

The Norwegian Healthcare
Investigation Board

Death at a psychiatric intensive care ward

Risk factors in conjunction with seclusion

Report 1-2020



The role of Norwegian Healthcare Investigation Board

The Norwegian Healthcare Investigation Board (Ukom) is an independent government agency tasked with investigating serious incidents and other serious conditions involving the Norwegian health and care services. Ukom shall investigate the sequence of events, factors that contributed to the outcome and causal relationships. The purpose of its investigations is to improve patient and user safety by learning and taking action to prevent future serious incidents.

Ukom does not assess civil or criminal liability or guilt. Ukom decides which serious incidents or circumstances to investigate, the timing and scope of the investigation, and how the investigation shall be carried out.

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Report 1-2020

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Investigation and report

Our investigation was instigated after we were informed about a serious incident where a young woman was found lifeless in her bedroom at a psychiatric intensive care ward. Resuscitation was unsuccessful. The autopsy report concluded that the likely cause of death was drug intoxication, probably due to the combination of several drugs. The purpose of this investigation is to examine and assess which factors contributed to this outcome and what can be done to prevent similar incidents occurring in the future.

The investigation is based on interviews with a selection of doctors, nurses and other health care workers who were involved in treating the patient during her hospital stay. Interviews have also been conducted with the supervisory commission and several of the patient's family members. Two hours was allowed for each interview.

Later, members of the hospital management team were interviewed about selected topics arising from the first set of interviews. The main sections of this report cover the following topics:

- Physical environment at the seclusion unit
- Number of doctors and nursing and support staff involved
- Milieu therapy received by the patient
- The patient's intellectual disability
- Medication
- The autopsy report

Ukom has also drawn on the patient's mental health records and other documents relating to the case (see Section 13).

The interviewees' professions, professional backgrounds and roles are stated where necessary for providing

context. Hence, individual employees are not identified.

We have limited the investigation to looking at which risk factors may have contributed to the patient ending up with so many medicines in her body while at the seclusion unit of the psychiatric intensive care ward. Our investigation has not, therefore, looked at issues such as why she became so ill that she was hospitalised or why seclusion was implemented. The report mainly relates to the final nine days of her life. Before the patient arrived at the intensive care ward, she spent three days in a short-stay assessment unit. In total, the patient spent 12 days in hospital.

The report has been written in a narrative style, closely following the descriptions of the events given by the interviewees. Anything classified as a finding in our report is based on coinciding information provided by several sources, or statements that are corroborated by the documentation examined.

Our findings have been analysed using AcciMap, but in this report they are presented in a narrative form. For a more detailed description of the methodology, see sections 14 and 15. In our investigation, we have drawn on knowledge of patient safety initiatives, nursing, IDD nursing, improvement science and administrative and organizational science, as well as specialist expertise in psychiatry, cardiology and general practice. The target group for this report is employees, managers and decision-makers in the health and care services, and psychiatric patients/users of mental health services and their families. Text boxes have been used where there is a need to clarify concepts or terminology.

INFORMATION

Seclusion

Seclusion is defined in the Regulations on the use of seclusion within mental health services, Section 2 Definition: Seclusion refers to any measures that involve a patient being kept wholly or partly segregated from other patients and from staff other than those involved in examining, treating and caring for them. These measures are implemented for clinical reasons or for the sake of other patients.

Introduction

Our investigation was carried out after a young woman died suddenly and unexpectedly at a psychiatric intensive care ward. The patient was suffering from a serious mental health disorder. She died 12 days after being admitted to hospital. The autopsy report concluded that the likely cause of death was combined drug intoxication involving antipsychotics, lithium and benzodiazepines.

Antipsychotics and benzodiazepines are often used in the treatment of acute mental illness and in exceptional circumstances to prevent patients from harming themselves or other people.

