

The Norwegian Health
Investigation Board

Early diagnosis and treatment of serious illness in the febrile child

Report 2-2020



Ukom

Norwegian Healthcare Investigation Board

The Norwegian Healthcare Investigation Board, hereafter Ukom, is an independent government agency. Our mandate is to investigate serious incidents and other serious concerns involving the Norwegian health care services.

We will investigate the sequence of events, factors that contributed to the outcome and causal relationships. Our purpose is to improve patient and user safety by learning and taking action to prevent future serious incidents. We do not assess civil or criminal liability or guilt.

We decide which serious incidents or circumstances to investigate, the timing and scope of the investigation, and how this will be executed.

The investigation is performed in dialogue with the parties involved, which include employees in health care services, patients/users of health care services and their families.

Our reports are public, however we make no reference to the names and addresses of individuals involved. The location for the adverse event may in some cases be disclosed.

Ukom's activities are regulated by Act no. 56 of 16 June 2017 on the Norwegian Healthcare Investigation Board.

Report 2-2020

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Summary

Ukom received a report of patient safety concern from the parents of 20-month old Lukas who died of bacterial meningitis in January 2019. Based on this report, we decided to investigate this serious incident. We started by obtaining relevant information from the parents, the emergency primary care centre, GP office, ambulance service, Emergency Medical Communication Centre, hospital, County Governor and the police. Subsequently, we interviewed the parents. We found in our investigation that 61 health care workers had been in direct and indirect contact with Lukas and his parents. We interviewed 19 of them. Our review of the information gathered allowed us to ascertain the sequence of events that had taken place.

Over the course of a four-day illness, Lukas and his parents were in contact with various medical service providers, including an emergency primary care centre, a GP office, the ambulance service, the local hospital and a university hospital. After reviewing the case history, it most likely started as a common infection. However, on the evening of the third day, his condition deteriorated. He died at the university hospital on the evening of day four. The autopsy report concluded that death was caused by pneumococcal meningitis, most likely spread from an airway infection.

The Norwegian primary health care-services are frequently visited by febrile children and consulted by parents calling about their febrile child. The most common cause of fever is a viral infection that poses no serious risk, however fever can also be a symptom of a bacterial infection that needs rapid treatment. It is important to

identify the children with serious infections so treatment can be initiated as soon as possible. The overall well-being and general condition play an important role in assessing how serious the illness is, though this can be difficult to assess – particularly in the youngest children.

Parents know their child best and they are therefore an important resource when health care workers assess the severity of the illness. Increased parental awareness of specific warning signs, could improve their health literacy. In turn, this may facilitate better communication and coordination between parents and the health service.

Based on the incident in question, Ukom has identified several areas for learning:

- Ukom recommends that healthcare professionals, including national bodies, develop a more unified understanding of how children's general condition should be described and assessed. This could help improve early diagnosis and treatment of acute illness in the febrile child.
- The clinical symptoms of meningitis in children may be ambiguous and its prevalence has changed. Are health care workers who deal with sick children sufficiently aware of this?
- Ukom recommends that the decision-support tools utilized by emergency primary care centres, also provide parents with information about specific warning signs in the febrile child.
- Ukom recommends that well-founded information on how to manage a febrile child and specific warning signs, should be easily accessible to parents.
- Ukom recommends that the chain of emergency services establish standards and practices for documentation of parents' observations and assessment of their child.

Content

Norwegian Healthcare Investigation Board	2
Summary	3
Contents.....	4
The report of patent safety concern.....	5
Sequence of events	7
Timeline.....	8
Health care workers	12
Analysis and recommendations.....	13
How can we improve early diagnosis of the febrile child?	14
Identifying the seriously ill child.....	14
Assessing general condition	16
Prevalence and symptoms of meningitis.....	19
Parents as a resource	21
How to improve parents' health literacy?	21
Communicating over the phone	21
Information available to parents.....	22
How can information provided by parents be used more systematically?	23
Methods.....	25
Documentation and interviews.....	26
Establishment of the facts and analysis.....	27
Special considerations for the analysis.....	27
Hindsight bias – "20/20 hindsight".....	27
Local Rationality	27
Conditions for validity	27
References.....	28

The report of patient safety concern

Ukom received a report of patient safety concern from the child's parents in May 2019 after their 20-month-old child died of bacterial meningitis in January 2019. To protect his identity, we named him Lukas.

Ukom initiated this investigation in June 2019.

Other public agencies' assessments

The incident was also reported to the Norwegian Board of Health Supervision. They decided not to investigate further after its initial inquiry. In response to a complaint by the parents, the County Governor initiated a supervisory review of the hospital, which on October 21, 2019 reached the following conclusion:

"The County Governor acknowledges that the initial admission and treatment of the patient at the short-stay assessment unit was not in line with good practice. In view of this, and the fact that the senior on-call doctor was not immediately contacted, the County Governor considers that the overall treatment of the patient at the short-stay assessment unit constitutes a breach of the requirement to provide appropriate care pursuant to Section 2-2 of the Specialist Health Services Act."

"The County Governor has concluded that the care and treatment provided during and after the change of shift was in line with good practice at Norwegian children's wards. However, antibiotics could have been administered an hour earlier, although it is unlikely this would have changed the outcome. There was no reason to perform a cerebral CT scan earlier since it is unclear whether this could have led to life-saving treatment."

Reports to Ukom

Ukom receive 2 types of reports

1) Serious adverse event report

These are reports of serious adverse events defined as death or serious injury beyond expected risk. These events are reported from the health services to both the Health Supervision Board and Ukom.

2) Report of patient safety concern

These are reports of serious adverse events or areas of concern regarding patient safety. Anyone can report a patient safety concern directly to Ukom through our website.

Lukas was a 20-month-old child. He went from being healthy to die of meningitis in just a few days.



CHAPTER 1

Sequence of events

Timeline

INFORMATION

CRP (C-reactive protein)
CRP is used as a general measure of inflammation in the body. It is not a specific test, so it does not tell you the cause or location of the inflammation. A CRP test during the first 12–24 hours of illness is of relatively limited value, because it takes some time for the CRP level to rise. CRP values must always be assessed in the light of clinical findings and other supplementary examinations. A rising CRP level increases the likelihood that the cause is a bacterial infection.

