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**Experiences of intellectually and
developmentally disabled peo-
ple in healthcare**

A Literature Review

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Abstract <p>There are several guides for nurses and other health care professionals about treating patients with intellectual and developmental disabilities (IDD): general guides, guides for people working in acute care and in palliative care, among others. However, the number of guides doesn't necessarily reflect in the way IDD patients are treated.</p> <p>The study aimed to find out what were the experiences of people with intellectual and developmental disabilities in health care. The purpose was to offer information and help health care professionals improve experiences of patients with IDD in health care.</p> <p>Using the databases of Google Scholar, EBSCO, and PubMed, a literature review was conducted. Three articles as well as two bachelor's theses were chosen for reviewing by using the PRISMA system. Answers to the research question were searched from the included articles and collected as results.</p> <p>Results gained from the research suggested that patients with IDD have more negative than positive experiences in health care. Given that there exists a wide variety of guides about IDD patients for health care professionals, it was suggested that they should be used for self-education. Due to the small amount of studies presenting IDD patients' own opinions rather than that of their guardians', further research was suggested about patient experiences by using communicational aides.</p>		
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1 Introduction

When working in health care, nurses encounter people from different patient groups. One of these patient groups is people with intellectual and developmental disabilities (IDD). However, as many nurses may not encounter IDD patients regularly, they may feel insecure and lack knowledge on how to treat them. There are several guidelines and instructions developed to help health care personnel communicate and treat patients with IDD in a way that leaves both parties satisfied. For example, Developmental Disabilities Primary Care Initiative has developed a toolkit website *Healthcare for Adults with Intellectual and Developmental Disabilities* (2011), from which health care providers can find guides on variety of things concerning patients with IDD, such as communication with patient, organizing the waiting rooms safely, and checklists for different physical and mental conditions.

Kehitysvammaisen lapsen ja hänen perheensä kohtaaminen: opas ensi- ja akuuttihoitoon (Raappana&Repo, 2011) offers guidelines for people working as paramedics and in acute care. The guide includes not only basic information about people with IDD, but also how to consider things from child patient's point of view. The authors have collected a detailed but compact guide on how to encounter the patient and their next of kin, and what kind of communication issues there might occur, and how to overcome them.

In their guide *Kehitysvammaisen saattohoito: opas henkilökunnalle* (2011, 10-34), Salenius and Salenius have gathered an encompassing collection of information about palliative and end of life care for IDD patients. The guide is not only for nurses, but for all professions working with IDD patients, and it addresses subjects like how to recognize pain and to alleviate it, common symptoms in palliative patients and how to treat them, and how to support friends and family in their grieving.

Additionally, though it is not specifically only meant for patients with IDD, perhaps the most important guidelines for nurses are the *Ethical Guidelines of Nursing developed by Assembly of the Finnish Nurses Association*. These basic guidelines offer nurses working in all fields rules they can apply on every patient. Nurses are obliged to treat "...every patient equally well according to the individual needs of the patient irrespective of the illness, sex, age, creed, language, traditions, race, colour, political opinion or social status of the patient". In other words, the nurse must provide the best care available to all patients, whether they have IDD or not. With these guides available for nurses and other health care personnel free of charge, it is in my interest to clarify if the amount of guides somehow reflects to the way patients with intellectual and developmental disabilities are treated.

The aim of this thesis is to find out what kind of experiences do people with IDD have in the healthcare. The purpose of this thesis is to offer information about IDD patients experiences to health care staff and help them improve their ability to work with IDD patients.

2 Intellectual and developmental disabilities and patient experiences

In this chapter essential terms to the subject - such as intellectual and developmental disabilities, and their effect on a person's health, as well as patient experiences - will be introduced.

2.1 IDD patients

A person who has intellectual and developmental disabilities is an individual whose development, especially intellectual, has been restricted or disturbed by a congenital disease, or an illness or defect acquired in the developing stage (Kehitysvammainen,

2017). In this thesis, I will mostly use the abbreviation IDD when referring to people with intellectual and developmental disabilities.