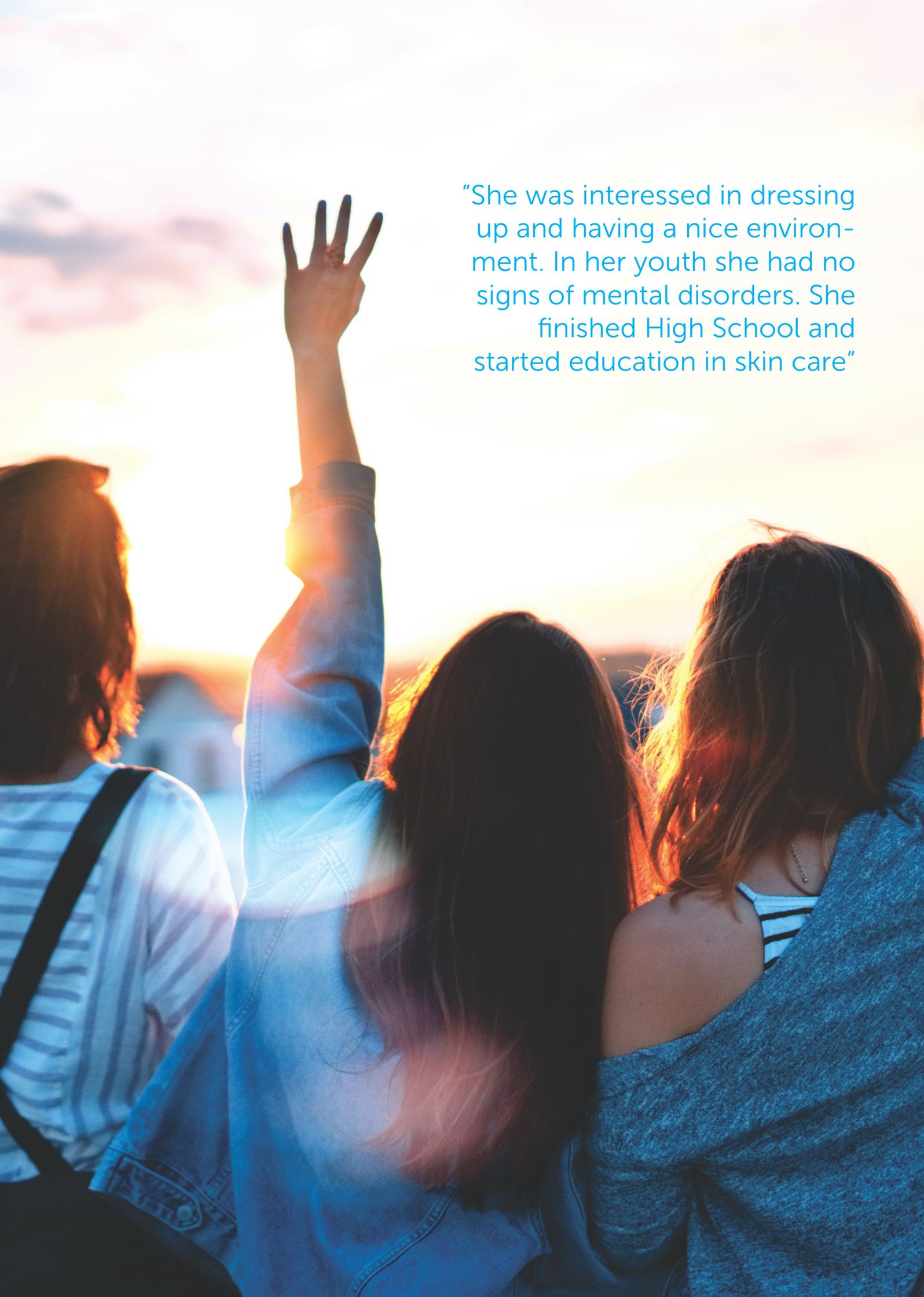
It can be hard to weigh up the benefits of antipsychotics against their negative side-effects and risks. It can also be challenging to respect the right of patients with acute mental illness to be involved in their own treatment.

Sudden, unexpected death is more frequent amongst people with serious mental health disorders than in the population at large. Little is known about the scope of this, and the reasons are not fully understood. Some deaths may be related to medication, often combined with a generally impaired state of health. The purpose of this investigation is to assess which factors led to the young woman being given several different medicines and why she died.