Lukas was a 20-month-old boy who in just a few days died of meningitis. He was in good general health and received routine childhood immunisations according to the national Childhood Immunisation Programme.

Prior to contact with the health service
On the morning of day 1, Lukas' grandmother was babysitting. She contacted his parents when he developed a fever.

Emergency primary care centre helpline and GP office
On day 1 in the afternoon, Lukas' parents called the emergency primary care centre helpline because his body temperature remained persistently high despite the administration of paracetamol. The emergency primary care centre advised them on the use of anti-pyretic and how to care for a febrile child.

On day 2, Lukas fever was high, and his parents kept him home from kindergarten.

On day 3, Lukas had an appointment with his GP as he still had a high temperature. His parents informed the doctor that he had a bit of a cough, had plenty to drink and had wet diapers. The doctor examined his lungs, throat and ears, and ruled out a stiff neck. Lukas appeared tired, but protested when she examined him. His CRP level was 37 mg/L. The origin of his fever was not found. The doctor wanted a urine sample to exclude urinary tract infection, so the parents were given a urine collection bag. Their attempt to collect a urine sample was unsuccessful, therefore a new appointment was scheduled for the following day at 11:00. That night Lukas slept with his parents. At 23:00 he woke up, cried and vomited. His temperature was 39.6 °C and he was given paracetamol again. His parents were concerned, however they didn't contact the emergency primary care centre since they had a GP appointment the next day.

On day 4 Lukas woke up screaming at around 06:00 and vomited several times. His parents called the emergency primary care centre helpline. His mother explained that they had seen their GP the previous day and that his CRP level had been measured. She also informed them that they had a doctor's appointment later that same day and planning to bring a urine sample. She mentioned that Lukas had vomited. During the conversation, the emergency primary care centre helpline ascertained that he didn't have a temperature and that he awoke easily when stimulated.



A common reason parents contact the emergency primary care centre, is to consult about their febrile child. (Illustration photo)

They agreed that Lukas' parents should contact their GP office as soon as it opened.

Lukas' father phoned the GP office when they opened to discuss whether to postpone the appointment. They were invited to come straight away, however they were told that since it was a busy day, there could be an extended wait. They decided to keep the original scheduled appointment at 11:00. Before leaving the house, Lukas was given paracetamol. There was a 40 minute wait at the clinic before Lukas was examined by a doctor. During that time a blood test was taken which showed that his CRP level had increased to 143 mg/L. In the waiting room, Lukas' father noticed that the child was warm and less responsive. Even though clinical examination could not ascertain the focus of the infection, the doctor was concerned because he was lethargic, offered little resistance upon clinical examination, and was less responsive than the day before. Based on these observations, she requested an ambulance to take him to the hospital immediately, and informed the junior doctor on-call at the local hospital's paediatric department about Lukas and his condition.

The ambulance

The ambulance arrived at the GP office a few minutes later. The paramedics examined Lukas, helped administer paracetamol and departed the GP office 30 minutes later. Lukas cried a bit when he was put on the stretcher. During the transport to the hospital, which took 30 minutes, his eyes were closed but he was easy to wake. His respiration and circulation parameters were normal, and on the Glasgow Coma Scale (level of consciousness), he scored 14 out of 15. Shortly before arrival the ambulance crew contacted the junior on-call

doctor to give him an update on his condition.

Short-stay assessment unit at the local hospital

Lukas was brought to the short-stay assessment unit in the paediatric ward at around 12:40. He was assessed by the junior on-call doctor and two nurses who examined him immediately. He seemed lethargic and was whimpering. His temperature was 36.0 °C. A peripheral venous catheter was inserted, and blood tests and blood culture were performed. Nasal and throat swabs were also taken. In addition, an attempt was made to obtain a urine sample by inserting a catheter into his bladder through the urethra (urinary catheterization). Lukas offered little resistance to these interventions. Due to suspected dehydration, he was given intravenous fluids.



In the assessment of a child's general condition, it is important to evaluate their interest in toys and general surroundings.

Mother is concerned about meningitis

Lukas' mother arrived at the hospital at around 13:40 and noticed that Lukas responded unusually when she entered the room. She had been advised by her sister, who is a nurse, to question whether it could be meningitis. When she did, she was told that the child didn't have the typical symptoms such as petechiae and a stiff neck. The parents were nevertheless very concerned and asked lots of questions. In order to test for a urinary tract infection, another attempt was made to insert a catheter into Lukas' bladder. Lukas responded less than the previous attempt.

Further assessments of Lukas' condition

Several tests and examinations were performed. Blood test showed that CRP levels had increased to 188 mg/L, but were otherwise normal. Lukas didn't have a fever.

INFORMATION

Petechiae

Are skin spots caused by bleeding, normally less than 2 mm in size, which typically don't fade if you press a glass against the skin. This is an alarm symptom that often appears at an advanced stage of meningitis.

INFORMATION

Assessing impaired consciousness and coma

Somnolence

The patient is drowsy but is easy to awake and can be kept awake for a while. The patient reacts adequately to questions.

Sopor

The patient can be woken and follow instructions, but quickly falls back to sleep if left alone. Reflexes are present, but not necessarily normal. The patient responds with protective reflexes to pain stimuli.

Coma

The patient doesn't respond to strong stimuli. The Glasgow Coma Scale (GCS) is widely used to classify levels of consciousness.
i. Glasgow komaskala (GCS), bruker mye for gradering av bevissthet.

