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# PEDIATRIC DELIRIUM IN INTENSIVE CARE

- a guide for parents



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## PEDIATRIC DELIRIUM IN INTENSIVE CARE

### - a guide for parents

This thesis is a part of a delirium project for Tyks that aims to increase knowledge about pediatric delirium. Pediatric delirium has been studied only a little and in hospitals pediatric delirium is diagnozed rarely. The challenge is especially lack of efficient delirium assessment tools and similar symptoms with pain and withdrawal symptoms. The purpose of this study was to create a guide about pediatric delirium. The aim of this thesis was to inform parents about pediatric delirium and help them recognize and cope with delirium symptoms.

This thesis was done as a literature review. In addition to a literature review, a guide was created in Finnish and English for delirium children's parents. This guide aims to give parents information about pediatric delirium and its symptoms, causes and treatment. The guide is given for the parents when their child is showing delirium symptoms. With the help of the guide the parents have an opportunity to get to know the topic when they have the best time for it. The guide was created to be clear and informative with the target group in mind.

As a result was found that pediatric delirium causes agitation, aggressiveness and changes in the child's cognitive level. After discharge from the hospital, the child might experience anxiety, depression and post-traumatic stress. That is why early recognition and treatment are important. Pediatric delirium has not been studied in Finland at all, so Finnish material about the topic was not available. International studies about delirium were found, but only a fraction of them considered pediatric delirium. It would have been important to also get Finnish material, because the guide is going to be used in Finland.

All the chosen articles presented the same type of results. Research has been done mainly on pediatric delirium symptoms, reasons and treatment. Future research could focus more on the after effects of delirium after discharge from the hospital. By further research and broader awareness of the topic, in the future pediatric delirium might be screened more in hospitals.

### **KEYWORDS:**

pediatric, children, delirium, intensive care, hospital, guide, parents

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### Annika Tirkkonen

## PEDIATRIC DELIRIUM IN INTENSIVE CARE

### - a guide for parents

Tämä opinnäytetyö on osa Tyksin delirium-projektia, jonka tavoitteena on lisätä tietoutta lasten deliriumista. Lasten deliriumia on tutkittu hyvin vähän ja sairaaloissa sitä diagnosoidaan harvoin. Haasteena on erityisesti tehokkaiden deliriumin tunnistamistyökalujen puuttuminen sekä deliriumin oireiden samankaltaisuus kivun ja lääkkeiden vieroitusoireiden kanssa. Tämän opinnäytetyön tarkoituksena oli luoda deliriumopas tehohoitopotilaan vanhemmille. Tavoitteena oli tuoda lasten delirium vanhempien tietoisuuteen ja opettaa heille keskeisimmät asiat deliriumista.

Opinnäytetyö toteutettiin kirjallisuuskatsauksena. Kirjallisuuskatsauksen lisäksi tehohoitopotilaiden vanhemmille luotiin deliriumopas, joka pyrkii informoimaan vanhempia deliriumin oireista ja oikeasta hoidosta. Opas annetaan vanhemmille tilanteessa, jossa heidän lapsellaan on ilmennyt deliriumin oireita. Oppaan avulla vanhemmilla on aikaa tutustua aiheeseen rauhassa. Opas pyrittiin toteuttamaan kohderyhmää ajatellen mahdollisimman selkeäksi ja informatiiviseksi.

Tuloksena huomattiin, että delirium aiheuttaa lapsissa levottomuutta, aggressiivisuutta sekä ajattelun tason häiriöitä. Sairaalasta kotiutumisen jälkeen lapsilla voi esiintyä deliriumin jälkioireita, kuten masennusta, ahdistusta sekä post-traumaattista stressiä. Tämän takia deliriumin aikainen tunnistaminen ja hoito ovat tärkeitä. Lasten deliriumia ei ole tutkittu Suomessa lainkaan, joten suomenkielistä materiaalia aiheesta ei ollut saatavilla. Kansainvälisiä tutkimuksia deliriumista löytyi, mutta vain murto-osa niistä käsitteli lasten deliriumia. Tietoa Suomen tilanteesta olisi ollut tärkeä saada, sillä opas tulee käyttöön Suomessa.

Kaikki kirjallisuuskatsauksessa käytetyt artikkelit toivat ilmi samankaltaisia tuloksia. Tämänhetkiset tutkimukset lasten deliriumista keskittyvät enimmäkseen deliriumin oireisiin, syihin ja hoitoon. Tulevaisuuden tutkimukset voisivat keskittyä deliriumin jälkiseurauksiin sairaalasta lähdön jälkeen. Kun aihetta tutkitaan lisää ja tietoisuus deliriumista kasvaa, deliriumin kartoitus sairaaloissa lisääntyy.

### ASIASANAT:

Pediatric, children, delirium, intensive care, hospital, guide, parents

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## **LIST OF ABBREVIATIONS**

CAPD Cornell Assessment of Pediatric Delirium

ICU Intensive care unit

PAED Pediatric Anesthesia Emergence Delirium Scale

pCAM-ICU Pediatric Confusion Assessment Method for Intensive Care

Unit

PD Pediatric delirium

PICU Pediatric intensive care unit

psCAM-ICU Preschool Confusion Assessment Method for Intensive Care

Unit

TIVA Total intravenous anesthesia

Tyks Turun yliopistollinen keskussairaala

## 1 INTRODUCTION

Delirium is a brain dysfunction that causes changes in the child's consciousness and behavior (Daoud et al. 2014). Delirium affects up to 30 % of pediatric intensive care patients (Bettencourt & Mullen 2017) and 20–80 % of patients in respiration machine treatment (Karlsson et al. 2017, 316). A study (Harris et al. 2016) found that after discharge from the hospital 33 % of pediatric intensive care patients face post-delirium symptoms.

The topic of this thesis is pediatric delirium in intensive care. The topic was requested by Tyks as a part of their pediatric intensive care unit's delirium project, because they find that pediatric delirium is underrecognized in Finland. This thesis is done to help parents get more information about pediatric delirium. In addition to the literature review, a guide is done for parents about pediatric delirium. This guide is distributed to teach the parents, whose child is experiencing delirium symptoms, the basics of delirium.

This thesis focuses only on pediatric delirium. There are three research questions in this thesis: what is pediatric delirium, how to recognize, treat and prevent delirium symptoms in intensive care and what parents should know when their child has delirium. This thesis is a narrative literature review. Nine articles were chosen as a baseline for this article.

It is important to do more research on this topic, because delirium is an unrecognized and undertreated problem in intensive care. However, the amount of research about pediatric delirium is increasing all the time. (Cunningham & Vogel 2019.) Because pediatric delirium is more and more recognized, it causes the assessment tools to be in a constant development (Flaigle et al, 2015). Although pediatric delirium scales are used in hospitals, they are still lacking a program to prevent pediatric delirium (Bettencourt & Mullen 2017).

The aim of this thesis is to inform parents about pediatric delirium and help them recognize delirium symptoms on their child and handle them. The purpose of this thesis study is to create an informative and compact guide about pediatric delirium.

## 2 BACKGROUND

### 2.1 Intensive care unit as a treatment environment

Intensive care means the treatment of a critically but not terminally ill patient with the aim of winning time to treat an illness and getting better. The patient's vital signs are constantly monitored and if any critical changes come up, vitals are supported with special machines. Because in intensive care the patient's state can deteriorate fast, the ward has the resources for action every hour of the day. (Koistinen et al. 2004, 429; Tyks 2017.) Intensive care units treat patients who have temporary dysfunctions in their organs. These dysfunctions can be caused by an acute illness or an injury. (Karlsson et al. 2017, 7.) Every patient is taken care of by 1–3 nurses, depending on the patient's medical condition. In intensive care, medical care is heavily emphasized and the patient's holisticness might be left secondary. (Koistinen et al. 2004, 430.) After surviving from the critical situation, the patients have a high propability for a good life after discharge from the hospital (Karlsson et al. 2017, 7). Tyks pediatric intensive care unit is southwest Finland's only pediatric intensive care unit. They treat severe surgery, infection and trauma patients. (Tyks 2017.)

Intensive care units are round-the-clock units. Patients around the ward are treated every hour of the day, and noise from hospital staff and used machines can burden other patients. Critically ill patients are most prone to harmful stimuli like noise, bright lights and strange environment. In addition to environmental disturbances, stress and pain can be harmful for the patient. Studies show that noise levels in intensive care units are over the recommended level. Long-term exposure to noise increases stress and elevates blood pressure and cortisole levels. Noise can be reduced by preferring one-person rooms over multiperson rooms, preparing for procedures outside the room and talking quietly especially during nighttime. Bright lights should be dimmed every time a treatment procedure is not done in the room. The patient's daily rhythm must also be taken into account when choosing the brightness of the lights. (Ritmala-Castrén et al. 2017, 550–551.)

Intensive care can cause neuropsychological symptoms, sleeping problems and delirium for the patients. Intensive care treatment burdens the patient and their family physically, mentally and socially. Intensive care staff must minimize these burdening factors as

much as possible and offer professional help for the family if needed. (Ritmala-Castrén et al. 2017, 551.)

Intermittent and small amount of sleep exposes the patient for nightmares, exhaustion and delirium. Pain prevents the patient from reaching the deepest stage of sleep. When the patient doesn't get enough deep sleep, they are exhausted even if they have had enough hours of sleep. Restrictions like catheters and respiration tubes disable the patient from moving. This can cause decline in muscle strength and an increased risk for thrombosis and pressure ulcers. (Ritmala-Castrén et al. 2017, 551–552.)

The patient can be burdened mentally due to strong medications, nightmares, hallucinations and rude, machine-like treatment from the hospital staff. These can cause memory loss, anxiety and delirium. The patient might be intentionally caused memory loss by giving them sleep and pain medications. This is done to reduce the patient's memory about unpleasant parts of the treatment. These blanks in the patient's memory can cause anxiety. Anxiety can also be caused by fear of death, pain and strange alarms around the ward. If anxiety is not noticed and treated, it speeds up the patient's vital functions. Sedation must be then increased, which lengthens the time in respiration machine treatment and the time in intensive care. (Ritmala-Castrén et al. 2017, 552–553.)

The cost of one intensive care treatment day is approximately 3000 euros. Mortality in intensive care has decreased by 20 % in Finland in ten years. Intensive care patients have a 90 % chance of survival in Finland. Prognosis of intensive care patients has improved even though patients are sicker than before. This improvement is the result of functioning treatment methods and correct and fast recognition of a disease. Fast recognition also lowers the number of days in intensive care and therefore reduces the costs of the treatment. (Karlsson et al. 2017, 7–8.)

