwarding the information. Teaching is described as teacher's intentional actions to help the student learn. Teaching itself does not lead to learning, student's active role as a learner besides teaching is in a key role in learning. (Tuononen & Pelkonen 2004, 70–72.)

When producing teaching material, defining the target group and setting the goals are important. When setting the goals, two concepts should be remembered: setting goals for the content and for the materials' pedagogic characterisation. (Tuononen & Pelkonen 2004, 77.) In this thesis the target group were nursing students. The writer did not define target group more detailed than that, because it was not known at what point of nursing studies this teaching material will be used. Also by doing this, the writer was not limiting the use of teaching material to a certain part of nursing studies. The goals

of this thesis and teaching material were to give a brief introduction about profound disabilities, what are the main characteristics when treating these people and what the nurses should remember when treating profoundly disabled patient.

4.4 Product of the thesis

The product of this thesis was done to give tools for future nurses to meet disabled patients. By the information found in the literature review, the focus of the thesis was on meeting the disabled patient and also giving information of most common health problems associated with disabilities. The writer decided to make the product as an electrical form, a PowerPoint presentation, which is easy to use and modify. It also serves the target group the best. The presentation was given to working life connection to be used. The product was written in Finnish since it is going to be used with Finnish nursing students.

In the writer's opinion, a PowerPoint presentation is a good form of teaching material, since it can be delivered straight to the students as an electrical form and they can concentrate on listening to the teacher instead of writing the notes. The writer tried to keep the language as simple as possible, though keeping in mind that the target group is nursing students. The writer organised the presentation so, that first slides were general information about disabilities followed by meeting the patient and most common health problems. References were placed at the end of the presentation. The writer decided not to use any pictures in the presentation because the copyright law is quite complex. Also if the writer would have wanted to take pictures herself, many permits should have been applied from the people in the pictures or their guardian or trustee and the institution the person lives.

5 DISCUSSION

In the following chapter the writer has reflected the bachelor's thesis writing process and discussed about trustworthiness and ethics of the thesis. If any limitations have occurred during the process, the discussion chapter is the part where they should be reflected as well.

5.1 Bachelor's thesis process

The whole bachelor's thesis process was new to the writer. In the beginning of the process, methodology studies were provided at school to familiarise student with their own methodology. In these studies, the book *Toiminnallinen opinnäytetyö* (2003) by Vilkkä & Airaksinen was presented to the students. The book was an excellent guide to functional bachelor's thesis and familiarised the writer with the study's nature. Throughout the process bachelor's thesis seminars were held. The seminars were very helpful, because the writer got feedback from the whole group, not just from the opponent and supervising teacher.

In early stages of the process, the writer made a schedule to ease the planning of the process. The plan was quite solid and helped the writer to be able to finish the thesis on time. The writer attended to meetings with the supervising teacher during the process. The supervising teacher was also the working life connection for the thesis, therefore the working life connection was all the time aware of where the process is going.

In the beginning of the process, finding information was difficult. In English language mental and physical disabilities are separated and have their own meanings, when in Finnish language disability covers mental and physical disability. The writer used quite plenty of time trying to find the accurate search words to find suitable resources. Topic of this thesis is studied, but not quite broadly, as was noticed when doing the research. This gave the writer some challenge, because she wanted to find as accurate information as possible. Few of the studies were rather old, but the thesis writer decided to include them as well since they had information that none other study had. Most of the studies are quite new and have fresh information and results. The resources of this thesis were mostly research articles, but some books and internet-based sources were also used.

During the bachelor's thesis process, a few limitations occurred. As mentioned before, the literature review was conducted mostly of articles that were found from CINAHL, because it provided the most usable resources. Even though CINAHL is the most known and used database, the writer would have wanted to use some other databases to have more possibilities to choose the resources from because it would have increased the reliability of this work.

The copyright law (1961/404) states that the writer of the thesis has the copyrights for the written report and the product. The writer however, has given the rights for Tampere University of Applied Sciences to use the product for teaching. The writer has also given permission for TAMK to modify the product, if and when significant new research information is published.