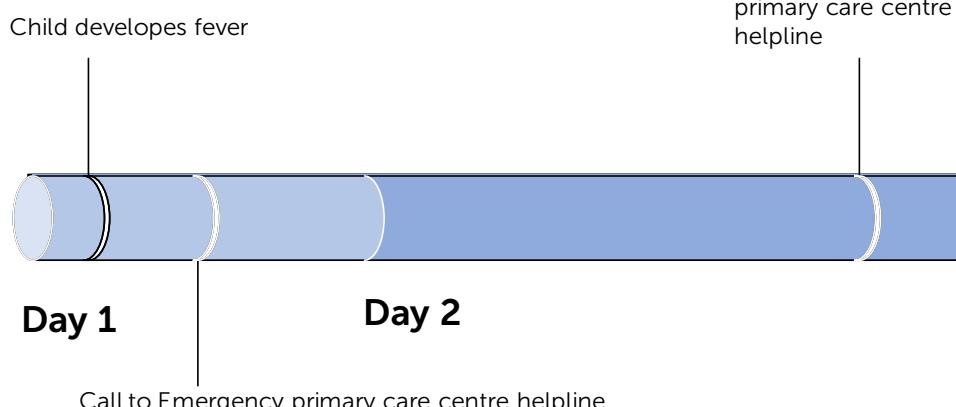
A structured assessment of his condition was performed using the Paediatric Early Warning Score (PEWS), which produced a low score, implying little evidence of serious illness. To be on the safe side, the junior on-call doctor considered giving Lukas antibiotics, but decided to wait since he didn't perceive him as seriously ill. Moreover, the cause of the infection was unknown. In order to confirm any bacterial infection, the junior on-call doctor wanted a urine sample before commencing antibiotics.

Change of shift for doctors and nurses
Both doctors and nurses change shifts at 15:00. The arriving paediatric admission nurse evaluated Lukas and considered him to be seriously ill since he didn't respond to her as a normal 20 month old child would, he appeared pale and lethargic. This made her very concerned, so she notified the doctors. The time was 15:50 and the doctors went in to examine him. They found him lethargic but noted that his vital signs were normal.

Consequently, the assessment and treatment remained unchanged. However, they observed him closely.

Treatment started

When Lukas didn't show any signs of improvement from the fluid therapy, the doctor considered more serious diagnoses such as meningitis and encephalitis. Due to Lukas' increasing somnolence (drowsiness), the doctor postponed performing a lumbar puncture to obtain a cerebrospinal fluid sample, which could confirm these diagnoses. Lukas remained lethargic, but he was breathing normally, and his pulse and blood pressure were stable. His arm and leg movements were normal, there was no neck stiffness and his pupillary reflexes were normal. His skin was warm and dry and he had no signs of petechiae. Since meningitis and encephalitis could not be excluded, antibiotic and antiviral medication was administered in the form of intravenous cefotaxime and acyclovir at 17:00. Prior to the initiation of this treatment, blood tests and blood



Timeline illustrates the sequence of events

culture were performed. The diagnosis was still unclear. Influenza was considered the most likely diagnosis, possibly combined with a urinary tract infection. Shortly after treatment was initiated, Lukas urinated spontaneously. The urine sample showed no signs of a urinary tract infection.

Inpatient ward

Lukas was admitted to the inpatient ward. His blood tests, taken at 17:00, revealed a CRP level of 191 mg/L, his white blood cell count was normal.

At around 19:20, Lukas' mother observed strange circular movements with his arm directed towards one of his eyes. She called a nurse, who attended him. Half an hour later, he suffered a seizure. The on-call doctor was notified, and Lukas was given medication to control his convulsions (midazolam). The seizure subsided, but Lukas' breathing was briefly interrupted, causing his blood oxygen level to drop. The "paediatric emergency alarm" protocol was implemented, and two anaesthetists

came to Lukas as well as the on-call paediatricians. While being closely monitored by the team of doctors, a cerebral CT was performed, and Lukas was transferred to the intensive care unit. The CT scan showed signs of swelling and increased pressure in the brain. The university hospital was contacted, and treatment to decrease the swelling was initiated.

University hospital

Lukas was taken to the university hospital by helicopter at 21:45. On arrival, an additional cerebral CT scan was performed which demonstrated that the blood flow to his brain had ceased. The neurosurgeon considered there was no more treatment to offer him. Lukas' parents consented to organ donation and he was kept on life support.

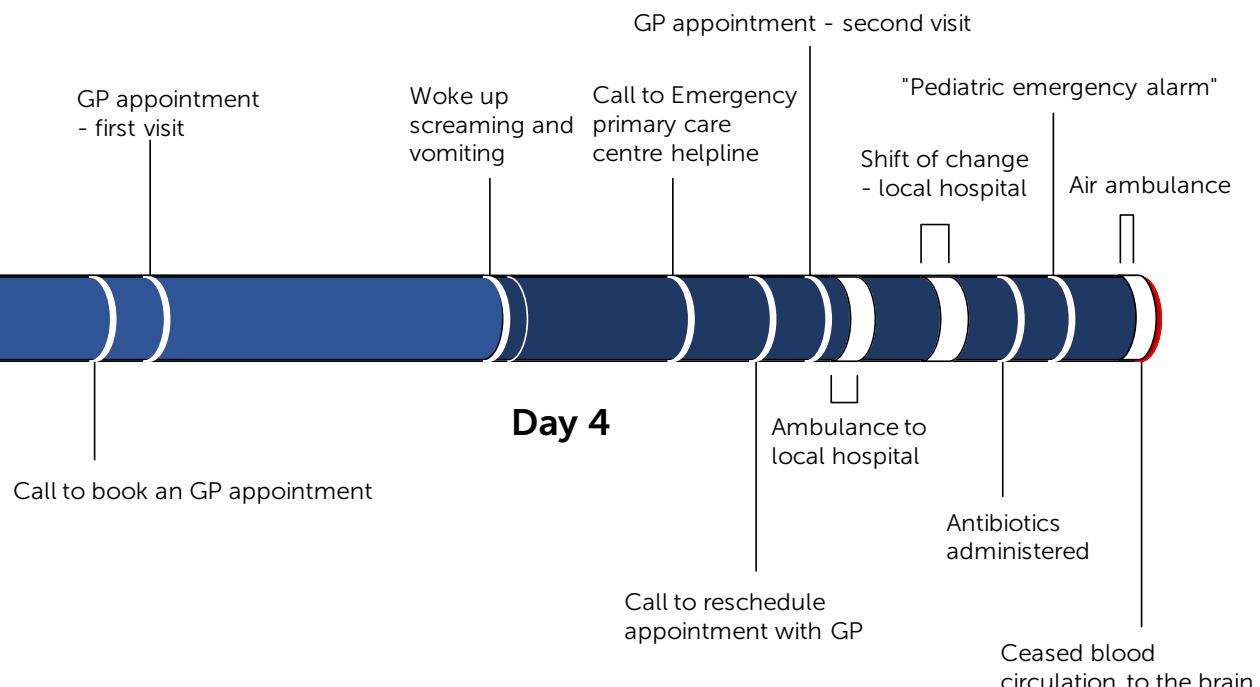
The next day the doctors decided that organ donation would not be possible.