### 2.2 Child as a patient

Like intensive care adult patients, child patients are sicker than before. Also, children's illnesses have changed their form. Children from ages 0–16 or 18 are considered child patients. (Muurinen & Surakka 2001, 3.) In Tyks pediatric intensive care unit, the patients are 0–16 years old (Tyks 2017). When taking care of a child patient, they must be treated as an individual because every child is different. The child might be scared and

overstrained due to a new and weird environment. The child should be closely monitored for any signs of mental burden. (Koistinen et al. 2004, 442.) The goal for the treatment is to promote the child's health and well-being. The child's life outside the hospital should be supported during the time in hospital. This includes home, school and daycare. (Muurinen & Surakka 2001, 13.)

Family is a big part of a child's life. The family is taken into account in every stage of the treatment and the child's care is planned together with the parents. This requires maintaining good communication throughout the care. (Muurinen & Surakka 2001, 13.) The family cannot be present all the time even though they would want to. Separation from the parents is difficult especially for small children. The biggest fear for children aged six months to six years is being away from their parents. After separation, under two-year-olds feel abandoned by their mother. For 2–6-year-olds separation from their parents is the most difficult. Ill adolescents need their parents as well as small children do. (Koistinen et al. 2004, 443.)

In intensive care, the child can express separation from their parents with three steps. First, the child can cry, scream and latch on to their parent when the parent is trying to leave. In the next stage, the child becomes passive and they are not interested in playing or eating. The child might ignore their parents when they visit and they might be grumpy and ignorant towards them. But when the parent tries to leave, the child starts screaming and latches on to their parent again. The final stage is when the child seems to have adjusted to the new situation. In reality, the child becomes submissive to the situation and tries to avoid their parent to relieve the pain that comes when their parent has to leave again. (Koistinen et al. 2004, 443.) The unit's visiting times should be as flexible as possible to ensure the parents' possibility for visitation. The treatment environment must be arranged in a way that is best for the child and their parents. (Koistinen et al. 2004, 429–443.)

2–6-year-old children are scared of damaging their body. They might resist the treatment strongly and be very negative. If a child in this age group doesn't get straightforward answers to their questions, their imagination then takes place and fills in the blanks. School-aged children are already able to fear death and possible disabling their sickness might cause. They tend to control their fears by absorbing every possible information. (Koistinen et al. 2004, 443.)

The child's privacy should be protected also during treatment. If the child shares a room with other children, the child's own space should be covered with a curtain during procedures and other things that require minimal clothing. If possible, the parts of the child that are bare should be covered during procedures with a blanket or a towel. Before starting a treatment procedure, the child should be told what is about to happen even if they are sedated. (Koistinen et al. 2004, 446.)

Children go through feelings and learn new things through their play. As well as a healthy child, a sick child needs stimuli and things to spend time with. If the child is not capable of moving, stories are also a good way for the child to express their emotions. The child should be brought their own familiar toys from home to bring comfort to them. A sleeping child should never be woken up. When talking to a child patient, it is important to address the child with their name. (Koistinen et al. 2004, 445–446.)

If the child is in bed for the most part of the day, their skin condition especially in the back should be monitored. The child's private areas are washed daily and bedsheets are changed regularly. A critically ill child is prone to infections. Good mouth care is especially important for them. If the child is treated with antibiotics, they have an increased risk for yeast infections in the mouth. Mouth care should be carried out at least twice a day. If the child has drains or surgical wounds, they must be kept clean and possible signs for infections should be closely monitored. (Koistinen et al. 2004, 444.)

When treating a child patient, it is really important to consider the child's age, size and developmental status in the treatment. Every child has their own habits which have to be found out before starting the treatment. This includes basic things such as communication, showing emotion and choosing treatment equipment. (Muurinen & Surakka 2001, 83.) The child's developmental stages are supported during treatment and the child is encouraged to do things as independently as possible. A child typically suffers a setback when they are in the hospital. These setbacks should be allowed in order for the child to get better. (Muurinen & Surakka 2001, 13.) Nurses should show compassion towards the child by talking, touching and closeness. The child's wishes should be respected and the child should be given an opportunity to make their own decisions within their age and physical capabilities. Comfort can be created for the child by the right type and right amount of clothing. Clothing and blankets are used every time it is possible. (Koistinen et al. 2004, 442–445.)

### 2.3 Current situation in pediatric delirium management

There is currently no recommendations for care about pediatric delirium in Käypä hoito. Only information about delirium is "Äkillisen sekavuustilan (delirium) diagnosointi", which is a very short article about diagnozing adult delirium. (Käypä hoito 2019.) Delirium can be life-threatening if left untreated. It requires immediate care in a medical environment. Although delirium is life-threatening for adults, it has been little researched on children. These few studies show that a critical illness is the most common cause of children's delirium. (Bettencourt & Mullen 2017.)

Although delirium causes severe complications in patients, one study (Kudchadkar et al. 2014) shows that 71 % of pediatric intensive care patients were not screened for signs of delirium. The study shows that the reason for this is that the nurses had difficulties in separating delirium from other possible diagnoses and symptoms of opioid withdrawal and pain. Nurses are also concerned that delirium assessment takes a lot of time and and the assessment tools are difficult to use (Flaigle et al, 2015). By providing material and tools for nurses about how to recognize delirium in children, more efficient treatment and prevention methods can be started early on (Bettencourt & Mullen 2017).

Delirium exposes the child for aspiration and infections, increases the risk for mortality and lengthens the time that is spent in the hospital (Bettencourt & Mullen 2017). A study (Flaigle et al. 2016) shows that hospital staff have very poor knowledge about pediatric delirium. Another study (Flaigle et al. 2015) shows that 38 % of nurses falsely claimed that benzodiazepines are efficient for delirium treatment, 13 % said that a urinary catheter reduces the risk for delirium and 43 % claimed that delirium only lasts for a couple of hours. Hospital staff should be taught the basics of prevention and treatment of pediatric delirium and most importantly, how to notice it (Bettencourt & Mullen 2017). By better detection and awareness the risk factors for pediatric delirium can be modified and more research can be done to assess the long-term effects that delirium causes for a child (Silver & Traube 2016).

## 3 PURPOSE AND AIMS OF THE STUDY, RESEARCH QUESTIONS

The purpose of this thesis study is to create an informative guide about pediatric delirium for parents. The guide is given to parents when their child is in intensive care and experiencing typical delirium symptoms. This way the parent gets an idea about why their child is acting in an atypical way.

The aim of the thesis study is to inform parents about delirium and help them recognize and cope with delirium symptoms their child is showing.

This thesis's research questions are:

- 1. What is pediatric delirium?
- 2. How to recognize, treat and prevent delirium symptoms in intensive care?
- 3. What parents should know when their child has delirium?

## 4 METHODS

### 4.1 Literature review

This thesis is a narrative literature review. A literature review is a systematic and reproducible written presentation that searches through previously published studies about a specific topic. The goal of a literature review is to find out what has previously been researched and what is still lacking knowledge and then evaluate the information, create new theory and form an overall picture about the topic. A literature review must be able to be critically evaluated, objective and the results must be public. A literature review's mistakes and outdated information should be able to later on be replaced with new research information. (Salminen 2011.)

The writer evaluates and classifies the texts they find and then critically analyses and reflects them into their own study. (Burns & Grove 2005, 93.) With a literature review, the reader is presented previous studies and their research problems. With this method, the researcher can get a good baseline for their own study. The purpose of a literature review is to answer to the research questions that have been previously presented by the writer of the review. (Salminen 2011.)

There are three types of categories for literature reviews: descriptive literature review, systematic review and meta-analysis. Narrative literature review is a part of descriptive literature review. A narrative literature review gives a broad and clear picture of the topic that is being researched on. However, it doesn't give the most analytical results. The aim for this review method is to gather incoherent information and organize and summarise the information into one coherent text. (Salminen 2011.)

### 4.2 Data collection

Before any data could be searched for this thesis, the research questions and the scope for the search was decided. Acceptable sources for this literature review were scientific books and articles. Other theses are not used as sources, because they might have false information and they are therefore not reliable sources. When searching for "lapsen delirium" from various databases, all the results in Finnish are about adult and elderly delirium. English results are easier to find, but there are still very few studies about it.

Information for the thesis was searched from Finna, PubMed, Cochrane, Medline, CINAHL, Melinda, ScienceDirect, ERIC and Medic from English hits. All of these databases are ethically reliable and have up-to-date articles.

Used materials for this thesis were chosen to be as diverse as possible. Used search words included mixes of words "delirium", "pediatric", "child", "children", "hospital" and "intensive care". Used source material for this literature review was chosen to be primarily between years 2009–2019. The most recent material is used for this thesis to get the most updated information for statistics, but basic information about for example hospital environment doesn't change very rapidly, so these references can be older than ten years. Because there is so little information available about pediatric delirium, used sources can be over ten years old if the information is still valid to this date.

Keywords that were used for the search were delirium AND pediatric delirium OR child delirium OR children delirium AND intensive care OR hospital. Many promising articles were not free to read, so they had to be ruled out from the search. Search with the word "delirium" showed 61470 results. Search with "pediatric delirium", "child delirium" or "children delirium" gave 5508 results. Combination of the words "pediatric delirium/child delirium/children delirium" + "intensive care/hospital" gave 6867 results. This search process is depicted in table 1.

Table 1. Databases and keywords used for searching the articles and the number of results.

Database	Delirium	Pediatric delirium OR child delirium OR children delirium	Pediatric delirium OR child delirium OR children delirium AND Intensive care OR hospital
Cochrane	40	179	4286
MedLinePlus	138	8	3
Melinda	966	11	1
Finna	907	21	4
Pubmed	16184	526	310
ScienceDirect	43210	4759	2262
ERIC	25	4	1
Total	61470	5508	6867

Chosen articles were written in Finnish or English so that would be completely understood without any risk for misinterpretation. The articles had to be completely free to read online from a reliable scientific source and specifically about pediatric delirium, not adult or elderly delirium. This inclusion and exclusion criteria is depicted in table 2.

Table 2. Criteria for choosing an article.

Inclusion criteria	Exclusion criteria	
Article written in Finnish or English	Article written in other languages	
Free article	Not free article	
Whole article available online or as a	a Only some parts of the article available	
book that is available	online or book not available	
Article newer than 2009	Article older than 2009	
Scientific article from a reliable source	Non-scientific article from a source that is	
	not reliable	
Article about pediatric delirium in	Article about another topic or adult	
intensive care	delirium	

The articles were chosen based on their headings. After that, abstract was read from promising articles that had a heading conserning pediatric delirium in some way. After reading the abstract, the article was either discarded or chosen for this thesis study.

Because there were so many results from Cochrane, results were organized within the best match. None of the articles concerned pediatric delirium and its treatment, so none was compatible for this thesis. MedLinePlus had three articles as a result for the search words, but two of these articles did not consider delirium at all and one was about adult delirium. Melinda had one promising book about delirium in intensive care, but the book was only available for loaning in Helsinki University library, so this source could not be used. Finna had four results, from which one was the same as in Melinda. Others did not consider delirium at all.