5.2 Trustworthiness

Kylmä and Juvakka (2007, 127–129) describe in their book four criteria according to which a qualitative study's trustworthiness can be evaluated. They mention that these criteria have evolved from many researcher's visions. These criteria are credibility, dependability, reflectivity and transferability. Polit & Beck (2012, 584–585) rely more on Lincoln & Guba's (1985) criteria which includes credibility, dependability, confirmability and transferability. Even though functional theses rely loosely to research methodology, the writer of this thesis decided to evaluate her work through these criteria, since being as transparent is a feature of a good quality research (Vilkka & Airaksinen 2003, 57; Polit & Beck 2012, 596).

Credibility means the study's and its results' credibility and how the writer indicates that in the study (Kylmä & Juvakka 2007, 128). Dependability's meaning is that if another researcher did the same study with similar participants and context, would they have same results as the first researcher. The study should be conducted in such a way that another researcher is able to come to the same conclusion with same equipment than the first researcher. Credibility and dependability go hand-in-hand and one cannot be present without the other. Confirmability means that the data represents the provided information and is not created by the researcher. Researchers own bias, point of view and motivations

should not be reflected from the results. (Polit & Beck 2012, 585.) According to transferability, the finding should be possible to transfer to another setting that is similar to the one that the research was done. The researcher should give enough of descriptive information about the study so that the reader can evaluate transferability. (Kylmä & Juvakka 2007, 129.)

The writer of this thesis has done her best to write the thesis according to these criteria. The writer used peer-reviewed articles that were published mostly in known journals to confirm the trustworthiness of the thesis. She also aimed to avoid plagiarism by correct citations and references. Plagiarism is defined as presenting for example ideas, results and someone's words without referring to the original source and giving credit to the original writer (Polit & Beck 2012, 169). To be as transparent as possible, the writer tried to be as punctual as possible when writing the report of the thesis, so that the reader can have a clear picture of what has been done and how.

Some grey literature was used in this thesis' literature review. The writer used ethics textbooks to define basics of nursing. The writer came to the conclusion that the ethics books had the best definitions about nursing and the information was not found elsewhere. The writer also found some studies about nursing, but they did not provide enough of information alone. Because of that, the writer made the decision to use the textbooks as well. Also Finnish books about disabilities were used with defining disabilities. The writer decided to use the books since they gave good information about disabilities in Finland. The books gave information that most of the articles and studies used could not provide since the articles and studies were mostly done abroad. Other one of the disability books was written by a known Finnish researcher, Maria Arvio. She has done several studies according to disabilities and is an adjunct professor of medical aspects of intellectual disability. (Arvio & Aaltonen 2011, 4.) The writer justified using the book with Arvio's background as a published researcher. Grey literature is not recommended to be used because it is unpublished and less accessible information that is usually modified or filtered several times and references are inadequately done (Polit & Beck 2012, 729; Vilkkä & Airaksinen 2003, 73).

5.3 Ethics

Finnish Advisory Board on Research Integrity that is appointed by Ministry of Education and Culture supervises the ethics in research in Finland. The board's mission is to promote research ethics, give information on research integrity and prevent misconducts in research. (Finnish Advisory Board on Research Integrity 2016.) The board has published guidelines for responsible conduct of research. The guidelines consist of nine parts of which the writer of this thesis will present of few that has the biggest role in this thesis. First guideline states that in a research, commonly accepted ways of working should be followed when conducting a research, these are honesty, meticulousness and punctuality. There are also guidelines about applying research permits and respecting other researchers work by citing them appropriately and giving their achievement credit. (The Responsible Conduct of Research 2012.)

The writer of this thesis has tried her best to follow all the previously mentioned guidelines. The process of the bachelor's thesis began with applying research permits from TAMK in January 2016. The writer has tried to be as honest, punctual and meticulous as possible when writing the thesis. The report was written clearly, citation of the references was done correctly and the citations were done so, that the matter remains the same but plagiarism is avoided. Writing the report as punctually as possible increases the ethical value of the work but also the trustworthiness. In ethical consideration, trustworthiness and ethics go hand-in-hand. (Kylmä & Juvakka 2007, 155.) In this report and product, the writer has tried to be reader-friendly by trying to avoid long sentences and paragraphs. The writer has searched for studied information and has stated everything transparently, not hiding anything.

6 CONCLUSION

The purpose of this thesis was to produce teaching material for TAMK. The form of the teaching material was not regulated by working life connection, so the writer of this thesis decided to make the product as a Power Point presentation. The writer came to the conclusion that it was the most useful form of teaching material. When there are new studies done about the topic, the teachers can easily add the new information to the presentation.