Lukas died at 22:59.

INFORMATION

Lumbar puncture

The spinal cord and brain are surrounded by fluid. During a lumbar puncture, a thin needle is inserted through the lower back and into the vertebral canal in order to obtain a fluid sample that can be tested for meningitis.



Post-mortem examination
 The autopsy report concluded: "Swollen brain with discoloured, yellow meninges, confirming acute meningitis. Culture results of pus from the meninges demonstrated pneumococci (*Streptococcus pneumoniae*). It is assumed that the meningitis was caused by an infection, presumably by pneumococcal bacteria. There is acute inflammation of the lungs and bronchioles as well as swollen lymph nodes in the neck."

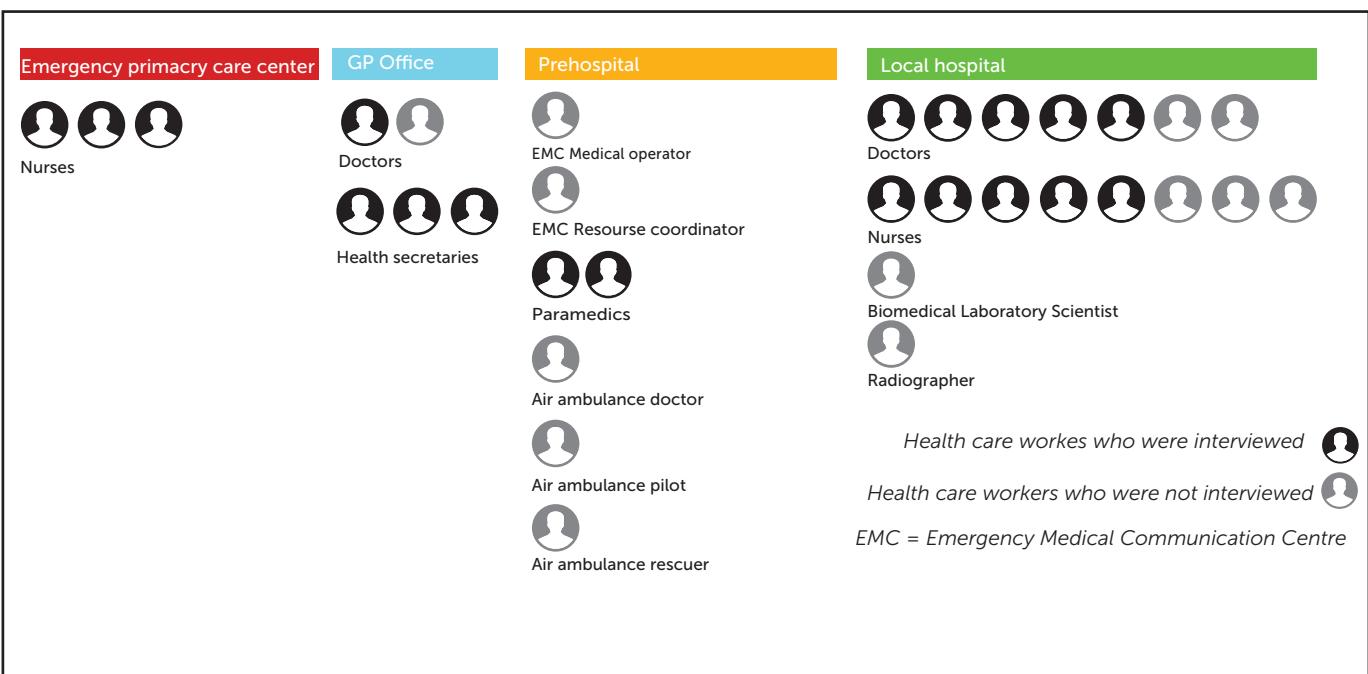
The infection may have started in the airways/lungs and then spread to the meninges."

A blood culture taken on admission was positive for *Streptococcus pneumoniae*.

Health care workers

Lukas and his parents met several different health care workers during these four days. In total, our investigation found 61 different health care workers who had been directly or indirectly involved. We consider that 32 of these people influenced the sequence of events leading up to Lukas' death. The diagram below summarises contact with health

care workers at the emergency primary care centre, GP office, ambulance service, Emergency Medical Communication Centre and local hospital. The health care workers who had direct or indirect contact with Lukas after he arrived at the university hospital, are not included in the diagram below as they were only involved in the last stage of his illness.



Overview of involved health care personnel

CHAPTER 2

Analysis and recommendations

How can we improve early diagnosis of the febrile child?

INFORMATION

Sepsis

Sepsis is a serious, life-threatening condition which generates a strong inflammatory response in the body. It can occur as a result of various bacteria entering the bloodstream. In Norway it is also referred to as "blood poisoning".

Acute febrile illness in children is commonly encountered in the health care services. Fever is part of the body's natural defence mechanisms, and it is defined as a body temperature above 37.9 °C. Viral infections that don't need treatment are the most common cause of fever in children, but it can also be caused by bacterial infections. Sometimes fever is a symptom of a serious bacterial infection that needs treatment, such as pneumonia, sepsis, meningitis or pyelonephritis. It is important to identify children with serious bacterial infections so that specific treatment can be initiated as soon as possible.

We have investigated the course of illness in a 20-month-old boy, who developed a serious bacterial infection. The warning signs were detected too late, and the child died. It probably started out as a viral infection, complicated by a serious bacterial infection occurring at a later stage.