Pubmed had 310 results. This database had the most articles about pediatric delirium, but many of them were not free. By choosing "free full text", the results dropped from 310 to 115. From these results, eight articles filled all the criteria and were chosen for this thesis. This database had the most articles about pediatric delirium.

ScienceDirect had over 2000 results. Most of them said "abstract only" on top of the heading, so free full articles were easy to spot. Out of all these, one article was selected for this study. The one result article from ERIC was about pediatric delirium, but full article was not available online.

All in all, nine articles were selected for this thesis study (table 3).

Table 3. Chosen articles for the thesis from all the result articles.

Databases	Result articles	Chosen articles
Cochrane	4286	0
MedLinePlus	3	0
Melinda	1	0
Finna	4	0
Pubmed	310	8
ScienceDirect	2262	1
ERIC	1	0
Total	6867	9

After the articles were chosen, they were gathered in one table (table 4) and their purpose, methods and research results were collected.

Table 4. Chosen articles, purposes of the studies and study results.

Title, authors and publication year	Purpose/aim of the study	Methods	Research results
Analgesia, sedation, and delirium in pediatric surgical critical care. Cunningham & Vogel 2019.	Pain and delirium management in intensive care.	Literature review	Pain management and delirium assessment are important, but there are too few studies about them. More studies need to be done to ensure the best type of treatment.
Clinical Recommendations for Pain, Sedation, Withdrawal and Delirium Assessment in Critically III Infants and Children: An ESPNIC Position Statement for Healthcare Professionals. Harris et al. 2016.	What are the recommendations for assessing delirium symptoms in children.	Literature review by a multidisclip nary group	Causes of delirium should be found out immediately to start actions to prevent it. Delirium should be assessed at least once per shift and assessment tools should be used for assessment.
Delirium in Children: Identification, Prevention, and Management. Bettencourt & Mullen 2017.	Risk factors for PD, knowing the correct assessment tools, how to prevent and	Literature review	Most PICU patients are not assessed for delirium. Restraints and sleep deprivation increase the risk. Family support is

Diagnostic accuracy of	manage delirium symptoms.	A	important in the recovery.  Nurses should be taught the importantness of PD assessment and the symptoms of PD.  PD research needs to be done
delirium diagnosis in pediatric intensive care: a systematic review. Daoud et al. 2014.	studied about PD. Prevalence, risk factors and outcomes of PD.	systematic research	more to determine how accurate PD screening tools actually are. This should be the main focus in health care research in the future.
Identifying Barriers to Delirium Screening and Prevention in the Pediatric ICU: Evaluation of PICU Staff Knowledge. Flaigle et al. 2015.	To find out how much PICU nurses know about PD.	A questionna ire study	Nurses had knowledge gaps in recognizing risk factors and correct treatment for PD: they stated that benzos are a good treatment method for PD and a catheter reduces the risk for PD.
Paediatric emergence delirium: a comprehensive review and interpretation of the literature. Mason 2017.	Examine unanswered questions about PD and the importance of PD screening.	Literature review	Delirium should be assessed as a vital sign with proper screening tools to increase delirium screening.
Pediatric Delirium and Accociated Risk Factors: A Single-Center Prospective Observational Study. Silver & Traube 2016.	To find out PD prevalence and its risk factors in ICU.	A prospectiv e observatio nal study	21 % prevalence of PD. Risk factors include young age, developmental delays and mechanical ventilation.
Pediatric Delirium in Critically-III Children: An International Point Prevalence Study. Traube et al. 2017.	To see how common PD is and what are its risk factors.	Multi- institutional point- prevalence study	25% had PD. Risks: low age, mechanical ventilation, high medication, physical restraints.

### 4.1 Data analysis

The articles were analysed by using content analysis. This method analyses the articles by searching similarities and differences. Content analysis aims to form a summary of the original content. (Tuomi & Sarajärvi 2002, 105.) Each article was first read once through. After that, the articles were read with the research questions in mind. Every sentence that considered one or more of the research questions was highlighted. The chosen sentences were compared with each other by creating a chart of their differences and similarities. After the sentences were collected and cathegorized, they were written under correct subtopics in the thesis.

## **5 RESULTS**

### 5.1 Delirium in children

Delirium is a brain dysfunction caused by malfunction of the brain and central nervous system which cannot be explained with a pre-existing neurological disorder. Delirium causes agitation, hallucinations and disturbances in cognition. When a child is restless, they are more exposed to harm due to a higher risk for falling or hurting themselves. (Bettencourt & Mullen 2017.) Delirium is an actual diagnosis, not a bunch of different symptoms. It is caused by many different factors. Delirium is classified as a brain injury, and it must be recognized as early as possible to ensure correct treatment and prevention of possible later problems. (Silver & Traube 2016.) After discharge from the hospital, delirium can cause depression, anxiety, post-traumatic stress and changes in the child's cognitive status (Cunningham & Vogel 2019).

Pediatric delirium has similar causing factors as adult delirium (Flaigle et al. 2015). Pediatric delirium is usually caused by a combination of three elements: the disease that the child is having, side effects that are caused by the treatment and an abnormal treatment environment (Silver & Traube 2016). One study found out that patients who are in pediatric intensive care unit due to inflammatory or infectious disease have the highest delirium rates. The risk for pediatric delirium increases dramatically from 20 % to 38 % after six days in intensive care. (Traube et al. 2018.) Use of analgesics and sedative medications increase the risk for pediatric delirium as well (Cunningham & Vogel 2019).

Risk factors can be divided into environmental factors, patient-related factors and treatment-related factors. Environmental risk factors include strange environment, lack of familiar items in the hospital room, absence of glasses or hearing aid, absence of family members and other familiar people and physical restraints. Patient-related factors include withdrawal after sudden stop of taking strong medications, stress, sleep deprivation, disturbances in fluid balance, infection and hypoxia. Treatment-related factors are high level of pain, length of time in intensive care, overmedication and oversedation. (Harris et al. 2016.)

Pediatric delirium can be prevented by early mobilization, treating and correcting hypoxia, physiotherapy, returning into a normal sleeping pattern and avoiding over-use of sedative medications and opioids (Hautamäki 2006). Delirium develops over a short

time, from one hour to 24 hours. Delirium symptoms can vary during the day, typically worsening in the evening. Sometimes the child might not experience these symptoms at all. (Harris et al. 2016.) Pediatric delirium patients can often be restless and aggressive and in a need for constant observation. Delirium is medicated primarily with antipsychotics and sedative medicines. Safe environment and familiar people, objects and staff decrease delirium. Music and light massage can calm a delirious child down. (Huttunen 2019.)

Pediatric delirium can be divided into hypoactive, hyperactive and mixed delirium. A hypoactive child speaks and moves slowly, is apathetic and doesn't try to contact other people. Hyperactive child is constantly moving and is difficult to sedate. Mixed delirium combines both types of delirium and can vary throughout the day. (Bettencourt & Mullen 2017.)

Delirium has no age limitations and can occur in children as young as three months old (Bettencourt & Mullen 2017). An increased risk group for getting pediatric delirium are under two-year olds, mechanically ventilated patients and patients whose treatment lasts over six days (Cunningham & Vogel 2019; Helppi & Korteniemi 2019). Also children with existing developmental delays are at a higher risk for getting delirium, because their atypical brain is more vulnerable to the effects of an illness. Their delirium can be harder to detect if their baseline behavior is not well known. In these cases, a parent's involvement is important, because they can tell what is normal for their child and what is not. (Silver & Traube 2016.) Gender and ethnical background don't affect on the prevalence of pediatric delirium (Traube et al. 2018).

Hypoactive delirium and hallucinations are very hard to assess on small children. Young children's delirium symptoms are also hard to assess due to their lack of verbality. In these cases, the child's behavior should be assessed instead. Also, children's developmental stages help evaluating what is normal for a specific aged child. (Harris et al. 2016.)

### 5.2 Pediatric delirium assessment tools

Majority of pediatric intensive care patients are still not screened for delirium. Signs of pediatric delirium should be assessed once in every shift to notice any changes in the child's behavior and therefore prevent possible future harm. Every child should be

preoperatively assessed for signs of delirium to spot any later changes in the recovery room. By checking delirium symptoms at the same time as vital signs, it becomes a routine and pediatric delirium symptoms become more familiar to the nurses. (Harris et al. 2016.)

Assessment tools have been created to help nurses to identify and assess pediatric delirium in intensive care. To ensure that these assessment tools are used, they should be user-friendly, reliable and fast to use. Delirium signs can be easily mixed with signs of pain, withdrawal symptoms and agitation. If the child is agitated, delirium signs can easily be masked under it. Pain assessment of pediatric patients can be difficult due to different developmental stages of each age group. When the child is sedated and in respiration machine treatment, assessment becomes even more difficult. (Harris et al. 2016.) Delirium changes the child's state of awareness and ability to pay attention. Bedside delirium assessment tools should be used if pain medications and sedatives are not making a difference in the child's behavior. (Bettencourt & Mullen 2017.) If an assessment tool is not in use, the child is at risk for inconsistent dosing of medications. Delirium should be assessed at least once per shift to notice any changes early on. (Harris et al. 2016.)

Pediatric Anesthesia Emergence Delirium Scale (PAED); (see appendix 1) is used to spot delirium in children over one years of age. The patient's behavior is assessed by evaluating their eye contact, actions, awareness, restlessness and consolability. The scale is 0 to 4 going from "not at all" to "extremely". This scale can be used to detect emergence or hyperactive delirium. However, the negative side of this assessment tool is that it cannot be used for detecting hypoactive delirium. (Bettencourt & Mullen 2017.) PAED scale is the most widely used pediatric delirium assessment tool. PAED assessment should be done for every child to detect possible changes in the recovery room. (Mason 2017.)

Cornell Assessment of Pediatric Delirium (CAPD); (see appendix 2) can be used for children of all ages. Its use is based on observation. It has eight questions and each one is scored from 0 to 4 from "never" to "always". If the combined score from the questions is more than 9, the child might have delirium. (Bettencourt & Mullen 2017.) CAPD is shown to have better accuracy than PAED (Daoud et al. 2014). CAPD is an improved version of PAED and can be better used to differentiate hypoactive and hyperactive delirium with a behavioural scale. This assessment tool doesn't require the child's

participation, so assessment should be easily done once per shift. (Bettencourt & Mullen 2017.)

Pediatric Confusion Assessment Method for Intensive Care Unit (pCAM-ICU) is used for children over five years of age. Preschool Confusion Assessment Method for Intensive Care Unit (psCAM-ICU) is used for kids aged six months to five years. (Bettencourt & Mullen 2017.) They both use the same template as Confusion Assessment Method for Intensive Care Unit (CAM-ICU) for adults, but the pediatric versions have been adjusted to match the age groups' different developmental levels (Cunningham & Vogel 2019). These assessment tools are cognitive-oriented and they require the patient's interaction unlike other assessment tools (Daoud et al. 2014). Neither of these tools can be used for children with developmental delays (Traube et al. 2018).