For further developing suggestions the writer would like to bring out the possibility of interviewing professionals, who work with the disabled people on a daily basis. To bring out their opinion of what are the aspects they think are the most important when meeting a profoundly disabled individual. Also more information about different degrees of disabilities (mild, moderate, severe) would be beneficial, since this thesis only covered profound disability.

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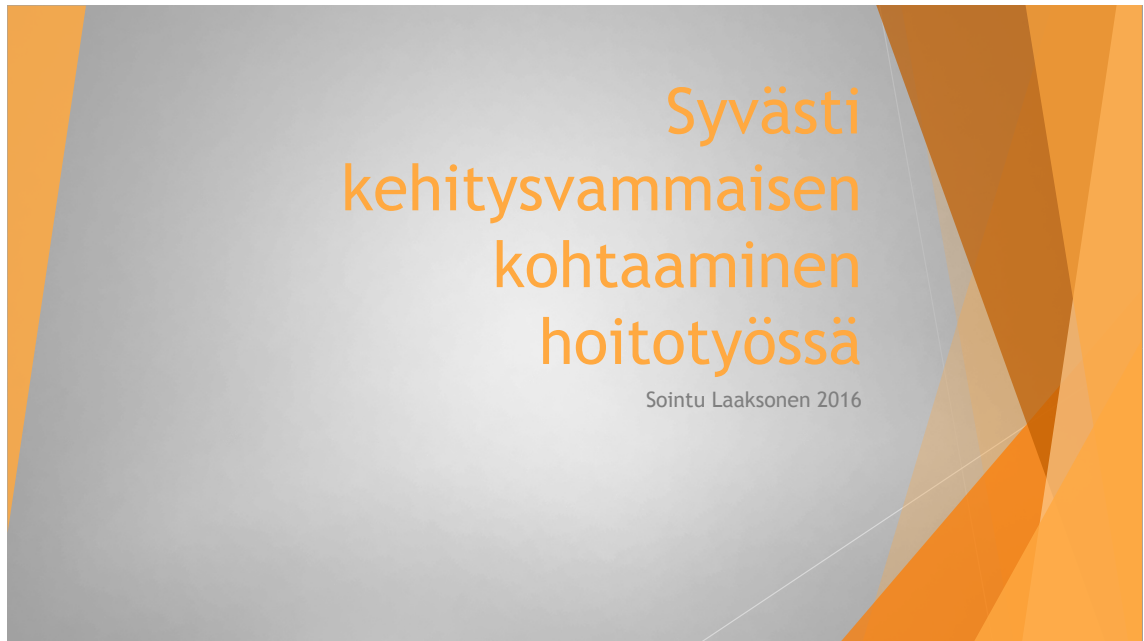
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APPENDICES

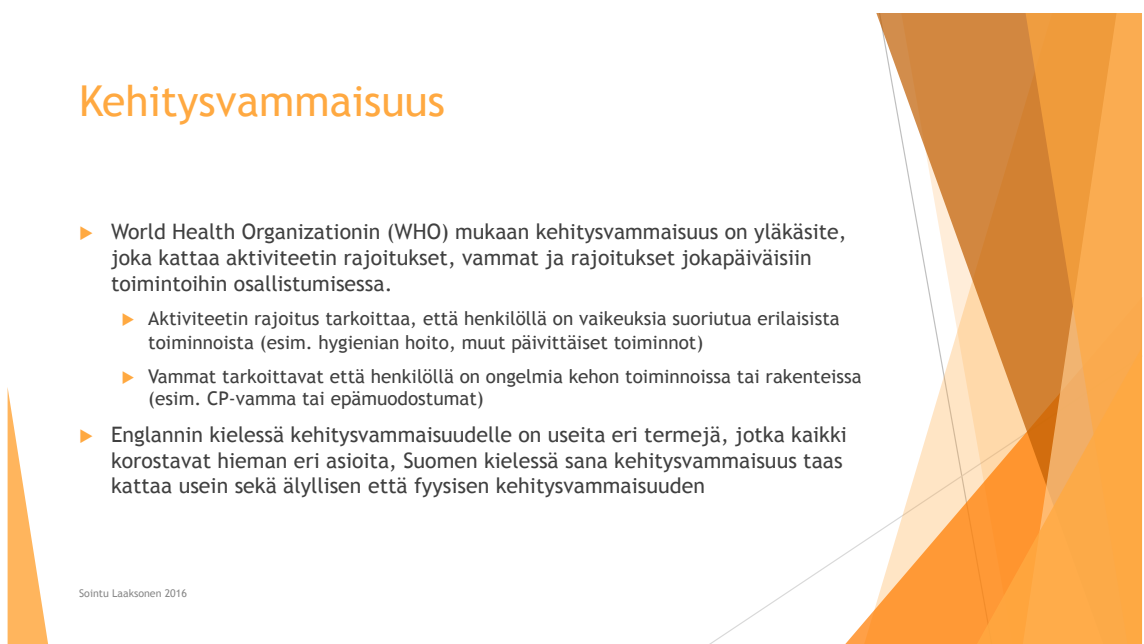
APPENDIX 1. Teaching material on profound disability