IDD can often be diagnosed immediately after birth, but can also occur later in life. As the reasons and gravity of IDD vary greatly on an individual level, so do the possible treatments and prognosis (Jalanko, 2016). According to Kaski, Manninen, and Pihko (2009, 15), the amount of people affected by disorders of the central nervous system that appeared at birth or early childhood is five to eight percent of the population.

According to Bartkowski, Barrie and Belanger (2015, 1) 1.5 to 3 % of the American population have IDD or a condition related to it, with Down syndrome being the most common. Other common conditions are autism spectrum disorders (or ASD), fragile X syndrome, fetal alcohol spectrum disorders, cerebral palsy, and epilepsy among others. There is a variety of possible causes for IDD, some of which are preventable, but others cannot be predicted, and thus cannot be prevented. Some of the common causes are genetic mutations, chromosomal abnormalities, in utero chemical exposure – for example if the mother is using narcotics or alcohol during the pregnancy, in utero infections, and childbirth complications.

IDD not only influences an individual's cognitive abilities, but also their physical health. According to Bartkowski et al. (2015, 2), "...patients with IDD are at a higher risk of experiencing co-occurring conditions, which complicates daily care, medical diagnoses, and treatments". Common health issues for IDD patients are bowel obstruction, gastroesophageal reflux disease, aspiration, dehydration, and seizures. For patients with Down syndrome, developmental issues in the heart's structure are a common ailment; up to 40 to 50 % of children with Down syndrome are diagnosed with a heart condition. Other often occurring conditions in Down children are tendency for obesity, problems in hearing and eyesight, infantile spasms and epilepsy, hypothyroidism, early onset dementia, and gastric anomalies (Downin oireyhtymä, 2010). For an individual with IDD, the co-existing health conditions may greatly reduce the life expectancy; for a deeply disabled person, the life span is expected to be 30 % shorter than the whole population, whereas mildly disabled person may live just as long as the rest of the population (Kaski, 2002, 150).

With such an array of different health issues, people with IDD are certain to need medical assistance on a regular basis during their lifetime. For example, even a generally healthy person with Down syndrome is expected to have an auditory check up every two years, and males are advised to an annual clinical assessment due to increased risk of testicular cancer. It is also advised that dental assessment should be done to Down syndrome patients every six months (Healthcare for adults with intellectual and developmental disabilities – Toolkit for primary care providers, 2017).

2.2 Patient experiences

Patient experience surveils patients on what they did or did not experience in their encounters with health care providers. Surveying these experiences is important, because patient experience is considered the most effective measure of patient-centeredness, which is especially crucial in the health care setting. Measuring patient experiences also serves as a means to understanding and improving the quality of care. Problems with returning test results, coordination and communication may be identified through patient surveys. Even though collection of the information is crucial, the goal is to use the information for improvement (Browne et al. 2010, 922).

When estimating patient experiences, there are five domains that can be taken into consideration. First, access and waiting, or how long did the patient wait until seeing a nurse or doctor. Second, safe, co-ordinated quality care, or was the patient informed about any danger signals regarding the illness or treatment. Third, information and choice, or did the patient feel like they were involved in decisions about their treatment. Fourth, building relationships, or did the doctors or nurses talk about the patient like they were not present. Fifth, clean, comfortable environment, or did the patient feel they were treated with respect and dignity. Overall patients' experiences have been good, showing modest improvements over time (Honeyford et al., 2017, 2).

3 Aim, Purpose, and Research Question

The aim of this study is to find what kind of experiences do people with IDD have in the healthcare. The purpose is to offer information about IDD patients experiences and thus help health care staff to improve their skills and knowledge about working with IDD patients.

Research question:

What are the experiences of patients with IDD in health care?