All of these assessment tools provide a rapid possibility to screen possible delirium symptoms (Traube et al. 2018). An unofficial version of CAPD has been used in Tyks for two years, and they got an official approved translation (see appendices 3 and 4) in autumn 2018. These assessment tools have been configured to the hospital's special needs into their Clinisoft-database. These are the only official pediatric delirium assessment tools that are used in Finland: a study done a few years ago showed that the other pediatric intensive care units in Helsinki and Oulu did not do any pediatric delirium screening. (Korteniemi 2019.) Assessment tools help the nursing staff to assess with scores a possible risk for delirium. When these meters are used regularly, delirium can be noticed earlier and prevented fast. (Helppi & Korteniemi 2019.)

### 5.3 Treatment of pediatric delirium

Delirious patients can be challenging to take care of. The treatment involves health care professionals from different fields. A delirious child's state can change rapidly and unpredictably. These changes need fast adjusting. Recognition of pediatric delirium needs to be done as early as possible to prevent negative outcomes. (Bettencourt & Mullen 2017.)

An underlying reason for the development of pediatric delirium can not always be corrected, so as much attention as possible must be paid to minimizing the risk for delirium as well as creating a safe and supportive ward environment for a delirious child. Before delirium treatment can be started, factors that cause the development of delirium

should be assessed and then modified. These include strong medications, hypoxia, pain, disturbances in metabolic system and anxiety. Effective pain treatment for hospitalized child patient decreases the risk for delirium. (Bettencourt & Mullen 2017.)

### 5.3.1 Non-pharmacological treatment of pediatric delirium

The treatment environment is important when it comes to reducing delirium. Unfamiliar and scary surroundings are one of the reasons that might cause delirium for the child. By providing a calm and consistent treatment environment for the child their anxiety decreases and they stay more aware of their surroundings. (Cunningham & Vogel 2019.) Video games or cartoons decrease the child's anxiety and therefore lower the risk for delirium. They also help the child to focus more on positive things. (Mason 2017.) If the child has hyperactive or mixed delirium, their room should be in the quieter side of the ward. A child with hypoactive delirium benefits from a room in the more active area of the ward. (Bettencourt & Mullen 2017.)

The hospital room should provide safety for the child. Hospital bed rails should be kept up every time the child is in bed to prevent them from falling. Treatment equipment should be kept out of the child's reach so they wouldn't hurt themselves. In addition to safety, the room should be cozy and bring comfort for the child. The hospital hygienic rules restrict overdecorating, but a few pictures, toys, colourful bedsheets and other familiar items from home create a more inviting environment for the child. The room should be big enough to fit visitors and maybe even fit a spare mattress for a parent to sleep on. (Muurinen & Surakka 2001, 85.) If the child wears glasses or a hearing aid, these should be used at all times in the hospital to help the child to be more orientated (Bettencourt & Mullen 2017).

Early mobilization should be provided by early removal or tubes, wires and other restraints (Bettencourt & Mullen 2017). Physically restrained pediatric patients have a four times bigger risk for delirium than a child who has no restraints (Traube et al. 2018). Prolonged immobilization time can cause stiffness in the child's joints and muscles. Exercise should be first started lightly and the intensity should be then added gradually when the child is getting better. Exercise can first be painful for the child, so movements must be done gently and carefully. Position shifting helps to prevent any type of damage in a bedridden patient's nerves and joints. (Koistinen et al. 2004, 445.)

Normal sleep pattern is especially important for a hospitalized critically ill patient, because it promotes the function of the immunity system and thermoregulation. If the child cannot get enough good quality sleep and their sleep is constantly disturbed, it promotes the development of delirium. Bright lights, noise and constant activity around the child are the key reasons for the disturbance of the child's normal daily routine. This is why delirium patients often have an upside-down sleeping pattern. Therefore, the child should be created a daily schedule to promote continuity and routine. The child should be woken up at the same time every day and the child should spend as little time as possible in bed during the day to clarify when to sleep and when to not. (Bettencourt & Mullen 2017.) If the child has trouble sleeping due to bright hospital lights and loud sounds, the lights should be kept bright during the day and then dimmed for the night. Also, an eye mask and earplugs can be helpful for a better sleep. (Cunningham & Vogel 2019.) A comfort increasing nest can be built for the child by hooping a long pillow. (Koistinen et al. 2004, 442).

Calm, slow and clear speech should be used when communicating with the child. The child should regularly be given an explanation to where they are and why they are there. A delirious child might not be able to engage in a conversation, so quiet presence from the staff should be then provided. The child should never be told that their hallucinations are stupid or not real. However, they should be told that what they see is not the same as other people see. Conversations with the child should not always concern the treatment. Talking about other nice things can make the child happy and more focused on normal life and the future. (Bettencourt & Mullen 2017.)

A delirious child benefits from including the family in the treatment as much as possible. The child's nursing staff should not change during the treatment process to promote consistency. The child's family should reorient the child to place and time during visits. The child and their family should be offered psychosocial support if needed. (Bettencourt & Mullen 2017.)

## 5.3.2 Pharmacological treatment of pediatric delirium

There are no medications available that could be used to prevent pediatric delirium. However, medication can be used when a child's safety is on the line to decrease the symptoms of delirium and therefore to prevent possible negative outcomes and shorten

the time that is needed to spend in the hospital. Medications should be used after the non-pharmacological methods have proven not to be correlative. (Bettencourt & Mullen 2017.) Adequate analgesia is important because pain symptoms can be misunderstood as delirium symptoms. Total intravenous anesthesia (TIVA) has been studied to cause less delirium than general anesthesia. The difference is that TIVA method doesn't use inhaled anesthetics. (Mason 2017.)

Delirium is typically treated with analgesics like morphine and fentanyl and sedatives like benzodiazepines (Harris et al. 2016). Benzodiazepines are great for decreasing anxiety, but they propose a high risk for delirium particularly in long-term use (Bettencourt & Mullen 2017). Specifically lorazepam is identified to be a serious risk factor for pediatric delirium (Flaigle et al. 2015). Benzodiazepines cause delirium to last longer and worsen the patient's delirium symptoms (Karlsson et al. 2017, 318). Prolonged analgesia and sedation have been identified to be a causing factor for delirium (Harris et al. 2016). The use of benzodiazepines should be slowly stopped at the earliest opportunity when they are no longer needed. If benzodiazepines have to be used for a long time, dexmedetomidine should be given intravenously instead for sedation. This is a method that has been effective in adult delirium treatment and might also be helpful in pediatric delirium. (Bettencourt & Mullen 2017.)

Antipsychotics can be used for delirious children even if they wouldn't have a psychiatric disorder to target. Although, antipsychotics can cause extrapyramidal symptoms as a side effect. These include spasms, restlessness, bradykinesia and tremor. (Cunningham & Vogel 2019.) The lowest possible dose is given initially and can be slowly increased if there is no response for the medication. Used atypical antipsychotics include risperidone, olanzapine, ziprasidone and quetiapine. Ziprasidone should not be used for children who are critically ill, because it increases the risk for arrhythmia. Atypical antipsychotic medications affect the child's dopamine and serotonin activity. Therefore, they are the most compatible for children with mixed and hypoactive delirium. (Bettencourt & Mullen 2017.)

If the child cannot take oral medications or other antipsychotics have not helped, fastacting haloperidol can be given intravenously for a hyperactive child. Haloperidol blocks the brain's dopamine receptors and therefore decreases the amount of hallucinations, calms the child down and helps them focus. However, haloperidol has a bigger risk for side effects than previously listed atypical antipsychotics and it should not be used for arrhythmia patients. (Bettencourt & Mullen 2017.) The child's QT interval should be monitored daily, especially for patients who are using haloperidol medication. If a child is being medicated for delirium, drug interactions should be monitored closely. The dose should be as small as possible, and the use of the medication should be stopped at the earliest opportunity to decrease the amount of side effects. Side effects can also be prevented by administrating anticholinergic drugs. Antipsychotic medications are used for sedation, so they should be given for the child prior to their bedtime. (Bettencourt & Mullen 2017.)

Delirium often interferes with the child's sleep. Melatonin can be used to help the child reach back to their normal sleeping rhythm and therefore decrease the risk for progression of delirium. (Bettencourt & Mullen 2017.) Melatonin has sedative, anxiolytic and analgesic effects and only a little side effects. It increases the total time of sleep, quality of sleep and the amount of REM sleep. (Cunningham & Vogel 2019.) If the child is agitated, they can be medicated with clonidine or dexmedetomidine. Clonidine can be administered with a patch, so they are good for prolonged use. Use of dexmedetomidine decreases the need for benzodiazepines which increase the risk for delirium. (Bettencourt & Mullen 2017.)

### 5.4 Parents' feelings about intensive care

Going to the hospital causes major changes in a child's life. They might resist going there, because hospital is a strange environment for them. Weird people, voices, smells and operations and being away from their parents can make the child afraid. Despite the child being scared, a new situation can also display emotions in the parents – They can be scared and unsure about how they can participate in their child's treatment. (Muurinen & Surakka 2001, 79–80.) The thing parents worry the most is their child's recovery (Ritmala-Castrén et al. 2017, 559). Also, quilt can occur if the parents feel that somehow their child's illness is their fault (Muurinen & Surakka 2001, 79–80). In addition to blaming themselves, the parents can sometimes blame each other or other people (Koistinen et al. 2004, 433).

Delirium does not only affect the child, but the parents as well – the child might not recognize their own family and their developmental status might set back. This might be confusing and stressful for the parents. (Cunningham & Vogel 2019.) A delirious child can be scary for a parent. They might worry that the changes in their child's behavior are permanent. (Bettencourt & Mullen 2017.)

Every parent feels like they know their child the best. Losing this expertise position in the hospital can be difficult to accept. Seeing their child's behavior change so suddenly can be frightening for a parent if they can't keep up with the changing care and new guidance on what to know about delirium. This might make them feel incapable of taking care of their own child. (Koistinen et al. 2004, 433.) The parents might experience hopefulness when they see their child getting better, but then suddenly the child gets disoriented and different from normal (Bettencourt & Mullen 2017). In a shocking situation the parents might not remember the guidance they have been given (Koistinen et al. 2004, 431). Giving the parents a guide about delirium can help them understand the situation better (Bettencourt & Mullen 2017). The guidance they are given should be up-to-date and honest. The parents might not remember what they have already been told, so their questions must be answered patiently. (Koistinen et al. 2004, 431.) In addition to the written guidance, the parents might also need emotional support (Ritmala-Castrén et al. 2017, 559). They must be offered an opportunity to discuss their child's treatment and medical records with a doctor who is in charge of the treatment (Koistinen et al. 2004, 431).