Slide 1.



**Syvästi
kehitysvammaisen
kohtaaminen
hoitotyössä**
 Sointu Laaksonen 2016

Slide 2.



Kehitysvammaisuus

- ▶ World Health Organizationin (WHO) mukaan kehitysvammaisuus on yläkäsite, joka kattaa aktiviteetin rajoitukset, vammat ja rajoitukset jokapäiväisiin toimintoihin osallistumisessa.
 - ▶ Aktiviteetin rajoitus tarkoittaa, että henkilöllä on vaikeuksia suoritua erilaisista toiminnoista (esim. hygienian hoito, muut päivittäiset toiminnot)
 - ▶ Vammat tarkoittavat että henkilöllä on ongelmia kehon toiminnoissa tai rakenteissa (esim. CP-vamma tai epämuodostumat)
- ▶ Englannin kielessä kehitysvammaisuudelle on useita eri termejä, jotka kaikki korostavat hieman eri asioita, Suomen kielessä sana kehitysvammaisuus taas kattaa usein sekä älyllisen että fyysisen kehitysvammaisuuden

Sointu Laaksonen 2016

Slide 3.

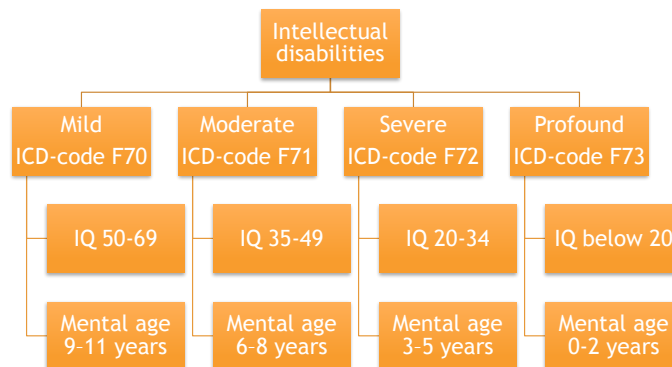
Kehitysvamman diagnosointi

- ▶ Jotta kehitysvamma voidaan diagnosoida, täytyy potilaan täyttää seuraavat kriteerit
 - ▶ Älykkyydosamäärä (ÄO) on alle 70
 - ▶ Merkittäviä rajoituksia ainakin kahdessa kyvyssä (esim. itseohjautuvuus, kommunikaatio ja sosiaaliset taidot)
 - ▶ Kehitysvamma on ilmennyt ennen 18 ikävuotta
- ▶ Noin puolella kehitysvammaisista vamma syntyy on selvä (esim. aivojen epämuodostuma, aivovamma tai perinnöllinen syy), puolessa alkuperä jää kuitenkin epäselväksi tutkimuksista huolimatta

Sointu Laaksonen 2016

Slide 4.

Kehitysvammojen luokittelu



Sointu Laaksonen 2016

Slide 5.