4 Methodology

4.1 Literature review

Literature review is a method where already existing researches are being re-searched. In other words, collecting research results to gain new results (Salminen, 2011, 1). When conducting a literature review, a research question is identified and then answered through systematic analyzation of relevant sources. By doing this, the researcher is able to develop new insights by considering all the information they have gathered (Aveyard, 2010, 5-6). Literature review provides a compact overview of "...vast and scattered assortment of articles on a topic..." to the reader who might not have the time nor the resources to review them all themselves (Baumeister&Leary, 1997, 311). Nurses and other health care personnel must always educate themselves about the ever-changing health care knowledge in this "age of accountability", where the status quo can no longer be accepted (Potter, 2015, 86), and in that sort of situation a literature review is useful. Literature review was chosen for this thesis in order to offer health care professionals a compact review on the subject.

4.2 Literature search

Literature search was done between early September and early November 2017. To allow a wider range, it was decided that also experiences from the IDD patients' guardians, and from other fields of health care were to be included, rather than limit the usable studies to those that only include the hospital or health center settings. Multiple databases were used in the process of finding information to acquire a sufficient amount of studies on the subject. The studies and articles used were found on Google Scholar, EBSCO, and PubMed databases. Other databases were also searched, but the studies found there were either not relevant or not freely accessible.

Search words used while searching information included in Finnish "kehitysvammainen", "potilas", "kokemus", and all of the afore mentioned together. In English "intellectual disability", "developmental disability", "intellectual and developmental disability", "IDD patient", and "patient experience" and all of the afore mentioned together. Inclusion criteria can be seen in figure 1.

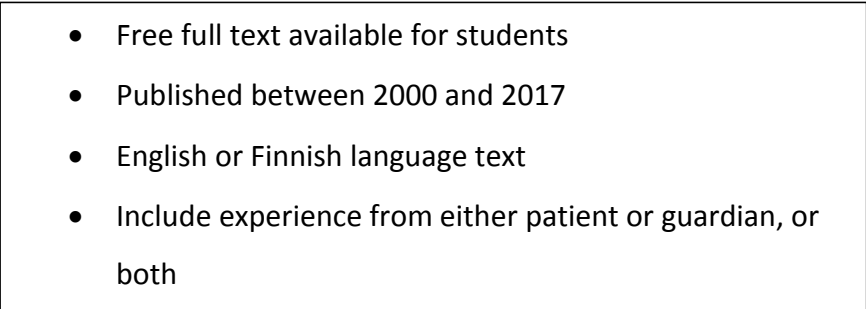
- 
- Free full text available for students
 - Published between 2000 and 2017
 - English or Finnish language text
 - Include experience from either patient or guardian, or both

Figure 1

If the found studies and articles did not fit the criteria, they were excluded from the results.

Initial search from the chosen databases showed that there were 113 526 articles to be found with the selected search words. Because search from the Google Scholar database produced such a large amount of results (108 000 in English and 3650 in Finnish), it was decided that only the first 30 studies to appear in the results from both English and Finnish searches were to be used. The same method was used when searching information from PubMed database (869 results). EBSCO database search produced seven results with the chosen search words, so they were entirely

screened. Data extraction was executed with the PRISMA or Preferred Reporting Items for Systematic Reviews and Analyses (Moher et al. 2009). Altogether 97 studies were screened. 91 studies were excluded based on titles and abstracts. The remaining six studies were then considered with the inclusion criteria, and three were included in the literature review. Because of the small amount of relevant studies found, two bachelor's thesis that were considered to be relevant to the research question were also included in the literature review. Reviewed articles are listed in figure 2.