A child's sudden serious illness is always shocking for a parent (Bettencourt & Mullen 2017). The parent might feel that this new situation stops their whole life. The child's previous health status affects on how the parent feels about their child's sudden illness. (Honkasalo et al. 2003, 171–172.) Management of a parent's anxiety is a key element in delirium management (Bettencourt & Mullen 2017). A child's reaction to their illness is based on how their parents react to it. If a parent is worried and anxious, those feelings reflect directly to the child. (Koistinen et al. 2004, 429.) The parents usually have an urge to talk about their feelings (Ritmala-Castrén et al. 2017, 560). Every parent copes with shock differently, for example they can be quiet, dismissive, in denial, emotionless or even hostile (Muurinen & Surakka 2001, 81; Koistinen et al. 2004, 432).

When a child gets sick, it affects the whole family on some level and requires reorganizing and flexibility (Koistinen et al. 2004, 432). In some cases, the parent has to stay in the hospital around the clock, so a nanny has to be possibly arranged for other children in the family. Parents might have to take days off from work, and this can cause worrying about keeping their job and the economic situation in the family. (Muurinen & Surakka 2001, 81–83.) If the child is in intensive care for a long period, the parents should be offered a possibility for a sick leave and a chance to talk with the hospital's social worker who can figure out possible allowances that the family could get (Koistinen et al.

2004, 433). The child's siblings might be left without attention because a sick child requires so much attention from parents. If this happens, the nursing staff should remind the parents that their child is in good care and they can continue their normal life at home as well. When visiting, the parents are recommended to only focus on their child and nothing else. (Koistinen et al. 2004, 433–446.)

The family rules and the parents' hopes have to be checked before starting the treatment (Koistinen et al. 2004, 430). Because the child is a part of a family, the child's family arrangements must be found out: does the child have both parents, do they have any siblings or does the family include other important people. It is the best for the child if their family can participate in their treatment as much as possible, so the child doesn't feel lonely and some parts of their life stay the same whilst being in a strange environment. If the parent is unable to meet the child's needs due to their own anxiety caused by the treatment, it is important to have a discussion with the parent and show them understanding and compassion. (Muurinen & Surakka 2001, 81-83.) It is also important that the parents are encouraged to involve in the child's treatment as much as possible, because parents are usually the first ones to notice a child's delirium (Bettencourt & Mullen 2017). If the parent doesn't want to participate in the medical treatment, they can participate in easy daily chores like feeding, cleaning, washing teeth, changing diapers and putting on lotion for the child. The goal of this is that the parent feels able to participate in their child's care and the family bond stays strong. (Muurinen & Surakka 2001, 84.)

The child's health should be discussed by focusing only on the positive sides of it. However, if the parent asks something, their questions must be answered truthfully and openly even if the news would not be nice to hear. (Koistinen et al. 2004, 430–443.) The given information must be consistent and understandable (Ritmala-Castrén et al. 2017, 560). The parent must be emphasized that there are no stupid questions. When talking with a parent, common words should be used to ensure that the parent understands what the nurse is saying. (Koistinen et al. 2004, 430–443.) The parents should be encouraged to write down questions already at home. When visiting the child, the parents should be asked how they understand their child's situation. If anything is unclear, the information should be repeated for them. (Ritmala-Castrén et al. 2017, 560.)

The child might feel perfectly normal when their pain and nausea are being treated. They might be confused about why they still have to be in the hospital. Nurses should support the child in being independent in their daily chores even though it might take a bit more

time, because doing normal daily chores enhances their self-esteem. (Muurinen & Surakka 2001, 83.)

The parents might fear visiting their child because they might feel that visiting puts the child in a stressful situation (Koistinen et al. 2004, 443). The parents must be emphasized that they should visit their child as much as they can and also take part in the treatment. Presence of a parent creates a feeling of safety for a child. (Muurinen & Surakka 2001, 81–83.) By showing compassion and taking the parents' feelings into consideration the ward nurses can help the parents cope in a difficult situation (Ritmala-Castrén et al. 2017, 561).

Parents' reactions to a crisis are normal reactions to a new situation. These reactions are different for everyone and some of these stages can overlapse. The first stage is shock stage. This stage protects the mind from a difficult situation. The parent functions like a machine, because shock numbs intolerable feelings. The time and place feel unreal and the parent might remember small details very clearly. Physical strength increases and the feelings of hunger and temperature changes might disappear. This stage lasts usually for one day, but the length varies individually. (Ritmala-Castrén et al. 2017, 561–562.)

The second stage is reaction stage. The parent realizes the situation and different types of feelings arise. This stage causes memory and focusing problems and physical symptoms in the body like shivering, nausea, fatigue and sleeping problems. When the shock stage is over, the parent has an opportunity to think about what has happened and how it changes the family's life. This stage lasts usually for a couple of weeks. (Ritmala-Castrén et al. 2017, 562.)

The third stage is processing stage. Emotions become more stable and the parent processes their feelings more on the inside. In this stage the parent still faces memory and focusing problems. The final stage is reorientation. In this stage, the parent goes through difficult feelings, but can already add hopefulness to their thoughts. (Ritmala-Castrén et al. 2017, 562.)

## 6 A GUIDE ABOUT PEDIATRIC DELIRIUM

### 6.1 Creating a good guide

In addition to a narrative literature review, a guide for parents about pediatric delirium is done for this thesis study. The guide is written based on characteristics on writing a good guide. A good guide is neutral, clear, compact and proceeds in a logical order. A good, health promotive guide takes their target group into account. (Hyvärinen 2005.) It has to be based on recent scientifically proven information and be ethically sustainable and reliable (Ritmala-Castrén et al. 2017, 560).

Every intensive care unit should have a written guide for supporting the families of the patients (Ritmala-Castrén et al. 2017, 560). A guide is done to answer the questions that the target group, in this case the parents, have. They have the possibility to learn new information when they have the best time for it and the guide also has the information availablefor them at all times. In tricky situations the guide can be used as a checklist. (Roivas & Karjalainen 2013, 118–119.) The parents are often in shock when their child is in hospital, so their capacity of receiving new information can be limited. That is why they should be given the information in a written form. The guide has to be compact but informative enough for the parents to get the information they need. (Muurinen & Surakka 2001, 81.)

Because this guide is about pediatric delirium, a good way to compose the guide is to organize it within subject matters: what is delirium, how is pediatric delirium treated and what causes it. Headings and subheadings are used to let the reader know the topic easily. They also lighten the text and make the guide more clear. Headings become more personal when they address the reader. Subheadings make it easier to spot a certain topic within a large mass of text. A clear table of contents with headings and subheadings makes it easier for the reader to find a specific topic they want to read about. (Hyvärinen 2005.)

The text consists of short chapters and things that address the same subject matter should be combined in the same chapter. If the chapters are too long, the text becomes heavy to read. (Hyvärinen 2005.) Dots should be preferred over other punctuation marks, because they are the most effective. Too long sentences can cause problems in understanding the point of the text. (Roivas & Karjalainen 2013, 35.) Use of fourth person

sentences should be avoided, because they can make the indications unclear for the reader. Active form should be used instead. (Hyvärinen 2005.)

Used language should be plain language in order for everyone to understand the guide. In the Finnish guide, foreign phrases and words should not be used, because they can easily be misunderstood or mixed with other similar sounding words. Too many small details can confuse the reader and make them forget the key point of the text. The text is carefully proofread to spot any misspellings that might complicate understanding of the guide. If there are many misspellings in the text, the reader might start to guess the writer's professionalism. Difficult words and phrases should be explained in a way that everybody can understand them and medical terms should be used as little as possible. In a guide, common words should be preferred over foreign phrases. If difficult words have to be used, they should be explained right after the difficult phrase or in a separate dictionary. (Hyvärinen 2005.)

A clear guide with a visual layout interests the reader more than a guide with only a lot of text and information (Hyvärinen 2005). Use of colors should be limited to one or two that match together. Too big color contrast difference can irritate the reader. The guide should not be overfilled with text and pictures. The images used in the guide should be copyright free and somehow be suitable in that specific place. The text font and line spacing should be big enough for a reader to understand the text. Choose a font that is easy to read. Important words and phrases can be bolded, but this method shouldn't be overused. (Roivas & Karjalainen 2013, 115–121.)

The guide is started with answers to the most important things that the reader wants to know and then moved on to less important topics. Readers want answers and advice for their questions in a way that following them doesn't affect their normal life. If the reader is suggested to do something, the reason for that claim should always be explained: Only telling the reader what to do with no explanation doesn't inspire the reader to change their habits. If the reason is combined with their own benefits, the reader is more motivated to change their habits. (Hyvärinen 2005.)

A guide should be clear enough for the reader to understand what they are reading without going it through with a nurse or other hospital staff member (Hyvärinen 2005). As requested by Tyks pediatric intensive care unit's coordinator, the guide is given for parents when their child is already in the hospital and showing delirium symptoms.

Therefore, no primary information about how to prepare the child for hospital is given in the guide.

This guide is written in two languages, Finnish and English. It is important to have the guide in multiple languages, because not all parents understand Finnish. If the information is only in Finnish, some relevant things might be misunderstood.

Pictures used in the guide were uploaded from pixabay.com where pictures are free-for-use for everyone without copyrights. Used search words for the pictures in the guide were child, hospital, question, speech bubble, medication, baby bottle, parent, checklist and child room. The guide was designed in an A4- size on Microsoft Word word processor. This software was chosen because it was found to be the easiest to use and free of charge. The guide is sent to the intensive care unit in an e-form so that it is easy to print out whenever needed. The guide was designed to be printed on each side of the paper with no folding needed. This is because nurses in the ward might not have time in the ward to fold the guide for the parent and they can easily just staple the pages together. The ready guide is given for Tyks pediatric care unit's coordinator to evaluate and comment if they want any changes made to the guide.

### 6.2 Content of the guide

The name of the guide ended up being "Confused about my child's confusion – a guide for a delirium patient's parents" in the English guide and "Kun lapseni käyttäytyy sekavasti – opas deliriumpotilaan vanhemmille" in the Finnish guide. These titles wake up the reader's interest, are compact and easy to remember. The guide involves basic information about pediatric delirium and how can a parent prevent it and treat it. The content of the guide was arranged under different subtopics.

After the content list, the guide should be started with an introduction where the reader is explained why the guide has been done and why it is important to follow the given directions. The introduction should be kept short and compact and the guide should get to the point fast. (Roivas & Karjalainen 2013, 120.) On the last page are links for online sites for more information about delirium and room for the parent's own notes.

The end result is a compact info guide about pediatric delirium. The sources used in this guide are all reliable and have current information about pediatric delirium. All in all, the

final guide has five pages. The guide is going to be in use for a long time, so it is important that the text is permanent and reproducible and doesn't have any false information.

## 7 ETHICAL ISSUES AND RELIABILITY

Scientific research is ethically acceptable if responsible conducts of research have been followed in making it. These principles include being honest and thorough when writing down and evaluating the study results, using ethically correct sources and getting proper research permits prior to starting the research. The researcher is self-responsible of following these conducts of research. When reviewing other people's literature, their work must be respected and proper quoting must be done when referring their work so that they get credit of their work. (Finnish National Board on Research Integrity 2019.) A literature review must built the best way possible on a work that has already been done. When doing a literature review, the research participants' concent might not always be easy to identify. It is important in this type of research to treat the work of others correctly and fairly. (The Research Ethics Guidebook 2019.)