A key question raised by this investigation is whether more accurate assessment and monitoring could have uncovered the signs of serious bacterial infection sooner, allowing

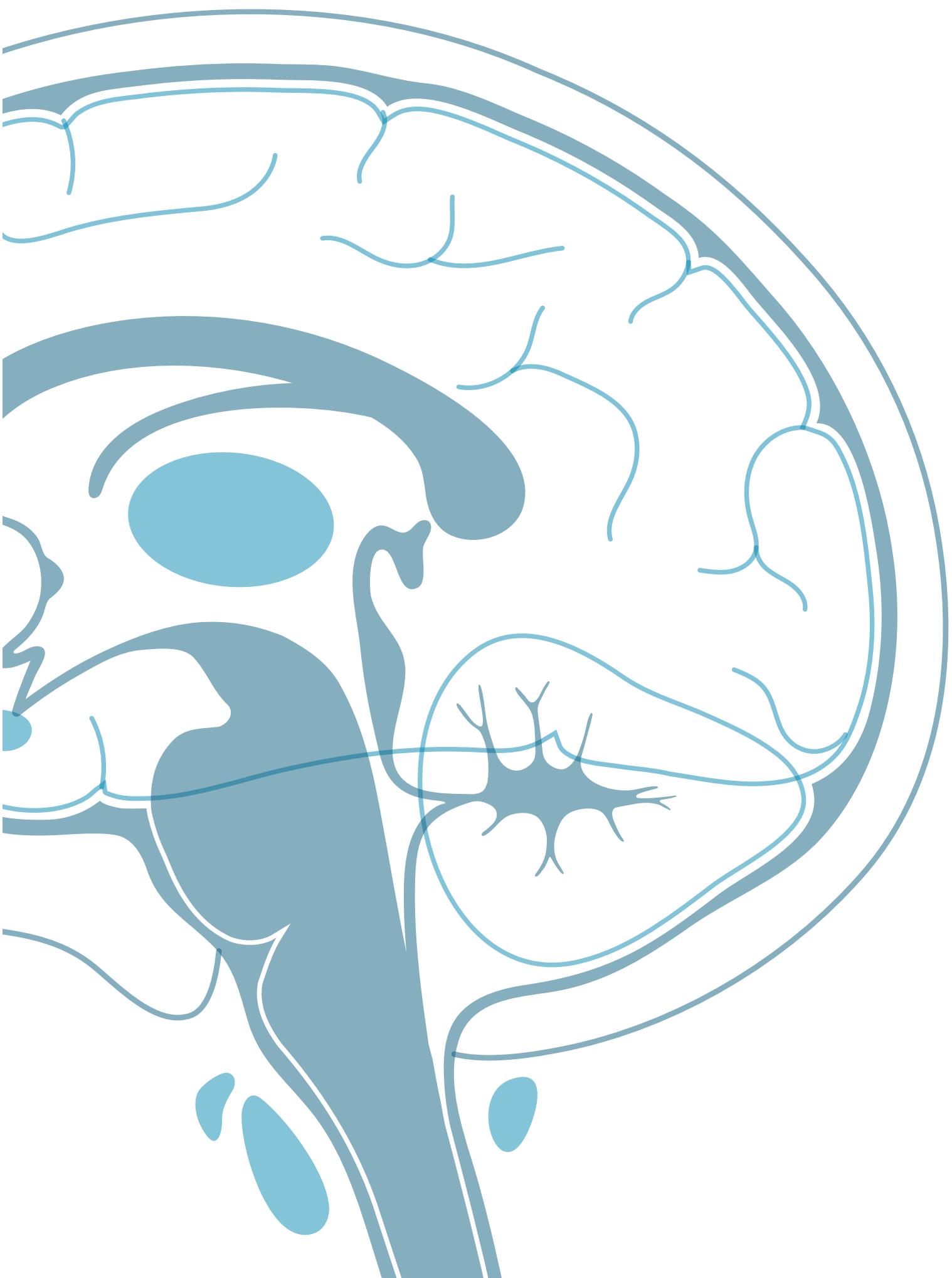
antibiotics to be administered at an earlier time. Our investigation shows that emergency treatment for children with fever is a complex, multilayer system involving numerous health care workers. Lukas was in contact with five different health care services over the course of a four-day illness, and over 60 different health care workers interacted directly or indirectly with him and his parents.

Young children can experience an illness trajectory like that of Lukas, where a life-threatening illness does not present with strong clinical signs or symptoms. Our investigation also shows that assessment of the severity of his illness varied among health care workers. Expertise, experience and a systematic approach to detect early signs of serious bacterial infections is required. Our investigation therefore highlights the need for a more systematic approach in assessing the general condition of a febrile child. Clear decision-support criteria may ensure early initiation of necessary treatment.

Identifying the seriously ill febrile child

A review of the case history gives the impression that Lukas had a viral infection for the first few days. A clinical deterioration occurred on the evening of day three, when Lukas woke up screaming and vomited. Although speculative, this could indicate the transition from a viral to a bacterial infection. This is also reflected by the sharp increase in CRP levels. Over the course of 24 hours, CRP increased from 37 mg/L to 143 mg/L.

Clinical parameters such as a rapid pulse, increased breathing rate, low blood pressure, pale and sickly skin, a slow central capillary refill time and an impaired general condition may indicate that a serious bacterial infections, is developing. Sometimes, however, the clinical parameters are normal, and even with a serious bacterial infection the CRP level may not necessarily be particularly elevated.



INFORMATION

Central capillary refill time

The capillary refill time is the time it takes for the circulation system to refill capillaries after they have been emptied of blood (typically by pressing down on the skin). It provides an indication of the strength of a person's microcirculation. Unless hypothermia is present, it shouldn't take more than three seconds for the area to recover its normal colour. If it takes longer, this may indicate poor circulation.

In such cases, a clinical assessment of the child's general condition is a vital tool for health care workers.

Apart from an elevated CRP level, his clinical parameters were within normal range. Our investigation has however uncovered divergent assessments of Lukas' general condition. The various medical service providers and health care workers involved had differing assessments of the severity of the illness. This illustrates how challenging it can be to assess a child's general condition, and thus to detect the development of a serious illness.