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"She was interested in dressing up and having a nice environment. In her youth she had no signs of mental disorders. She finished High School and started education in skin care"

CHAPTER 1

The incident

The incident

INFORMATION

Schizoaffective disorder

A psychosis is often defined as a condition that impairs someone's ability to realistically evaluate themselves, other people and their relationship with their surroundings. The term schizoaffective disorder refers to a type of psychosis that falls somewhere between schizophrenia and bipolar disorder. It is characterised by simultaneous symptoms of schizophrenia and mania or depression lasting for more than two weeks. The functional impairment and prognosis lies between schizophrenia and bipolar disorder.

In consultation with the family, we have chosen to call the patient Hanna. She was from an ethnic minority background.

Early one morning, after spending 12 days in hospital, Hanna was found lifeless on a mattress on the floor of her room in the seclusion unit. Cardiopulmonary resuscitation was attempted, but the medical emergency team was unable to bring her back to life. The emergency care provided is not covered by our investigation. Hanna had previously been diagnosed as suffering from schizoaffective disorder and triple X syndrome (a chromosome disorder), and she also had a mild intellectual disability. Prior to being hospitalised her condition had gradually deteriorated, and she herself wanted help from the specialist health service. She came to the clinic with one of her siblings.

The patient record and interviewees describe her as psychotic, and often agitated and frightened. Hanna made loud noises, she had trouble sleeping,

and her condition deteriorated during her hospital stay. It became apparent that restrictions were imposed on her both for the sake of other patients and as part of her treatment. Looking back, health care workers stated that they were concerned that Hanna would collapse, and they felt that her condition was life-threatening on account of her mania. The use of psychopharmaceuticals was often discussed, particularly due to Hanna's agitation and the need for her and her fellow patients to get some rest and sleep.

Various medicines were tried, which were administered both orally and by injection.

Hanna died suddenly and unexpectedly one morning, after spending 12 days in hospital. The autopsy report concluded that the likely cause of death was combined drug intoxication. Our investigation has tried to uncover the reasons why Hanna was given so much medication, which created a high-risk situation, while she was at hospital.

The investigation covers the period from Hanna's admission to the short-stay assessment unit until she received her final dose of medicines the evening prior to her death. The main focus is on her stay at the intensive care ward. Near the start of the report, we have included some of the thoughts of Hanna's family members. Their story covers a longer period than the one that our investigation concentrates on.



She was found lifeless in the patient room and resuscitation was not successful (Stock image)

The family's story

During the introductory phase of the investigation, Ukom held conversations with several of Hanna's close family members. There follows a summary of what they had to say. In this section we look at who Hanna was, the family's thoughts about her hospitalisation and death, and what the family believes that mental health services should learn from the story.

Who was Hanna?

The family found Hanna's sectioning very challenging. They felt that the hospital didn't cooperate with them and that Hanna wasn't being well looked after.

Hanna died suddenly and unexpectedly. Her death has caused the family a lot of pain, and they find it hard to come to terms with what happened.

Hanna was a cheerful person who was happiest in the company of other people. She has several siblings, and her family was important to her. She liked to look good and to be in attractive surroundings. During her adolescence, she showed no signs of mental illness. She completed sixth-form college and went on to study cosmetics. Her family say that Hanna achieved good grades at college and good references from the part-time jobs she had at shops. In Hanna's medical records, her parents read that she had been diagnosed as having a mild intellectual disability. They didn't recognise that diagnosis. To them she came across as immature, but not intellectually disabled.

After a painful divorce, life became more difficult for Hanna. She suffered serious mental illness, and was hospitalised at psychiatric institutions three or four times. In her day-to-day life, she received good support from



her social worker and general practitioner. She kept on top of her medication herself.

Apart from her mental illness, Hanna was healthy and outgoing. She had her own flat and managed her own finances. However, she found it lonely living alone and didn't want to be on her own when she became sick. Hanna therefore moved back home to her parents.

Her final hospitalisation

Hanna wasn't sleeping in the period prior to her final hospitalisation. She said and did many things that worried her family. Hanna became agitated and wasn't herself. She wanted help, and her family accompanied her to the emergency clinic. They wanted her to recover and be happy.

The family felt that there were too many patients and too few doctors on her ward. They didn't feel confident in the treatment she was receiving:

"There were lots of people on duty, but who was really responsible for Hanna?"

Hanna told her family that she felt the staff didn't understand her. They would have liked to have a fixed contact person who was responsible throughout.