Figure 2

Author/s	Year, country	Title	Method	Main findings
Bonell, S., McCarthy, J, Underwood, L. & Radhakrishnan, V.	2012, United Kingdom	<i>Experiences of mental health services by people with intellectual disabilities from different ethnic groups: a Delphi consultation</i>	Two-round Delphi process and rating by using a Likert scale	White IDD patients had more positive experiences in health care than their black counterparts.
Bye, A. & Aston, M	2015, Canada	<i>Brenna's story – A critical reflection and analysis of one mother's experience of navigating the medical system with a child with intellectual disabilities</i>	Critical reflection and analysis	Forced procedures and misinformation may cause negative experiences for both patient and their guardian.
Iacono, T., Bigby, C., Unsworth, C., Douglas, J. & Fitzpatrick, P	2014, United Kingdom	<i>A systematic review of hospital experiences of people with intellectual disability</i>	Systematic literature review	Limited knowledge or problematic attitudes of the staff may result in neglect of patients with IDD.
Keppo, K.	2012, Finland	<i>Kehitysvammaisten kokemukset kohtaamisista palvelujärjestelmässä – Autonominen käyttäjä vai riippuvainen avuntarvitsija</i>	Themed interview and analysis	Listening and respecting may lead to more positive patient experiences.
Korhonen, P.	2014, Finland	<i>Kehitysvammaisten terveyspalveluiden asiakkaana – saattavan omaisen näkökulma</i>	Qualitative research and interview	Not addressing patients themselves may result in negative experiences.

4.3 Data analysis

When analysing the data, two things should be considered: relevancy and quality. Whether the article is relevant or not to the study can be simply identified by reading the material and determining whether it answers the research question. Determining the quality of the read articles is the responsibility of the reader. For example, if the article is relevant to the research question, but it is noticed that it has not been undertaken in a proper manner, the researcher must consider whether they want to use such article in their literature review (Aveyard, 2010, 90-91). Relevant articles from scientific journals were used to gain the results. The included articles were read and searched for answers to the research question. The results were then gathered and described in the 'Results' chapter.

5 Results

Negative experiences

The patients described their encounters with healthcare mostly in a positive way, but some negative aspects were found as well. Especially patients over the age of 40 expressed they had negative memories about medical treatments. It was not uncommon in the 1970's for the patient to be tied down if they refused to cooperate, and even children would often spend long periods of time in the hospital without their parents. One patient described a memory of a traumatizing dentist treatment, during which he was tied down against his will, and "all the teeth were ripped off" (Keppo, 2012, 49).

Some IDD patients and their guardians have reported to be fearful about hospital visits, and also to have more negative experiences and outcomes in health care, often because of limited knowledge or problematic attitudes of the staff. Out of 119 IDD

patients, 39% reported that they were not able to get to the toilet when they felt the need, and only 12% of them received the correct medication (Iacono et al., 2014). One mother of an IDD patient also expressed her dissatisfaction about forced procedures: it is hard for the parent to see their child undergo painful or otherwise uncomfortable examinations, especially if the parent is not informed on why the examination is necessary. This particular mother was also told that her "daughter will never function in society" by a doctor, which both the mother and patient found very unsettling and unjustified, because despite her learning disabilities, the daughter was happy and healthy (Bye&Aston, 2015, 82-92).

Another negative example can be found in a thesis by Korhonen (2014, 27), where patients' next of kin reported that healthcare staff doesn't always know or make the effort to communicate with the patient in a way they can understand, and also executing procedures on the patient without warning the patient beforehand. Some patients also found it insulting if the doctor or nurse didn't address the patient themselves, but their parent or assistant instead when talking about medical information concerning the patient.

Positive experiences

Though some patients had negative experiences about health care staff addressing their guardian rather than the patient themselves, some patients found this a good practice to some extent. For example, a patient with epilepsy thought it was a good idea to ask about his seizures from someone else – after all, he didn't know what they were like as he would be unconscious when they occurred (Keppo, 2012, 53). Positive experiences were found elsewhere, too. Overall, the patients thought they had received good care in health care. Being respected and listened to were important to all the interviewed patients. General care giving, such as ensuring sufficient pain medication after a surgery or other procedures was also mentioned to be a crucial factor to the patients when considering whether they were happy with the way they were treated (Keppo, *ibid.*).

In a study conducted in mental health institute in London, there was some variation in patient experience between different patient groups. Whereas most white patients had positive experiences about how the staff treat them and the care they receive, there was significantly less patients who thought so among black patients. Though neither white or black patient groups reported to have experienced or witnessed racist behaviour from the staff, black patients reported more negative experiences, especially concerning the staff rather giving them medication than talking to them and discussing with the patients (Bonell et al. 2012, 907).