This thesis was done by using a large variety of different type of reliable sources. Because this thesis is about children, it is important that it has no false information and all the relevant information is included. References must be marked correctly and in a way that their validity can be checked by anyone at anytime (Finnish National Board on Research Integrity 2019).

This thesis is a narrative literature review. This form of a literature review forms an overall picture about existing research information. (Johansson et al. 2007, 3.) The quality of a literature review can suffer if the chosen articles have false information in them. Source criticism increases reliability of the thesis and this method was used in choosing research articles and other sources for this thesis. Source criticism is the way of evaluating a source by its origin, date, currency and fairness. (Hirsjärvi et al. 2009, 113–114.) Only original sources were used in writing this thesis and as new articles were used as possible to get the newest available information.

The articles that were chosen were from years 2014–2019, but some library books that were used in this thesis were older than that. These books could be used in this thesis because information about parents' thoughts about their child getting sick doesn't get old, and newer information about the topic was not available. In these books, source criticism must be especially used and no statistic information cannot be taken from them. When choosing research articles, source criticism must be used. Only reliable databases were used for the article search. Neutral view has to be used when writing down the

results. (Finnish National Board on Research Integrity 2019.) In addition, some results might have been ruled out from this study due to the search words that were used.

The guide can lack important information that the writer has thought to be too obvious to write down. To add reliability to the guide, the final version is sent for approval for Tyks delirium project's coordinator and they can then tell if some information still has to be added the guide. The guide couldn't be tested in action to see how a real parent feels about it due to a strict thesis schedule. This test would have increased the reliability of the guide. Distribution of the guide in Tyks cannot be controlled because nurses decide by their best practices when to give the guide to a patient. The finished guide can be good to use now, but in a couple of years the information can be outdated. Then the guide should be modified according to the new information.

## 8 DISCUSSION

The purpose of this study was to find out through a narrative literature review what is pediatric delirium, what causes it and how it is treated. All the nine chosen research articles for this thesis were English articles, because there are currently no research articles about pediatric delirium written in Finnish (Korteniemi 2019). The articles were combined with each other, and all of them presented similar results. The articles mostly gave answers to delirium symptoms and the treatment of it. No studies were found that considered the parents' point of view. The results are still functional in Finnish settings as well, because delirium symptoms are the same in every country. It would have been good to have Finnish articles in this study as well because the guide is going to be used in Finland.

Results showed that pediatric delirium is only screened in Tyks in Finland (Korteniemi 2019). Hospital staff in other university hospitals in Finland should be taught the importance of this topic and the serious consequences that can occur if pediatric delirium is left untreated. The problem in making this thesis was that there was only concise information about pediatric delirium available. Studies about pediatric delirium are constantly in evolution but still lacking critical information (Cunningham & Vogel 2019).

A few research problems came up in making the thesis. Results could not be compared with other theses about pediatric delirium because there are currently none available. No Finnish studies could be used, because pediatric delirium has not been researched in Finland. The research questions narrowed the scope for searching the articles. This can rule out good reseaches from the literature review. There is also limited information available about pediatric delirium. However, research material about pediatric delirium is constantly in evolution. (Cunningham & Vogel 2019.)

Pediatric delirium is an illness that causes changes in the child's cognition. Delirium can occur due to a long period in intensive care, strange environment, overmedication and oversedation, physical restraints, sleep deprivation, hypoxia, stress and pain (Harris et al. 2016). Adequate pain medication, proper sedation, early mobilization, reducing anxiety and stress and providing comfort for the child are proven to be helpful in reducing the risk of delirium (Hautamäki 2006). Pediatric delirium is medically treated with adequate analgesia, melatonin and antipsychotics (Harris et al. 2016; Bettencourt & Mullen 2017). The child benefits of the presence of family members, calm and pleasant

treatment environment, regular daily schedule and a normal sleeping pattern (Muurinen & Surakka 2001, 81–83; Traube et al. 2018; Cunningham & Vogel 2019; Bettencourt & Mullen 2017). Early recognition and proper treatment reduce mortality and negative side effects after discharge from the hospital (Bettencourt & Mullen 2017). Because small children are not able to express their discomfort, pain or fear verbally, they are in an elevated risk for overmedication and oversedation (Harris et al. 2016).

Adult delirium is common and widely known and proper assessment tools are used to detect it. However, pediatric delirium assessment has not yet become a normal daily routine in hospital environment. Pediatric patients need regular assessment to notice any small changes that might indicate delirium. (Bettencourt & Mullen 2017; Cunningham & Vogel 2019.) This can be achieved by teaching nurses about pediatric delirium, making the assessment tools easy and fast to use and making assessment of delirium as important as assessing a vital sign. It is difficult to differentiate pain, withdrawal symptoms and delirium from each other. All of these symptoms require different type of treatment. Assessment tools have been created to help the nurses assess their patients better and recognize delirium symptoms and therefore to improve the quality of the treatment. All nurses should be taught a correct way to use these assessment tools. (Harris et al. 2016.) Studies have shown that nurses have little information about how to recognize delirium symptoms and the correct way to treat them. By doing more research on the matter of this topic, serious consequences of unrecognized delirium can be prevented. (Kudchadkar et al. 2014; Bettencourt & Mullen 2017; Flaigle et al, 2015.)

In children, long-term concequences of pediatric delirium have not been highly studied. Pediatric delirium has been shown to cause children delusional memories and post-traumatic stress after discharge from the hospital. More research is needed to figure out preventive methods and better treatment methods for pediatric delirium. (Silver & Traube 2016; Harris et al. 2016.)

Parents are in a key role in a child's treatment. They know their child better than anyone, and therefore they can notice any slight changes in their child's behavior. This is especially important in small children's treatment. The parents can provide valuable information for the nurses and improve the treatment of their child. A sick child requires a lot of time from their parents (Muurinen & Surakka 2001, 81–83). The parents should be encouraged to participate in the treatment as much as possible by doing normal daily routines with the child (Bettencourt & Mullen 2017).

A child in intensive care causes the parent to be worried and scared. Their emotions can range from emotionless to furious. (Cunningham & Vogel 2019; Muurinen & Surakka 2001, 81.) The parent's thoughts about the illness depend on the crisis stage they are in (Ritmala-Castrén et al. 2017, 561). The parent's reaction to their child's situation is important, because a child reflects their parent's feelings directly to themselves (Koistinen et al. 2004, 429). When the parent is in shock, they are not capable of remembering all the information they have been given in the hospital. Therefore, all the information should be given in a written form. (Koistinen et al. 2004, 431; Bettencourt & Mullen 2017.)

The guide aims to inform parents about pediatric delirium and its risk factors and treatment methods. The guide was created to be clear and neutral and therefore as ethical as possible. Room for notes was left on the last page, because when a parent visits the hectic intensive care unit they might forget important questions they had in mind at home (Koistinen et al. 2004, 431). The pictures used in the guide were downloaded from a copyright free webpage. The information in the guide can be misunderstood depending on the person who is reading it. The possibility for misunderstandings that consider language barriers was reduced by making the guide in two languages.

# 9 CONCLUSION

All the chosen articles presented the same type of results: pediatric delirium is underdiagnosed globally and it creates a risk for the child's current and future well-being. It also increases the costs in health care settings, because delirium adds the days that are needed to spend in the hospital. Research that has been done on the topic mainly focuses on the basic things of pediatric delirium such as symptoms, reasons and treatment. Future research could focus more on the after effects of delirium after discharge from the hospital.

Pediatric delirium has not been studied enough globally, and Finland is especially lacking research about the topic. Nurses find it difficult to assess pediatric patients' delirium due to lack of knowledge about the illness, lack of good and user-friendly assessment tools and lack of time. Mandatory training about pediatric delirium should be provided for the nurses and doctors in Finland. Adult delirium is already a part of mandatory studies in nursing school in Finland. Pediatric delirium should be added to those mandatory studies as well because then nurses in working life would already be familiar with the topic when they would face it.

There is currently no articles about pediatric delirium in Käypä hoito web page. A good informative article about pediatric delirium should be added to the website to help increase awareness of the topic. When awareness is increased, nurses might be able to recognize delirium symptoms better and differentiate them from pain and withdrawal symptoms. If delirium would be assessed in intensive care as often as vital signs, it would become a routine for nurses and the assessment would become easier and faster. This way more delirious patients could be helped.

In Finland, pediatric delirium is only screened in Tyks. By further research and broader awareness of the topic, in the future pediatric delirium might be screened in other university hospitals as well.

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Appendix 3. Pediatric Anesthesia Emergence Delirium Scale.

- 1. The child makes eye contact with the caregiver.
- 2. The child's actions are purposeful.
- 3. The child is aware of his/her surroundings.
- 4. The child is restless.
- 5. The child is inconsolable.

Items 1, 2, and 3 are reversed scored as follows: 4 = not at all, 3 = just a little, 2 = quite a bit, 1 = very much, 0 = extremely. Items 4 and 5 are scored as follows: 0 = not at all, 1 = just a little, 2 = quite a bit, 3 = very much, 4 = extremely. The scores of each item were summed to obtain a total Pediatric Anesthesia Emergence Delirium (PAED) scale score. The degree of emergence delirium increased directly with the total score.

Source: Sikich N. & Lerman J. Development and psychometric evaluation of the pediatric anesthesia emergence delirium scale.

Appendix 2. Cornell Assessment of Pediatric Delirium. (CAPD).

	Never 4	Rarely 3	Sometimes 2	Often 1	Always 0	Score
Does the child make eye contact with caregiver?						
Are the child's actions purposeful?						
Is the child aware of his/her surroundings?						
Does the child communicate need and wants?						
	Never 0	Rarely 1	Sometimes 2	Often 3	Always 4	Score

Is the child restless?

Is the child inconsolable?

Is the child underactive- very little movement while awake?

Does it take the child a long time to respond to interactions?

Source: Cunningham & Vogel. Analgesia, sedation, and delirium in pediatric surgical critical care.

Arviointi suoritettu:

Pvm \_\_\_\_ Kello \_\_\_

# Appendix 6. Official CAPD version that is used in Tyks for 0-21-year-olds.

### <u>DELIRIUM-ARVIOINTI 0-21-VUOTIAILLE LAPSILLE JA NUORILLE</u> – Cornell Assessment of Pediatric Delirium (CAPD)

→Arvioi ensin potilaan sedaatiotaso. (Mikäli potilas on ärsykkeisiin reagoimaton tai täysin tajuton, deliriumia ei voi arvioida.)