The family felt that communication and cooperation with the hospital was difficult. It was hard for them to understand when and if they were allowed to visit. It was hard for them to get involved and make a positive contribution.

When the family visited, they met Hanna in a separate visiting room. The first time Hanna's parents and siblings saw her bedroom was on the morning she died. They thought it was a depressing sight. Hanna had nothing in her room. According to the fami-

ly, "if you weren't crazy already, you go crazy from being there. It's that simple."

It is heart-rending for the family to think about the circumstances surrounding Hanna's death.

"It's hard to put our loss and sorrow into words. We'll live with our sorrow for the rest of our lives. She is our angel".

The family believes that the hospital should cooperate much more closely with the families of inpatients.

"You feel really small and there are so many people involved. Lots of things went wrong, but who should we blame, the system or individuals? We're just left with our sorrow, and unfortunately there's nothing else we can do."



CHAPTER 2

Sequence of events at the hospital

Sequence of events at the hospital

There follows a description of the sequence of events as described in Hanna's patient records. Ukom has selected extracts with the most important information, but it has not altered their wording. In some places it has been necessary to make some linguistic adjustments, due to e.g. abbreviations and errata. In some places we have substituted the pseudonym Hanna.

DAY

0

Hanna is sectioned

Hanna is sectioned after voluntarily attending the emergency clinic with her brother. She does not put up any opposition, but the doctor who admits her does not consider her to understand her illness or to be in a state to consent to being admitted to the psychiatric intensive care ward.

Hanna walks into the ward herself. Her body language is stiff and tense, and her hands are shaking slightly. During the admission interview, she cooperates and comes across as clear and informed, and she responds adequately at a functional level. However, her emotional response is affected by her agitated state of mind. Hanna is assessed to be suffering from manic psychosis. This requires treatment at a psychiatric inpatient unit, so she can be given medication and be placed a low-stimulus environment, as well as to prevent her from harming herself through uncritical or aggressive behaviour. Hanna is sectioned for observation.

As well as her regular medicines, Hanna is prescribed olanzapine 15 mg for three days and zolpidem 5 mg in the evening to provide extra help with sleeping. During previous hospital stays, Hanna has required seclusion, but on this occasion that is not considered necessary when she is admitted.

1

Need for seclusion

Hanna displays manic behaviour in which she dances, gets undressed, throws things when she becomes irritated and hits out at staff. The decision is taken to put her in a seclusion unit.

2

Has slept little and is agitated

Hanna has slept little during the night. She has showered with her clothes on and walked around the ward singing loudly, and staff have to ask her to behave. Over the course of the day Hanna becomes calmer, but she has three showers while still dressed. She interacts calmly with staff.

3

Restless night. Noisy, agitated and suffering from delusions

Restless night during which Hanna throws the bedclothes out of her room and is reprimanded several times for her behaviour by staff. Her sleep is interrupted several times.

During the day, Hanna is noisy, agitated and suffering from delusions. She doesn't want to eat the food she is offered.

In the evening, Hanna alternates between listening calmly to music, breaking into spontaneous laughter and crying loudly and being tearful. Hanna sleeps for three hours during the night, and takes off the bedclothes several times. She throws clothes, cups and sandals around. A doctor prescribes zolpidem 5 mg to provide extra help with sleeping, but it does not have the intended effect.

Hanna is moved to the intensive care ward

4

DAY

After being moved, Hanna is boisterous, prone to laughter, shouty and agitated, but she soon calms down. Staff perceive her as being calmer than before. She expresses vague visual and auditory hallucinations involving people dancing. She is taken straight to the seclusion unit.

Sleeps right through the night with the help of sleeping pills

5

The patient has slept (snoring) through the night with the help of sleeping pills and oxazepam. In conversations with her doctor, Hanna is less responsive at both a functional and emotional level. Only maintains some eye contact. Agrees to cooperate with medication. In the afternoon Hanna must be secluded in her room, as she is screaming. Hanna accepts being secluded in her room. She eats very well in the evening and is visited by her mother and brother. She becomes sad when they leave and wants to go home with them.