General condition

A child's general condition is important when assessing acute illness. When a child appears to be very poorly, there is reason to suspect serious illness.

Although the term general condition is widely used by health care workers

in Norway, it is not entirely clear what is meant if someone's general condition is said to be good or impaired. The ability to assess a patient's general condition can be seen as an example of "tacit knowledge" or experiential knowledge; in other words, something that health care workers acquire over time (1).

Attempts have been made to describe what might define whether a child's general condition is good or impaired. In 1982, McCarthy et al. described how to measure children's "general condition" by utilizing six parameters, four of which are related to behaviour and two of which are related to circulation (2) . McCarthy's work resulted in the Acute Illness Observation Scales (AIOS), which were translated and modified for Norwegian conditions by the paediatrician Trond Markestad. Amongst other places, they have been published in Markedstad's textbook Klinisk Pediatri

Criterion	General condition		
	Normal	Moderate	Poor
Cry	Cries loudly at normal pitch, or is satisfied and doesn't cry	Cries weakly, whimpering	Moans and is irritable
Reaction to parental stimuli	Stops crying or is pleased	Alternates between crying and being calm	Little or no change in behaviour
Alertness	If awake: stays awake. If asleep: easy to wake up.	Wakes up, but quickly closes eyes again or only wakes up in response to powerful stimuli.	Falls asleep. Hard to wake up.
Reaction to examination	Smiles/is energetic and responsive	Only briefly smiles or gives brief contact	Doesn't smile, no interest in surroundings, "worried" expression
Skin colour	Even pink	Pale extremities or bluish hue in peripheral areas	Pale, cyanotic, grey or mottled
Hydration	Skin has normal elasticity; eyes are not sunken and mucous membranes are moist	Skin normal, eyes may be slightly sunken, slightly dry mouth	Doughy skin or raised folds of skin (skin turgor), dry mucous membranes, sunken eyes

Table 1 General condition according to McCarthy et al. and Markestad. From: Legevakthåndboken ("The emergency care manual") (8)

Points	0	1	2	3
Respiration A - Respiratory rate B - Respiratory effort - Need for extra O ₂	- Normal respiratory rate AND - No retractions AND - No need for extra O ₂	- Respiratory rate ≥ 10 above normal OR - Retractions OR - Need for extra O ₂	- Respiratory rate ≥ 20 above normal OR - Jugular retractions OR - Need for extra O ₂ ≥ 40% O ₂ OR ≥ 5 L/min O ₂	- Respiratory rate ≥ 30 above normal OR - Respiratory rate ≥ 5 below normal with retractions and grunting OR - Respiratory rate ≥ 5 below normal under the influence of respiratory suppressant medications OR Need for extra O ₂ ≥ 50% O ₂ OR ≥ 8 L/min O ₂
Circulation C - Skin colour - Pulse - Capillary refill time	- Normal/unremarkable skin colour AND - Capillary refill time 1-2 secs	- Pale OR - Capillary refill time 3 secs	- Grey/cyanotic OR - Tachycardia, heart rate ≥ 20 above normal value OR - Capillary refill time 4 secs	- Grey/cyanotic AND mottled OR - Tachycardia, heart rate ≥ 30 above normal value OR - Bradycardia, heart rate ≥ 5 below normal value OR - Capillary refill time ≥ 5 secs
Behaviour D	Awake and normally responsive, interest in surroundings	Lethargic, reduced activity sleeping	Somnolent, irritable	Unconscious, cramps, reduced responsiveness to pain stimuli

2 extra points for inhalations > every 15 minutes /HFNC /CPAP / BIPAP
 2 extra points for persistent vomiting/ postoperative vomiting (more than twice an hour)

Table 2 PEWS – Paediatric Early Warning Score. Retrieved from Pedsafe.no (June 2020), an education and training programme for health care workers.

("Clinical Paediatrics") (3). They are also used in the textbook Allmennmedisin ("General Practice") by Steinar Hunskår (4) , as well as Legevakthåndboken ("Emergency care manual") (5) (table 1).

McCarthy et al. stress that "general condition" is critical in any assessment of the febrile child. (6) . In the Norwegian Paediatric Association's guide to acute paediatrics, the chapter on "Children with acute febrile illness" states that an assessment of general condition is the most important tool for diagnosis and examination (7) .

Behaviour plays a key role when assessing a child's general condition. The decision-support tool used by many emergency primary care centres recommends asking "What is the child doing right now?" in order to

get a picture of the child's behaviour. Alternatively, one can ask, "How is the child behaving right now?" The intention is to get the parents to describe the child's behaviour as objectively as possible. It is particularly important to ask these questions during phone calls, when the health care workers cannot observe the child.

Today, most paediatric wards use scoring tools. The Paediatric Early Warning Score (PEWS) is a scoring tool that quantifies the severity of the child's clinical condition, independently of the diagnosis, and identifies children who are at risk of clinical deterioration (9). Note that behaviour is one of the parameters that are included in the assessment (Table 2).

There are fewer categories of behaviour in the PEWS than in McCarthy et al.'s

Green paper published by the Norwegian Directorate of Health

Early detection and rapid response to deterioration in physical health.

The Norwegian Directorate of Health issues clinical guidelines, guides and national recommendations. The Directorate of Health published a green paper in the spring of 2020 dealing with the national recommendations on "Early detection and rapid response to deterioration in physical health."

Ukom contributed to the process by sharing its experiences from this incident investigation. We indicated the need for a more unified understanding of what is meant by general condition, particularly in small children where behaviour can be difficult to assess. We also stressed the importance of having a system for documenting the observations and assessments of family members.

The Norwegian Directorate of Health published the national recommendations on early detection and rapid response to deterioration in physical health.

30 April 2020 (11)

description of general condition. For example, at times it can be challenging to distinguish whether the child is asleep, somnolent or has impaired consciousness. It is essential to awaken the child in order to perform a proper assessment while assessing the PEWS score. In order to avoid confusion over terminology, it might be useful for the medical community to define the terms more precisely, as in the case covered by this investigation, the ambiguity of the terms may have led to differences in how health care workers assessed Lukas' level of consciousness. This may in turn have affected his diagnosis and treatment.