Syvästi kehitysvammainen 1/2

- ▶ Syvästi kehitysvammainen henkilö on täysin riippuvainen toisten avusta ympäri vuorokauden
- ▶ Heillä on vakavia vajavuuksia kommunikoinnissa ja liikkumisessa ja he ovat kykenemättömiä huolehtimaan asioistaan
 - ▶ He eivät myöskään kykene hallitsemaan rakkoaan tai suolen liikkeitään
- ▶ Suomessa tehdyssä tutkimuksessa on todettu, että 60%:lla vaikeasti ja syvästi kehitysvammaisista henkilöistä on vaikeuksia ilmaista itseään ja ymmärtää puhetta
- ▶ Samassa tutkimuksessa selvitetty, että 50%:lla vaikeasti ja syvästi kehitysvammaisista on liitännäissairautena epilepsia, 35%:lla erilaisia fyysisiä rajoitteita ja 22%:lla on psykiatrisia ongelmia

Sointu Laaksonen 2016

Slide 6.

Syvästi kehitysvammainen 2/2

- ▶ Yleisimmät liitännäisongelmat vaikeasti ja syvästi kehitysvammaisilla henkilöillä ovat puheen tuoton ongelmat, epilepsia ja motoriset vammat.
- ▶ Vuonna 2001 tehdyssä väitöskirjassa kirjoittaja totesi, että syvästi kehitysvammaisilla on huonompi elinajanodote kuin terveillä ihmisillä, mutta matala älykkyys ei välttämättä ole syy lyhyelle elämälle.
- ▶ Koska eliniänodote on noussut verrattuna siihen, mitä se oli esimerkiksi 1960-luvulla (siltoin noin 18 vuotta), on odotettavissa, että kehitysvammaisille kehittyä samantlaisia iän mukanaan tuomia sairauksia kuin ei-kehitysvammaisille henkilöille
 - ▶ Näistä esimerkkeinä sydän- ja verisuonisairaudet, diabetes ja erilaiset syövät

Sointu Laaksonen 2016

Slide 7.

Potilaan kohtaaminen 1/2

- ▶ Potilas tulisi kohdata ihmisenä, ei vain sairautena tai oireena, joka hänellä on.
- ▶ Potilaan luottamuksen saavuttaminen on hyödyllistä hoitosuhteen kannalta.
 - ▶ Erityisryhmien (esim. dementikot, kehitysvammaiset) potilaille on tyypillistä, että heillä on yksi/muutama hoitaja, johon he luottavat ja nämä hoitajat saavat eniten "irti" potilaasta.
- ▶ Tehokas kommunikaatio ja positiivinen vuorovaikutussuhde potilaan ja hoitajan välillä on tärkeää.

Sointu Laaksonen 2016

Slide 8.

Potilaan kohtaaminen 2/2

- ▶ Kommunikaatio on tärkeää jokaisessa potilassuhteessa, mutta erityisen tärkeää kehitysvammaisen potilaan kanssa.
 - ▶ Tukena voidaan käyttää kommunikoinnin apuvälineitä (esim. kuvat, tukiviittomat)
- ▶ Tutkimusten mukaan kehitysvammaiset potilaat vastaanottavat vähemmän ennaltaehkäisevää hoitoa kuin terveet vertaisensa, vaikka heillä todennäköisemmin on hoitoa vaativia terveysongelmia.

Sointu Laaksonen 2016

Slide 9.

Kommunikointi syvästi kehitysvammaisen potilaan kanssa 1/2

- ▶ Huomioi potilas ja kommunikoi suoraan hänen kanssaan.
- ▶ Kerro potilaalle mitä teet ja miksi, käytä potilaan iän mukaista kieltä.
- ▶ Käytä yksinkertaista kieltä ja huomioi potilaan ymmärryksen taso
 - ▶ Vältä ammattisanastoa potilaalle puhuessa, tue puhetta tarvittaessa esim. kuvilla
- ▶ Arvioi ja tarkastele potilaan käytöstä tulotilanteessa
 - ▶ Käytöksen muutokset saattavat kieliä potilaan tilanteen muutoksesta (uusi oire ilmenee, kipu pahenee jne.)

Sointu Laaksonen 2016

Slide 10.

Kommunikointi syvästi kehitysvammaisen potilaan kanssa 2/2

- ▶ On tärkeää huomioida myös saattaja, joka usein on potilaan hoitaja tai omainen
 - ▶ Saattaja yleensä osaa kertoa tarkemmin ilmenneistä oireista ja ongelmista joiden vuoksi potilas on tullut sairaalaan
 - ▶ Kysy saattajalta potilaan historiasta ja perussairauksista
 - ▶ Kysy, ilmentääkö potilas pelkoa tms. jollain tietyllä tapaa, miten mahdolliset epilepsiakohtaukset ilmenevät
 - ▶ Kysy myös muita tärkeitä tietoja: millaista ruokaa potilas syö, mistä hän pitää, mitä hän pelkää, miten hänet saa rauhoittumaan

Sointu Laaksonen 2016

Slide 11.