Sleepless night and must frequently be secluded in her room

6

Hanna hasn't slept during the night. She is suffering from delusions and does not respond when staff reprimand her behaviour. During the day, Hanna's mood fluctuates and she must be confined to her room on several occasions (seclusion).

Hanna is agitated, anxious and has hallucinations, and she wanders up and down the corridor. She does not respond to being given extra diazepam.

Highly agitated

7

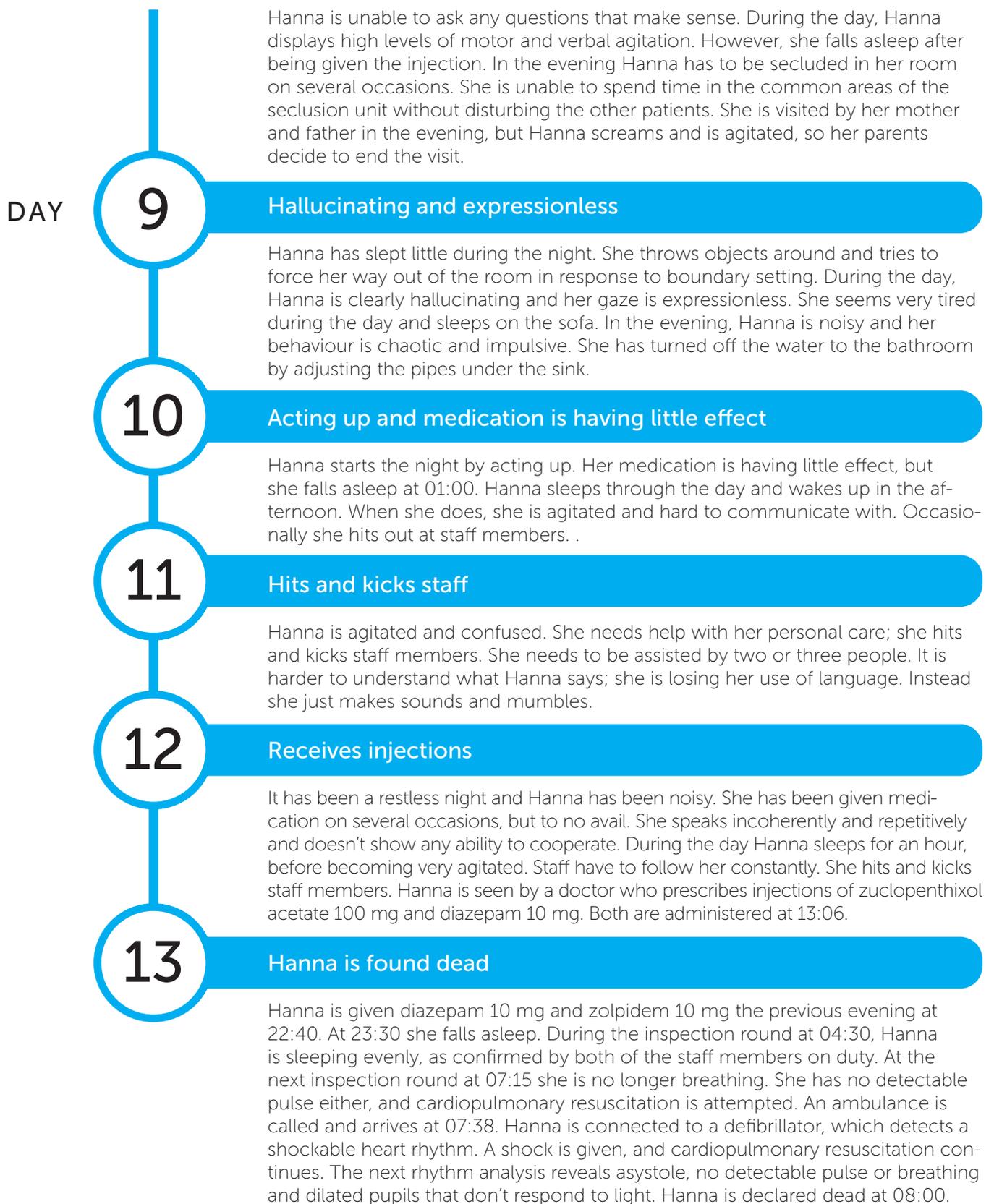
Hanna is highly agitated, messes up her bed and makes a lot of noise. Doesn't sleep until 02:45 after being given oxazepam.