The National Institute for Health

and Care Excellence (NICE) is an organisation responsible for national guidelines for health care in England and Wales. In its guidelines on detecting sepsis (10), it emphasises observed behaviour in a similar way to McCarthy's table. Behaviours such as a lack of response to social cues, somnolence, weak, high-pitched or continuous cry, and change in mental state/behaviour are considered high-risk criteria for sepsis in children. This supports the idea that behaviour plays a key role in assessing seriously ill children. According to the NICE criteria, there is also a high risk of sepsis if the child is assessed to be very ill by health care workers. This suggests that it is acceptable to admit a child to hospital or start administering antibiotics based on intuition even without specific clinical findings.

Assessing a child's general condition is difficult, however it is vital to determine the severity of the illness. Which observations health care workers base their assessment of a child's general condition on, may vary. We noted that health care workers in different parts of the health service had quite diverging perceptions of Lukas' general condition. The PEWS – which is designed to identify and assess the degree of illness in children – was used both on admission to the hospital and after change of shift. However, it failed to detect the severity of the child's illness. It would be helpful if the medical community, as part of a national initiative, would provide a more unified definition of the term general condition. This could help to improve early diagnosis and treatment of acute febrile illness in children.

Ukom recommends that healthcare professionals, including national bodies, develop a more unified understanding of how children's general condition should be described and

assessed. This could help improve early diagnosis and treatment of acute illness in the febrile child.

Prevalence and symptoms of meningitis

There are far fewer cases of meningitis today than just a few decades ago, and the epidemiology has changed over time. Part of the reason for this is the introduction of vaccines against pneumococcal bacteria and *Haemophilus influenzae* type b.

The pneumococcal vaccine given in the national Childhood Immunisation Programme protects against 13 different serotypes. Before the vaccine was introduced, these serotypes were responsible for most serious pneumococcal infections in children under the age of two (12). In total there are over 90 different types of pneumococcal bacteria, thus the vaccine doesn't give full protection against pneumococcal infections. The pneumococcal vaccine is continuously being improved. Three hospitals in Norway are currently testing a new vaccine that is designed to protect against two additional strains of pneumococcal bacteria, which would further reduce the risk of developing serious disease (13).

Lukas had meningitis caused by pneumococcal bacteria. Our investigation found that health care workers perceived that the absence of petechiae and a neck stiffness made the diagnosis meningitis less likely. This may have led to a delay in his diagnosis and treatment. The absence of petechiae and a neck stiffness does not rule out meningitis. The symptoms in children, particularly those under the age of two, are dominated by the child appearing ill, lethargic, irritable and/or unresponsive. Other symptoms include vomiting, headache, light sensitivity, a stiff neck/back and seizures. Petechiae

are more common in meningococcal septicaemia or a serious infection with coagulation abnormalities.

The NICE guidelines "Fever in under 5s; assessment and initial management" (14) stress that, in the case of children with a decreased level of consciousness and fever, intravenous antibiotics should be administered immediately, and look for signs of meningitis. Although meningitis is a rare diagnosis today, it must still be considered early on in the febrile child with an impaired general condition.

The clinical symptoms of meningitis in children may be ambiguous and its prevalence has changed. Are health care workers who deal with sick children sufficiently aware of this?



The pneumococcal vaccine in national Childhood Immunization Program does not protect against every type of pneumococcal bacteria. (Illustration photo)



Parents as a resource

How to improve parents' health literacy?

Parents observe the child at home and are familiar with the child's normal response patterns. If parents are provided well founded information about warning signs, this may ensure them to contact the health care service at an earlier stage in the disease development. This kind of information could also facilitate better communication between the parents and health care workers, by helping the parents to provide clear and important information about their child.

Since all children experience fever, it is important for the health service to provide general information about the warning signs in febrile children. It is also particularly relevant to provide parents with tailored, specific information about warning signs when they contact health care services concerning their child.

Communicating over the phone

Emergency primary care centre helpline have frequent contact with parents over the phone. This is also true of medical staff at GP offices. It remains a challenge to build an adequate clinical expertise to make sure correct information is obtained and provided, and that correct decisions are made. Consequently, decision-support tools have been developed. These consisting of simple, searchable reference databases that play an important role in ensuring that the correct advice is provided.

Telefonråd is a decision-support tool aimed at emergency primary care centre helplines which is freely available online. It is used by two thirds of emergency primary care centres in Norway. The tool is administered by the National Centre for Emergency Primary Health Care and is linked to the Norwegian Index for Emergency Medical Assistance.

The Norwegian Index is a collection of cards with flow diagrams for emergency primary care centre helplines and Emergency Medical Communication Centres to use. The flow diagrams are available online within Telefonråd, but the Norwegian Index for Emergency Medical Assistance is also available in print and can be used regardless of the technology available. This implies it is simple and effective to use even in places with technological limitations. Since the Norwegian Index has been developed to be used by Emergency Medical Communication Centres and emergency primary care centres helplines for emergency calls only, the Norwegian Index is limited with regard to the information and advice concerning warnings signs in febrile children.

The emergency primary care centre covered by this investigation had both Telefonråd and Norwegian Index for Emergency Medical Assistance available when contacted by Lukas' parents. The parents were given advice on how to manage a child with a fever. They were not told which warning signs would indicate when to recontact the health service again.

There is no information about warning signs in either Telefonråd or the

Information for patients/parents

"A child's general condition can change quickly. Children with a fever should therefore be checked up on frequently. In some cases, it makes sense to recommend checking up on the child during the night. Advice on care should take into account the child's age, state of well-being and suspected diagnosis. It is important to explain what, if anything, the carers should look for.

They should contact the health service again if the child's general condition deteriorates or if symptoms become worse. Particularly look out for petechiae, a neck stiffness, lethargy, unresponsiveness, irritability, paleness, vomiting, heavy breathing, pain, reduced fluid intake, dry nappies or a fever than lasts more than four days.