Yleisimmät liitännäissairaudet

- ▶ Hollantilaiset tutkijat saivat tutkimuksessaan selville, että kehitysvammaisilla henkilöillä on 2.5 kertaa enemmän terveysongelmia kuin ei-kehitysvammaisilla henkilöillä.
- ▶ Näistä yleisimmät ovat epilepsia ja mielenterveysongelmat
- ▶ Tutkimuksissa todettu, että noin 35-60%:lla kehitysvammaisista on epilepsia
 - ▶ Epilepsian esiintyvyys kehitysvammaisilla on 20 kertaa suurempi kuin ei-kehitysvammaisilla
 - ▶ Epilepsian esiintyvyys on suhteessa kehitysvamman vaikeuteen → vaikeasti ja syvästi kehitysvammaisilla henkilöillä todetaan enemmän epilepsiaa kuin lievästi ja keskivaikeasti kehitysvammaisilla

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Slide 12.

Epilepsia kehitysvamman liitännäissairautena 1/3

- ▶ Epilepsia on häiriötila aivojen sähköisessä toiminnassa, joka ilmenee uusiutuvina kohtauksina
- ▶ Kohtauksia on kahdentyyppisiä ja ne jaotellaan alkamistavan mukaan
 - ▶ Yleistyneet kohtaukset
 - ▶ Yleistyneet kohtaukset alkavat tietystä aivojen osassa yhdellä aivopuoliskolla ja nopeasti yleistyvät koko aivojen alueelle
 - ▶ Oireita: tajunnanmenetykset, voimakkaasti kouristavat raajat ja vartalo, potilas voi purra kieltänsä ja virtsata ja ulostaa allensa
 - ▶ Kohtaus menee yleensä ohi muutamassa minuutissa, jälkioireina yleensä esiintyy väsymystä ja sekavuutta, jotka voivat kestää jopa tunteja

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Slide 13.

Epilepsia kehitysvamman liitännäissairautena 2/3

- ▶ Paikallisalkuiset kohtaukset
 - ▶ Paikallisalkuiset kohtaukset alkavat tietyssä osassa aivoja yhdellä aivopuoliskolla, tämän tyyppiset kohtaukset voivat pysyä paikallisina tai myös yleistyä
 - ▶ Oireita: tajunnan hämartymistä, ”pysähtyneisyyttä”, potilas ei reagoi ulkoisiin ärsykkeisiin, poikkeavaa käytöstä, voi liittyä raajojen nykimistä
 - ▶ Potilas ei yleensä muista kohtausta jälkeenpäin
- ▶ Kehitysvammaisilla epilepsiakohtauksen oireet saattavat olla hyvinkin erilaisia normaaliväestöön nähden, joten muista aina kysyä kehitysvammaisen kotiyksiköstä, kuinka epilepsiakohtaus kyseisellä potilaalla ilmenee

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Slide 14.

Epilepsia kehitysvamman liitännäissairautena 3/3

- ▶ Vaikeasti ja syvästi kehitysvammaisilla epilepsiakohtausten on todettu olevan vakavampia ja vaikeahoitaisempia kuin lievästi tai keskivaikeasti kehitysvammaisilla potilailla
- ▶ Heillä esiintyy myös usein molempia kohtautyypppejä
- ▶ Iso-Britanniassa tehdyn tutkimuksen mukaan jopa 75% epilepsiakohtauksista reagoi huonosti hoitoon ja kehitysvammaisilla ilmenevää epilepsiaa on tavallista hankalampaa hallita

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Slide 15.

Epilepsialääkkeet

- ▶ Lääkityksen valinta on hankalaa, koska kaikki lääkkeet eivät tehoa kaikkiin kohtaustyypeihin
- ▶ Epilepsiaa sairastavat syövät säännöllisesti kohtauksia estäviä lääkkeitä
- ▶ Lisäksi on epilepsiakohtauksen lopettamiseen käytettäviä lääkkeitä
 - ▶ Niistä yleisin on rektaalisesti annettava diatsepaami
 - ▶ Usein käytetään myös bukkalisesti annettavaa midatsolaamia
- ▶ Useimmat kohtaukset menevät ohi itsekseen muutamassa minuutissa, mutta mitä kauemmin kohtaus kestää, sitä hankalampi se on saada loppumaan

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Slide 16.