A doctor makes changes to her medication, discontinuing oxazepam, prescribing diazepam 10 mg x 3 and increasing her dose of zolpidem from 5 to 10 mg because it isn't having any effect. During the day, Hanna is agitated; it is hard to get her to behave and she is given oxazepam 15 mg and diazepam 10 mg. After this she becomes calmer and stays in her room. In the evening, Hanna is agitated and very loud the whole time. She is seen by the on-call doctor and receives an additional 10 mg of diazepam to induce sleep.

Given intramuscular injection

8

Hanna sleeps from 01:30 onwards. After conversations with her doctor, she is prescribed zuclopenthixol acetate 100 mg as an intramuscular injection, and her phenazine dose is halved. During her conversation with her doctor,



CHAPTER 3

Findings

What can we learn from the investigation?

In our investigation of this incident, we will focus particularly on the topics listed below. In combination, they may have led to Hanna receiving many different medicines and probably dying of combined drug intoxication.

1. The seclusion unit was unsuitable for agitated patients

The premises were not equipped to deal with lots of agitation and loud noises, and any exacerbation of symptoms had to be doused quickly for the sake of other patients, particularly at night. Hanna's bedroom was sterile and without furnishings. It just had a mattress on the floor. That may have contributed to her agitation and aggravated her psychosis.

and continuity in the nursing and support staff, but there were no plans or structures in place to ensure this. Hanna had contact with at least 41 different members of staff during the 12 days she was in hospital. Her main contact person kept changing. One challenge was that several nurses became worn out by her. Therefore, the person responsible for her often changed during shifts, but this lack of continuity was probably difficult for Hanna to deal with.

2. There were many different, unfamiliar members of staff

Hospital staff at all levels highlighted the importance of stability

3. Great variation in rules and boundaries

Hanna's stay at the seclusion unit



This is Hannas patient room. She slept on a mattress on the floor. (Photo: Ukom)

involved lots of boundary setting and reprimands. The rules and boundaries varied from shift to shift, which led to conflicts. Her agitation and the ways in which she expressed her suffering were hard to deal with. Attempts were made to confine her to her room, and on some occasions the door was closed.

4. Impact of her intellectual disability on care and treatment

Hanna had a chromosome disorder known as triple X syndrome and was diagnosed as having a minor intellectual disability. The syndrome predisposes people to

psychosis and strong emotional reactions to stress. These diagnoses were not taken into account in her treatment, in spite of the fact that they meant she had special needs for tailored care, tolerance, understanding and support.

5. Medication was considered the most important aspect of treatment

Medication was normalised and was presented as the only effective solution. When the initial doses were ineffective, doses were increased. Antipsychotic and benzodiazepine injections were prescribed to reduce her agitation and help her sleep.

The report sheds light on how, in combination, these issues led to Hanna receiving many different medicines. In addition, the report highlights several other areas that it will be important to study further and learn from:

1. There is a discrepancy between how families and the hospital view the level of cooperation, communication and involvement.
 2. It is important to maintain the practice of carrying out an autopsy on patients who die unexpectedly while hospitalised in a psychiatric institution.
 3. There is a discrepancy between the legislative requirements and how the rules in the Act on the provision and implementation of mental health care (Norwegian Mental Health Care Act) are put into practice.
 4. There are big differences between mental health services and general intensive care wards in terms of staff qualifications, the quality of premises, interdisciplinarity, planning and patient dignity.
 5. The approval scheme for the institutions responsible for people undergoing compulsory mental health treatment does not ensure that they provide a good physical environment.
 6. Having an intellectual disability may constitute a risk to patient safety when being treated for mental illness.
 7. Coming from an ethnic minority may constitute a risk to patient safety when being treated for mental illness.
 8. Funding and prioritising the maintenance of buildings housing mental health facilities has an impact on patient safety.
 9. The actions of the supervisory commission, including welfare monitoring, affect patient safety.
 10. Patient safety within mental health services must be improved by the organisations responsible carrying out thorough analyses after serious unwanted incidents, involving patients' families and using incidents to review clinical practice.
- It will be necessary to investigate these matters in greater depth than we do in this report. At Ukom, we will also monitor these areas in our future work.