Source: Legevakthåndboken ("The urgency care manual")⁵

Norwegian Index for Emergency Medical Assistance, but they are described in Legevakthåndboken ("The urgent care manual") (15). However, this manual is primarily aimed for doctors at the emergency primary care centres, and it is not presented in a way that makes it practical to use for other staff.

Teléfonoråd is in the process of being revised. This new version includes updated information to parents with febrile children and follow up is being described.

Ukom recommends that the decision-support tools utilized by emergency primary care centres, also provide parents with information about specific warning signs in the febrile child.

Information available to parents

In May 2019, the Norwegian government presented a strategy to increase health literacy in the population for the period 2019-2023 (16). Health

literacy is defined as "people's ability to understand, assess and use health-care information in order to make informed decisions in relation to their own health. This includes decisions relating to lifestyle choices, preventing and coping with illness, and using health and care services."

Our investigation has revealed the importance of giving parents general information about managing a child with a fever, and which warning signs to look for. Especially in young children. This basic information may help parents when they contact the emergency primary care centre or their GP. If parents and health care workers have a shared understanding of the warning signs, it could help to improve communication between them.

Currently, parents of young children receive a lot of information in conjunction with their children attending Child Health Centres. This is a service that is provided for children aged younger than 5 to monitor the child's physical and psychological development. This investigation does not cover the Child Health Centres, thus we have not surveyed the information provided on the subject of "the febrile child".

Parents often start by looking for relevant information about their child's illness on the Internet. However, the information they find may be confusing, and the reliability can be difficult to ascertain. Well-founded information on official websites, primarily helsenorge.no, can help increase parents' health literacy. It would be advisable for the health service to refer parents to helsenorge.no as an additional resource.

Ukom recommends that well-founded information on how to manage a febrile child and specific warning signs, should be easily accessible to parents.

How can information provided by parents be utilized more systematically?

Experts agree that information provided by parents play an important role in helping health care workers assess children. Moreover, both medical textbooks and articles suggest that it is important to obtain the parents' assessment of their child. Guidelines on good practice such as those published by NICE (17), as well as the Norwegian Index for Emergency Medical Assistance, emphasise the importance of the parents' assessment.

In the case covered by our investigation, the parents provided information about the child as the illness developed, however their observations and assessments were not documented. Currently, the assumption is that parents' assessments will be listened to and documented in the case history. We found a lack of tools to help health care workers systematically collect details of the case history and to obtain the parents' own assessment of the child's condition.

We would suggest that the parents' assessment could be a specified note for inclusion in a standard patient record. If there were standards in place for keeping patient records that explicitly included the parents' observations and assessment, it might help to give a clearer picture of the child's state.

Ukom recommends that the chain of emergency services establish standards and practices for documentation of parents' observations and assessment of their child

Information provided by parents is essential in diagnosing a child's condition (Illustration photo)





CHAPTER 3

Methods

Methods

Documentation and interviews

Ukom started by collecting relevant documentation from the parents, hospital and County Governor. This documentation was reviewed prior to the interviews.

The official records of the Health Trust in question were also reviewed, as well as minutes of staff meetings at the local hospital and of management- and board meetings. Documentation from the police,

emergency primary care centre and Emergency Medical Communication Centre as well as further documentation from the County Governor, was collected later on in the investigation.

Ukom interviewed a total of 21 people. Ukom interviewed the parents first, then the health care workers at the emergency primary care centre, GP office, ambulance service and local hospital. Semi-structured interviews

Table 3:
Summary of the information that was collected prior to the first set of interviews.

PROVIDED BY	TYPE OF DOCUMENTATION
Parents	Medical information they had obtained themselves, their diary and a copy of their letter to the Norwegian System of Patient Injury Compensation (NPE).
Hospital	Relevant procedures. Documentation provided by the hospital to the County Governor: GP records, ambulance records, patient records from both hospitals and the emergency primary care centre records.
County Governor	Documentation collected by the County Governor in conjunction with the supervisory review.

Table 4:
Summary of the information that was collected prior to the first set of interviews.

PROVIDED BY	TYPE OF DOCUMENTATION
Police	Autopsy report and audio files from police interviews.
Emergency primary care centre	The patient record and recordings of all telephone conversations with the parents.
Emergency Medical Communication Centre	All recordings of the incident.
County Governor	Expert opinion and final supervisory report.

were used, focusing on a number of topics. The names of individuals and organisations are not given in this report.

Establishment of the facts and analysis

A review of the documentation and interviews allowed us to identify the health care workers involved in the incident. We then established the reference event and drew up a timeline to visualise the incident. The timeline was continuously updated if warranted by the documentation and interviews.

The timeline was also used to uncover more general issues. The data collected was presented systematically using a multi-layer diagram (AcciMap) in order to visualise how issues at different organisational levels influence one another.

Special considerations for the analysis

Hindsight bias – “20/20 hindsight”

Knowing the outcome of an incident will influence how you remember and assess it in hindsight (18). Even if you are conscious of this, it is virtually impossible to avoid this kind of hindsight bias.

When looking at the reasons why an incident has occurred, it is important to be aware of hindsight bias as a source of error. It isn't possible to test causal relationships, which affects the conditions for validity that can be set.

Local rationality principle

The concept of local rationality is based on the assumption that everyone acts in good faith. The challenge is that

individuals are not aware of all the factors that may affect the outcome of any given action or decision. Therefore, people act partly on the basis of their own understanding, professional expertise and resource limitations (18, 19).

Any assessment of what best practice is may vary between treatment providers, and individual providers will often not be in a position to see the whole picture. This assessment therefore becomes more complicated with an increasing number of entities involved in providing treatment. As such, local rationality at the institutional level can lead to knock-on errors. An external evaluation with a broader perspective may help uncover blind spots and promote learning.

Conditions for validity

Ukom has set three conditions for any explanation of the incident to be considered valid:

1. It must be possible to link the explanation directly to incidents or phenomena that are documented in the written reports and/or interview statements.
2. The explanation must have been presented to the relevant interviewees who were involved in the incident to ensure the explanation is based on a description of the sequence of events that the interviewees consider accurate.
3. The explanation must have been presented to an expert panel to see whether it considers the explanation reasonable based on its professional experience.

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