Status epilepticus 1/2

- ▶ Status epilepticus tarkoittaa pitkittyntä epilepsiakohtausta
 - ▶ Jos epilepsiakohtaus kestää yli 30 minuuttia, se määritellään status epilepticukseksi
 - ▶ Kuolleisuus ja vammautumisen riski lisääntyvät huomattavasti
 - ▶ Jos potilas saa useita peräkkäisiä kohtauksia eikä ehdi toipua niiden välillä → status epilepticus
 - ▶ Jos epilepsiakohtaus kestää yli 5 minuuttia, tulee sitä hoitaa uhkaavana status epilepticuksena
 - ▶ Jos potilaalla on vaikeahoitoinen epilepsia, voidaan hoitavan lääkärin kanssa sopia erilaisista kriteereistä, joiden perusteella tilaa aletaan hoitaa status epilepticuksena

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Slide 17.

Status epilepticus 2/2

- ▶ Hoito
 - ▶ Ensivaiheen hoito
 - ▶ Ensiapulääkkeet (p.r. Diatsepaami ja bukkaalinen midatsolaami)
 - ▶ Suonensisäinen diatsepaami ja loratsepaami
 - ▶ Toisen vaiheen lääkkeet
 - ▶ Fosfentyoiini, valproaatti
 - ▶ Jos kerran annetut toisen vaiheen lääkkeet eivät auta → yleisanestesia

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Slide 18.

Mielenterveysongelmat kehitysvamman liitännäissairautena 1/2

- ▶ Tutkimusten mukaan kehitysvammaisilla on tavallista väestöä suurempi riski sairastua mielenterveysongelmiin
- ▶ Mielenterveysongelmien diagnosointi kehitysvammaisilla on hankalaa, koska heillä on rajoittuneet kognitiiviset kyvyt ja hankaluuksia kommunikoida
- ▶ Tarkkaa mielenterveysongelmien määrää on kuitenkin hankala määrittää
- ▶ Iso-Britanniassa tehdyssä tutkimuksessa selvitettiin mielialalääkkeiden määräämistä kehitysvammaisille
 - ▶ Yleisimmät indikaatiot olivat ahdistus, aggressiivisuus, uhkaava käytös sekä itsensä vahingoittaminen

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Slide 19.

Mielenterveysongelmat kehitysvamman liitännäissairautena 2/2

- ▶ Käytöshäiriöiden ja autismin kirjon ongelmien on todettu olevan yleisempää vaikeasti ja syvästi kehitysvammaisilla miehillä kuin naisilla
- ▶ Kehitysvammaiset usein oirehtivat epätyypillisellä tavalla, joten sairauksien ja ongelmien tunnistaminen voi olla haastavaa
- ▶ Haastava käytös on yleistä kehitysvammaisilla, sen esiintyvyys vaihtelee eri lähteiden mukaan 2 ja 60 % välillä
- ▶ Tutkijat ovat huomanneet yhteyden haastavan käytöksen ja ahdistuneisuuden välillä
 - ▶ Yhteys on molemminpuolinen, eli haastava käytös aiheuttaa ahdistuneisuutta ja ahdistuneisuus aiheuttaa haastavaa käytöstä

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Slide 20.

Haastava käytös

- ▶ Haastava käytös saattaa johtua yksilön kokemasta stressistä
- ▶ Haastavaa käytöstä ilmenee, kun yksilö yrittää saada stressin loppumaan tai päästäkseen eroon asiasta, joka aiheuttaa hänelle stressiä
- ▶ Haastava käytös saattaa myös aiheuttaa yksilölle positiivista stimulaatiota, jonka avulla stressi lievittyy
- ▶ Jos henkilö on kykenemätön ilmaisemaan itseään verbaalisesti, saattaa hän käyttää haastavaa käytöstä itsensä ilmaisuun
 - ▶ Haastavalla käytöksellä hän yrittää viestittää muille, että kaikki ei ole hyvin

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