Our discussions with professional bodies and stakeholder organisations have confirmed that our findings and the issues listed above are relevant to many psychiatric hospitals. In this report, we have chosen to highlight three clinical recommendations (see Section 13), which will be sent to all inpatient mental health institutions in Norway. After concluding our work on this report, we will assess whether we should also provide separate

recommendations to the competent authorities, administrative agencies or supervisory bodies. They would be related to other areas for improvement uncovered by our investigation.

Physical environment at the seclusion unit

This section describes the physical environment at the seclusion unit. Some quotations have been included to exemplify some of our findings. The most important ones are:

- The section was poky, badly maintained, poorly sound insulated and had deficient acoustic absorption. Hanna's bedroom was sterile, with no furnishings, and she only had a mattress on the floor.
- Any agitation and loud noises had to be suppressed quickly for the sake of other patients, particularly at night.
- The staff had grown to accept the conditions as they were, but they found them challenging and problematic for both patients and staff. The supervisory commission was not sure what should be considered adequate in terms of the physical environment.



This corridor was used as a livingroom for Hanna. (Photo: Ukom)

The intensive care ward's seclusion unit was located in an old brick building.

The stairwells, external walls and many parts of the internal walls were made of brick. There was very poor sound insulation between rooms and different storeys. The finishes were predominantly concrete, brick, bare floors and white walls. This meant that sound of all frequencies was reflected. The amount of resonance amplified sounds and noises.

The corridor in the seclusion unit acted as a day room for the patients and staff. It had no natural light, was sparingly furnished and had doors to the bedrooms, shared toilet and sluice room.

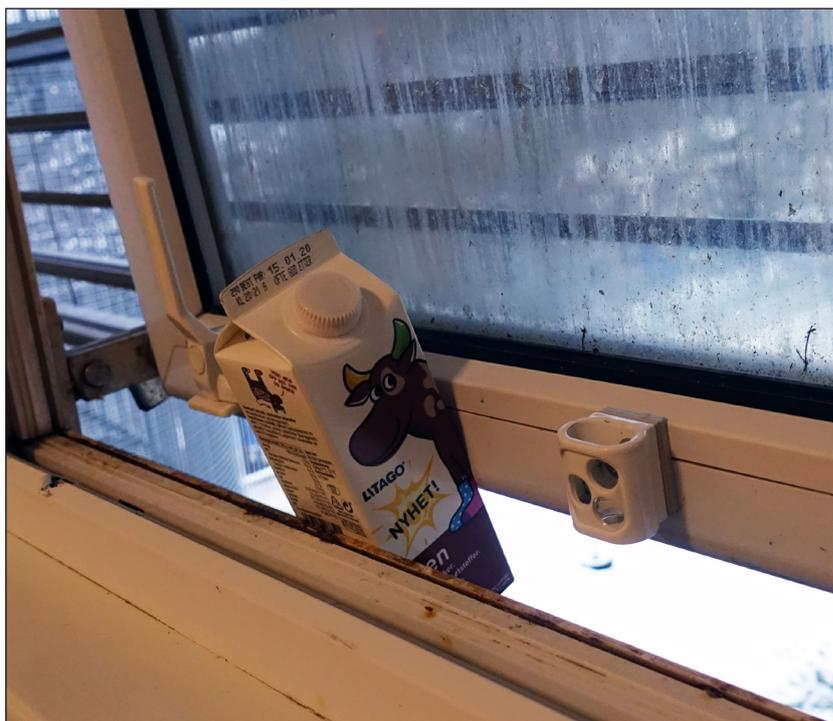
The wall lights in the corridor lacked lamp shades and light bulbs. Some of the ceiling boards were badly damaged and had big, old stains. The walls, ceiling and doors showed signs of lots of wear and tear and damage. Several interviewees reported that it is a problem that patients often cause damage.

Hanna's bedroom had no other furniture than a mattress on the floor and a washbasin. There was one window in her room, which didn't provide a clear view out. Sun shading was provided by an external metal blind. Due to inadequate cleaning, it was hard to see out through the window.

When we visited, the door to Hanna's room was damaged on the inside.