6 Discussion and suggestions for future research

6.1 Reliability of the results

The research was conducted according to the Ethical Principles for JAMK university of Applied Sciences (JAMK, 2013). The findings were sufficient taking into consideration that only one research article was found in which IDD patients themselves had answered questions. The rest of the material about IDD patients' experiences in health care was from the patients' guardians point of view. Due to the limited amount of relevant studies found, two bachelor's theses had to be included as sources of information concerning the research question. However concise, the findings were relevant considering the objective. All the sources concerning the research question are fairly current, all of them from the years 2000 to 2017. Though not all the results were found in articles specifically about nursing, the gained information can be also applied in the nursing field.

6.2 Discussion of the results

The objective of this thesis was to find out what kind of experiences do people with intellectual and developmental disabilities have in health care. Research showed that patients had both positive and negative encounters with health care staff.

Negative experiences included for example forced procedures against patient's will, tying the patient, staff using medication as a result to patients' problems instead of discussing about it, and limited knowledge as well as problematic attitudes towards patients with IDD (Bonell et al., 2012; Bye&Aston, 2015; Iacono et al., 2014; Keppo, 2012). Not addressing the patient themselves rather than their guardian was also seen as a negative impact on patient experience, though some patients found it a good practice that the health care staff spoke to their guardian rather than the patient themselves, because they figured the guardian could offer information the patient themselves might not be able to provide (Korhonen, 2014). Positive experiences also included being taken good care of after operation, such as providing sufficient pain medication to the patient. Being respected and listened to were also noted as positive experiences (Keppo, 2012). There was a difference between experiences of different ethnic groups: white patients reported mainly positive experiences, whereas black patients were less pleased with their treatment in mental health services (Bonell et al., 2012).

When searching for the answer to the research question, the results that were found strongly suggest that patients with intellectual and developmental disabilities seem to have more negative than positive experiences from health care. Positive experiences exist too, and even between different patient groups the results between positive and negative differ greatly. However, negative experiences seem to surpass the positive ones. Only a small number of patients with IDD received their correct medication (Iacono et al., 2014). People with IDD might not live as long as the general population even if medicated correctly, let alone when given incorrect medication, so special care should be put in ensuring safe medication (Kaski, 2002, 150).

There is a wide variety of guidelines for nurses and other health care professionals about taking care of IDD patients in different scenarios, so they should be used if unsure how to deal with this particular patient group. Health care professionals do not have the luxury of ever knowing everything there is to know about their field of work, so limited knowledge cannot be used as an excuse of unequal treatment of already disadvantaged patients. Every patient should be treated equally no matter what their illness, sex, age, creed, language, traditions, race, colour, political opinion or social status might be (Assembly of the Finnish Nurses Association, 1996). IDD patients should be treated with equal respects and care as people without IDD, and in the light of the results of this research, many health care professionals have room for improvement when it comes to ensuring quality care for their disabled patients.

6.3 Suggestions for further research

It was surprising to see how few researches there had been conducted about IDD patients' experiences from their own point of view. Perhaps one of the reasons for this is that people with IDD often have troubles communicating, such as producing speech understandable speech, understanding what is being said, and expressing themselves so that they are understood because of vocabulary and sentence formulation limitations. With this in mind, it may be difficult for researchers to interview IDD patients. However, future researchers could make use of interpreters, and communication aides such as visual charts and pictures and simplified sign language used by some people with IDD (Tuffrey-Wijne&McEnhill, 2008, 190). From my professional experience as a nurse, with patients who are able to understand written language, pen and paper, or even a tablet computer may be used to ease communication. This way, simple interviews and questionnaires could be conducted, and precious information gained from IDD patients themselves. Some people with IDD are so severely disabled that they cannot communicate in any way, but I firmly believe that the ones who can communicate at least on some level could offer health care staff new insights on how to improve IDD patients' experiences in health care, and thus also their quality of life.

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