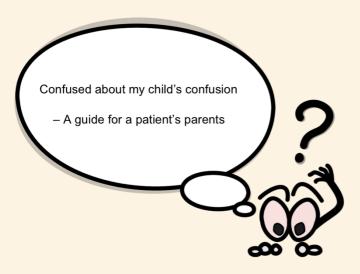
Arvioidaan vähintään 1x/työvuoro	Ei koskaan	Harvoin	Joskus	Usein	Aina	Pisteet
	4	3	2	1	0	
Ottaako lapsi katsekontaktin vanhempaan tai häntä hoitavaan henkilöön?						
(Vauva: kiinnittää huomion kasvoihin, seuraa liikkuvaa kohdetta	a. Lapsi: katsoo	puhujaan, s	suosii vanhe	mpiaan.)		
2. Toimiiko lapsi määrätietoisesti?						
(Vauva: tarttuu tai kurottaa kädellä kohti, symmetriset liikkeet.	Lapsi: käsittele	e esineitä, r	nuuttaa ase	ntoaan, jos	pystyy.)	
3. Onko lapsi tietoinen ympäristöstään?						
(Vauva: hymyilee, jokeltaa, ujostelee. Lapsi: suosii vanhempiaan, hakee lohtua tutuista esineistä.)						
4. Ilmaiseeko lapsi tarpeitaan ja halujaan?						
(Vauva: itkee nälkää tai epämukavuutta. Lapsi: kertoo tarpeistaan sanoin tai osoittamalla.)						
	Ei koskaan	Harvoin	Joskus	Usein	Aina	Pisteet
	0	1	2	3	4	
5. Onko lapsi levoton?						
(Vauva: jatkuvasti hereillä, touhukas. Lapsi: rauhaton, valittelee, touhukas.)						
6. Onko lapsi lohduton?						
(Vauva: ei tyynny tavallisin keinoin, esim. syli, syöttäminen, laulaminen. Lapsi: ei tyynny tavallisin keinoin, esim. syli, juttelu, laulaminen.)						
7. Liikkuuko lapsi hereillä ollessaan epätavallisen vähän?						
(Vauva: ei tartu päättäväisesti tai työnnä epämiellyttäviä asioita pois. Lapsi: ei juurikaan pyri leikkimään, istumaan tai liikkumaan.)						
8. Vastaako lapsi vuorovaikutukseen viiveellä?						
(Vauva: ei kohdista katsetta, jokella tai hymyile. Lapsi: ei noudata yksinkertaisia ohjeita tai ei kykene keskusteluun.)						

PISTEET: 0–6: ei deliriumia, 7–9: mahdollinen delirium (arvioitava pian uudelleen), yli 10 pistettä: delirium

# Appendix 5. Official CAPD version that is used in Tyks for 0 to 2-year-olds.

	Vastasyntynyt	4-viikkoinen	6-viikkoinen	8-viikkoinen	28-viikkoinen	1-vuotias	2-vuotias
1. Ottaako lapsi katsekontaktin vanhempaan tai hoitajaan?	Katsoo kasvoja.	Säilyttää katsekontaktin hetkellisesti, seuraa 90 astetta.	Säilyttää katsekontaktin.	Seuraa keskittyneesti liikkuvia esineitä/vanhempaa/hoitajaa keskilinjan yli.	Säilyttää katsekontaktin, suosii vanhempiaan, katsoo puhujaan.	Säilyttää katsekontaktin, suosii vanhempiaan, katsoo puhujaa.	Säilyttää katsekontaktin, suosi vanhempiaan, katsoo puhujaa
2. Toimiiko lapsi määrätietoisesti?	Liikuttaa päätään sivuille, refleksisiä liikkeitä.	Kurottaa kädellä kohti (hieman hapuillen).	Kurottaa kädellä kohti.	Symmetrisiä liikkeitä, puristaa ojennettua esinettä passiivisesti.	Tarttuu hyvällä koordinaatiolla, sujuvia liikkeitä.	Tarttuu esineisiin ja käsittelee niitä, yrittää vaihtaa asentoa, yrittää nousta ylös, jos mahdollista.	Tarttuu esineisiin ja käsittelee niitä, yrittää vaihtaa asentoa, yrittää nousta ylös ja kävellä, jos mahdollista.
3. Onko lapsi tietoinen ympäristöstään?	Rauhallinen hereillä ollessaan.	Virkeä hereillä ollessaan, tunnistaa vanhempansa tai huoltajansa äänen ja saattaa tunnistaa tämän tuoksun.	Enenevissä määrin virkeänä hereillä, tunnistaa vanhempansa tai huoltajansa äänen ja saattaa tunnistaa tämän tuoksun.	On ilmeikäs ja vastaa hymyllä nyökyttelyyn, ilmeilyyn tai ääntelyyn. Kurtistaa kulmiaan kellon äänelle. Jokeltelee.	Suosii vahvasti äitiään ja muita tuttuja. Erottaa tutut ja vieraat esineet.	Valitsee ensisijaisesti vanhempansa, sitten muut tutut. Hermostuu, jos erotetaan vanhemmastaan tai huoltajastaan. Saa lohtua tutuista esineistä, erityisesti lempipeitosta tai pehmolelusta.	Valitsee ensisijaisesti vanhempansa, sitten muut tutut. Hermostuu, jos erotetaan vanhemmastaan tai huoltajastaan. Saa lohtua tutuista esineistä, erityisesti lempipeitosta tai pehmolelusta.
4. Ilmaiseeko lapsi tarpeitaan ja halujaan?	Itkee ollessaan nälkäinen tai kun olo on epämukava.	Itkee ollessaan nälkäinen tai kun olo on epämukava.	Itkee ollessaan nälkäinen tai kun olo on epämukava,	Itkee ollessaan nälkäinen tai kun olo on epämukava.	Ilmaisee tarpeitaan: esim. nälkä, epämukavuus, mielenkiinto asioihin, esineisiin ja ympäristöön.	Käyttää yksittäisiä sanoja tai viittomia.	Käyttää 3–4-sanaisia lauseita tai viittomia. Ilmaisee wc- tarvetta. Viittaa itseensä sanoilla "minä" tai "itse".
5. Onko lapsi levoton?	Ei ole pitkään virkeänä hereillä.	Ei ole rauhallinen pitkää aikaa kerrallaan.	Ei ole rauhallinen pitkää aikaa kerrallaan.	Ei ole rauhallinen pitkää aikaa kerrallaan.	Ei ole rauhallinen pitkää aikaa kerrallaan.	Ei ole rauhallinen pitkää aikaa kerrallaan.	Ei ole rauhallinen pitkää aikaa kerrallaan.
6. Onko lapsi lohduton?	Ei rauhoitu vanhempien keinutteluun, lauluun, syöttämiseen, lohdutteluun.	Ei rauhoitu vanhempien keinutteluun, lauluun, syöttämiseen, lohdutteluun.	Ei rauhoitu vanhempien keinutteluun, lauluun, syöttämiseen, lohdutteluun.	Ei rauhoitu vanhempien keinutteluun, lauluun, syöttämiseen, lohdutteluun.	Ei rauhoitu tavanomaisin keinoin, kuten lauluun, sylissä pitoon tai jutteluun.	Ei rauhoitu tavanomaisin keinoin, kuten lauluun, sylissä pitoon, jutteluun tai lukemiseen.	Ei rauhoitu tavanomaisin keinoin, kuten lauluun, sylissä pitoon, jutteluun tai lukemiseen. Voi saada raivonpuuskia, mutta pystyy myös rauhoittumaan.
7. Onko lapsen aktiivisuustaso alentunut; liikkuuko lapsi hereillä ollessaan epätavallisen vähän?	Vähän jos lainkaan lihasjännitystä ja refleksejä. (Vauvan tulisi nukkua mukavasti suurimman osan aikaa.)	Vähän jos lainkaan tavoittelua, potkimista, tarttumista (voi vielä olla kuitenkin hapuilevaa).	Vähän jos lainkaan tavoittelua, potkimista, tarttumista (alkaa olla hieman enemmän koordinoitua).	Vähän jos lainkaan tarkoituksenmukaista tarttumista, pään kannattelua, käsien liikkeitä, ei epämiellyttävien asioiden pois työntämistä.	Vähän jos lainkaan tavoittelua, tarttumista, liikkumista sängyssä, tavaroiden pois työntämistä.	Vähän jos lainkaan yritystä leikkiä, yritystä nousta istumaan, punnertaa ylös, ryömiä tai kävellä.	Vähän jos lainkaan yritystä leikkiä kehittyneemmin, istua, liikkua, ja jos pystyy seisomaan, kävellä tai hyppiä.
8. Vastaako lapsi vuorovaikutukseen viiveellä?	Ei ääntele tai reagoi odotetulla tavalla (tarttumis-, imu-, moro-refleksit).	Ei ääntele tai reagoi odotetulla tavalla (tarttumis-, imu-, moro- refleksit).	ei reagoi epämiellyttävään ärsykkeeseen potkimalla tai itkemällä.	Ei vastaa vuorovaikutukseen jokeltelemalla, nauramalla tai ottamalla katsekontaktia.	Ei reagoi sosiaaliseen kanssakäymiseen jokeltelemalla tai hymyilemällä (jopa aktiivisesti kieltäytyy kanssakäymisestä).	Ei noudata helppoja ohjeita. Vaikka ymmärtäisi puhetta, ei ryhdy helppoon dialogiin sanoilla tai siansaksalla.	Ei noudata yksinkertaisia 1-2 sanan käskyjä. Jos puhuu, ei kykene monimutkaisempaan dialogiin.

Source for appendix 3 and 4: Korteniemi. 2019. Henkilökohtainen tiedonanto.



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	Communicating	3
	Providing comfort	4
	Participating in the treatment	4
Final words		5

### Introduction

A child's sudden illness can be confusing and stressful. This guide helps you to familiarize with your child's changed situation. If you have any questions after reading this guide, there is room for your own thoughts and questions in the end.

# What is pediatric delirium?

Delirium, also called acute confusion state is a brain dysfunction that can occur as a side effect of an illness and its treatment. Delirium is typically a rapidly passing state. Nurses assess and screen for delirium regularly and try to minimize the things that might be causing delirium as much as possible. Usually your child's treatment might require the factors, for example medications, that increase delirium.

Delirium can develop during a very short time. Delirium symptoms tend to worsen in the evening and the intensity of the symptoms can vary a lot during the day. Some children might not experience delirium symptoms at all. Delirium symptoms can be for example decreased capability for observation, restlessness, wandering speech and hallucinations.

# Some possible reasons for delirium:

- o strange environment
- o illness process
- o extensive medication
- o pain
- stress
- sleep deprivation
- o being away from family
- o physical restraints like tubes and wires
- long period in intensive care

## Delirium can be prevented and treated with for example:

- o active moving and rehabilitation
- o treating and correcting possible lack of oxygen
- o returning into a normal sleeping pattern
- o avoiding over-use of sedative medications and opioids
- o avoiding certain sedative drugs if possible
- adequate pain treatment
- o treating sleeplessness and anxiety
- o presence of family members
- o calm and pleasant treatment environment
- o regular daily schedule

In some cases, for example the use of sedatives and opioids are required for your child's well-being, and therefore not all of these preventive methods can be used.



#### How can I support my child?

#### Playing and activity

Discuss with a nurse about how you can help your child. Children learn new things through their play. Your child needs age-appropriate stimuli and things to spend time with in the hospital. If possible, bring your child his/her own familiar toys from home. You should play with your child or if your child is not able to play, you can read books for him/her. This way your child can express his/her emotions. Listening to music and watching child-friendly television shows or movies can help your child get his/her mind out of difficult things. Light touch can calm your child down.

Providing your child early activity helps him/her recover from delirium. Help him/her move out of bed as much as he/she can. If your child is able to do his/her own chores, you should encourage him/her to do them even if they might take a bit more time. If your child uses glasses or a hearing aid, make sure that he/she wears these in the hospital. This helps him/her to be more orientated.

#### Sleeping

A delirious child's daily rhythm can be reversed. If you visit in the morning or during daytime, make sure that your child is out of bed. This helps to create a normal daily rhythm for your child. However, getting out of bed is not always possible for a patient. If you visit in the evening, calm the situation by playing calmly with your child. Stories are also good in the evenings. Try bringing familiar bedtime routines into the hospital environment. Dim the lights in the room and close the television. By adjusting the lights according to what time of day it is, your child learns when to sleep and when to not. Your child needs rest to get better, so if your child is asleep when you come to visit him/her, you should not wake him/her up. If your child still cannot sleep during the night, you should try bringing him/her an eye mask and earplugs. This can help to close out any extra irritants.



# Communicating

It is possible that due to delirium your child might not recognize you. Use calm, slow and clear speech when talking with your child. Help your child to get more orientated by telling them about the time of day, date and time of year. Your child might ask where they are and why they are there, and the answer should be given patiently even if your child would ask this often. If your child has hallucinations, you should explain him/her that they are alright and not stupid at all. However, he/she should be explained that what they see is not the same as other people see.

When visiting, focus on talking about nice things with your child. When talking about other things than the treatment, your child can become happier and get more focused on normal life and the future. Shut down your phone and focus only on your child when you come to visit him/her.



# Providing comfort

Hospital rules don't allow much decorating, but a few familiar items from home can be beneficial for your child's recovery. Try bringing family photos, his/her favourite stuffed toy or a safety blanket.

# Participating in the treatment

Your child benefits from your involvement in his/her treatment. It is important that you participate in your child's treatment, because you know your child best and you can help the nurses to identify if your child is acting differently than normal. You can actively tell the nurses about how your child is different from normal. This helps the nurses in your child's treatment. If taking part in the treatment feels too much for you, you can participate in daily things like changing a diaper, washing your child, feeding and putting on lotion. This helps you to bond with your child and your child also feels safe when you are near him/her.

## Final words

<u>Notes</u>

Your child's changed presence might make you feel anxious or scared. Remember that if you have any concerns about the treatment, ask bravely for more information from the hospital staff. There are no stupid questions.



Kun lapseni käyttäytyy sekavasti

– opas potilaan vanhemmille

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# Johdanto

Lapsen äkillinen sairastuminen voi aiheuttaa vanhemmille hämmennystä ja stressiä. Tämän oppaan avulla voit tutustua lapsesi muuttuneeseen tilanteeseen. Jos sinulle jää kysymyksiä oppaan lukemisen jälkeen, lopussa on tilaa omien ajatuksien ja kysymyksien muistiin kirjoittamiselle.

#### Mitä on lapsen delirium?

Delirium eli sekavuustila on aivotoiminnan häiriö, joka voi aiheutua sairaalahoitoa vaativan sairauden ja sen hoidon sivuvaikutuksena. Delirium on useimmiten nopeasti ohimenevä tila. Hoitajat seuraavat ja seulovat deliriumia säännöllisesti ja pyrkivät minimoimaan deliriumia aiheuttavia tekijöitä mahdollisuuksien mukaan. Usein lapsesi sairaus voi vaatia deliriumin riskiä lisäävien tekijöiden, kuten lääkkeiden, käyttöä. Delirium voi kehittyä hyvinkin lyhyessä ajassa. Oireet tyypillisesti pahenevat iltaa kohden ja niiden voimakkuus voi vaihdella. Joskus joillakin lapsilla ei välttämättä ilmene deliriumin oireita ollenkaan. Deliriumin oireita voivat olla esimerkiksi heikentynyt huomiokyky, levottomuus, harhaileva puhe sekä hallusinaatiot.

#### Deliriumin syitä:

- vieras ympäristö
- sairausprosessi
- voimakas lääkitys
- o kipu
- stressi
- o univaje
- o ero perheestä
- liikkumista estävät rajoitteet kuten letkut ja johdot
- pitkäkestoinen tehohoito

#### Deliriumia voi ehkäistä ja hoitaa esimerkiksi:

- o aktiivinen liikkuminen ja kuntouttaminen
- o aikainen unirytmin korjaaminen
- o säännöllinen vuorokausirytmi
- rauhoittavien lääkkeiden ja vahvojen kipulääkkeiden runsaan käytön välttäminen
- o hyvä kivunhoito
- o unettomuuden ja ahdistuksen hoito
- o mahdollisen happivajeen korjaaminen
- o perheen ja muiden läheisten ihmisten läsnäolo
- o rauhallinen, turvallinen ja miellyttävä hoitoympäristö

Joissain tilanteissa esimerkiksi rauhoittavien lääkkeiden ja kipulääkkeiden käyttö on välttämätöntä lapsen hyvinvoinnin kannalta, joten kaikkia deliriumia aiheuttavia tekijöitä ei voida minimoida lapsen hoidossa.



## Kuinka voin tukea lastani?

#### Leikki ja aktiviteetti

Keskustele hoitajan kanssa, millä tavoin voit auttaa lastasi. Lapsesi oppii uusia asioita leikin avulla. Hän tarvitsee ikätasoistaan toimintaa sekä virikkeitä, joiden parissa viettää aikaa sairaalassa. Jos mahdollista, tuo lapsellesi kotoa hänelle tuttuja leluja. Vieraillessasi pyri leikkimään lapsesi kanssa hänen vointinsa mukaan. Jos lapsesi ei kykene leikkimään, voit lukea hänelle satukirjoja. Satujen avulla lapsesi pystyy ilmaisemaan tunteitaan. Musiikin kuuntelu ja lapsiystävällisten televisio-ohjelmien ja elokuvien katsominen voi auttaa lastasi keskittymään hoidon ohella myös mukaviin asioihin. Kosketus voi auttaa lastasi rauhoittumaan.

Aikainen fyysinen aktivointi auttaa deliriumista toipumisessa. Auta lastasi lähtemään liikkeelle niin paljon kuin hänen vointinsa mahdollistaa. Rohkaise lastasi tekemään vointinsa rajoissa mahdollisimman paljon itse, vaikka se veisikin hieman enemmän aikaa. Jos lapsellasi on silmälasit tai kuulolaite, varmista että hän käyttää niitä myös sairaalassa. Niiden käyttö auttaa lastasi orientoitumaan paikkaan ja aikaan.

## <u>Uni ja lepo</u>

Deliriumiin sairastuneen lapsen päivärytmi voi olla täysin käänteinen. Jos vierailet lapsesi luona aamulla tai päivällä, varmista että lapsesi on noussut ylös sängystä. Sängystä ylösnousu edesauttaa päivärytmin syntymistä. Aina sängystä nouseminen ei ole kuitenkaan mahdollista. Jos vierailet illalla, rauhoita mahdollisesti riehaantunut lapsesi rauhallisella leikillä tai iltasadulla. Lapsesi voi myös hyötyä tuttujen iltarutiinien tuomisesta sairaalaympäristöön. Himmennä huoneen valot ja sulje televisio illalla. Valojen kirkkauden säätely kellonajan mukaan opettaa lapsellesi, milloin kuuluu nukkua ja milloin ei. Jos lapsesi kuitenkin nukkuu saapuessasi vierailulle, älä herätä häntä. Lapsi tarvitsee unta toipuakseen. Jos lapsesi näistä huolimatta ei saa unta öisin, kokeile tuoda hänelle silmälaput sekä korvatulpat. Tämä voi auttaa sulkemaan pois ylimääräisiä ärsykkeitä.



#### Kommunikointi

On mahdollista, että lapsesi ei deliriumin vuoksi tunnista vanhempiaan. Puhu lapsesi kanssa rauhallisesti ja selkeästi. Pyri vahvistamaan lapsesi orientoitumista kertomalla hänelle vuorokaudenajasta, päivästä ja vuodenajasta. Lapsesi saattaa kysyä useasti missä hän on ja miksi hän on siellä. Toistuviin kysymyksiin tulee vastata kärsivällisesti. Jos lapsesi näkee harhoja, niitä ei saa vähätellä. Lapsellesi tulee kertoa, että näyt ovat hyväksyttäviä, mutta hän näkee eri asioita kuin muut ihmiset.

Keskitä vieraillessasi puhe mukaviin asioihin ja pois hoidosta. Tavallisista asioista puhuminen nostaa lapsesi mielialaa ja saa hänet keskittymään normaaliin elämään ja tulevaisuuteen. Sulje puhelimesi vierailun ajaksi ja keskity ainoastaan lapseesi.



#### Mukavuuden lisääminen

Sairaalan tiukat hygieniasäännöt eivät salli huoneen sisustamista, mutta muutama kotoa tuotu tuttu tavara edistää lapsesi toipumista. Tuo huoneeseen esimerkiksi valokuvia perheestä, lapsesi oma turvariepu tai lempipehmolelu.

#### Hoitoon osallistuminen

Lapsesi hyötyy läsnäolostasi ja osallistumisestasi hoitoon. On tärkeää, että osallistut lapsesi hoitoon, sillä sinä tunnet lapsesi parhaiten ja voit auttaa hoitajia tunnistamaan lapsen käyttäytymisen muutokset. Voit aktiivisesti kertoa hoitajille millainen lapsesi on normaaliin verrattuna. Tämä auttaa hoitajia lapsesi hoidossa. Jos hoitoon osallistuminen tuntuu vaikealta, voit osallistua päivittäisiin hoitotoimenpiteisiin kuten vaipanvaihtoon, lapsesi pesuihin, syöttämiseen ja ihovoiteen levittämiseen. Tämä auttaa sinua ylläpitämään suhdetta lapseesi ja luo lapsellesi turvallisuuden tunteen.

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<u>Lopuksi</u>	
Lapsesi muuttunut käytös saattaa aiheuttaa ahdistusta tai stressiä.	
Jos sinulla on huolia tai kysymyksiä lapsesi hoidosta, kysy rohkeasti	
lisätietoa hoitohenkilökunnalta. Tyhmiä kysymyksiä ei ole olemassa.	
Muistiinpanot	