In interviews with Ukom, several people stated that the seclusion unit was not considered conducive to recovery; on the contrary, it could exacerbate and extend psychotic disorders. One doctor put it like this:

"When you pack several people together in a small space. People who are



The window from this patient room was, like the others, hard to see through because of poor cleaning. (Photo: Ukom)

agitated, afraid, paranoid and psychotic ... well, it's ... It would be better if the conditions were different. Yes, there's no doubt about that."

The doctor explained that the facility can work fine if there are three patients in the section. "They can cope with that, but when there are four or five, it's too crowded. If you're in seclusion to get some peace and calm, you don't often get it."

The corridor, which acted as the day room, had been converted to make it possible to separate patients from one another. That meant no daylight entered when the doors were closed. Hanna had to use a shared toilet and bathroom. She therefore had to go past fellow patients several times a day. One nurse commented on how this was unfortunate:

"She came into contact with the same

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INFORMATION

Supervisory commissions

The role of supervisory commissions is to protect the legal rights of individuals in their dealings with mental health services. The commission oversees administrative decisions on coercive means, deals with complaints and performs patient welfare inspections. The commission consists of a judge (as the legal expert), a doctor and two representatives without any medical or legal background. The commission's main role is to protect the legal rights of individual patients in their dealings with mental health services.

ill patients, with perhaps 100 contact points over the course of a day. She was sent back into her room, in the middle of a seclusion corridor, with noise from all directions (...) So I imagine that with her level of function, her way of thinking and being, I think she had every reason to be frightened."

Another member of staff put it like this:

"Obviously it's tough working in that corridor, without any windows, so you can imagine that it's really difficult being a patient. Because sometimes there are loud noises, someone is shouting, screaming and then of course it's a stress factor being hospitalised. The lighting and air quality are bad, and it's incredibly cold."

When the doors were closed, Hanna didn't have any daylight in the day room, in other words the corridor. Over the course of 12 days, she went outside twice to get some fresh air. Sometimes she went out onto the porch. The lack of daylight and fresh air may have affected her sleep. When the doors in the corridor were open, daylight could enter from both sides via porches secured with grilles.

Impact of the physical environment on the treatment regimen

The seclusion unit's physical limitations increased the need to suppress noise for the sake of other patients, particularly at night. So it was important for Hanna to sleep.

"And the fact that the patients ... stress each other out, agitate one another sometimes ... That creates insecurity and makes the recovery process slower, you might say. So the physical conditions are not good", said one doctor.

An auxiliary nurse put it like this: "The seclusion unit is rather awkward. They often get into conflicts with each other too. We keep them in their separate cubicles."

Hanna's agitation created noise. The nursing and support staff found her tiring. This feeling was reinforced by their responsibility for the other patients' well-being. One nurse said:

"Very poor sound insulation from the seclusion unit above, which is also



Patient rooms in the seclusion unit. Hannas room was unfurnished. (Photo: Ukom)

very noisy. It's badly set up; you hear the slightest noise so well. The room isn't cosy or pleasant. And you could hear Hanna's singing throughout the ward. It must be absolutely awful to be a patient here."

As the seclusion unit's layout means that any disturbances affect the other patients, the nursing and support staff felt at a loss and frustrated. Several interviewees said that Hanna was kept in her room in contravention of the regulations. Staff did this by blocking her door with their feet, and she was also subject to other types of physical force, such as being led away or held. No administrative decision to use coercive means was taken prior to doing this. The interviewees were in no doubt that the physical conditions in the seclusion unit increased the need for coercion:

"There is more use of coercion because the patients get on top of each other. And the seclusion isn't as good as it should be. It's not a pleasant environment", according to a doctor

Supervisory commission and patient welfare inspections

All inpatient mental health institutions have a supervisory commission which, in addition to overseeing administrative decisions and dealing with complaints, shall perform the necessary monitoring of patient welfare.

According to the supervisory commission for the intensive care ward where Hanna died, a lot of its work consists of reviewing administrative decisions. A patient welfare inspection involves the supervisory commission visiting the unit to get an impression of what the conditions are like for patients and staff:



The roofing sheets was dirty and damaged. (Photo: Ukom)

"We look at state of the premises, whether the rooms are pleasant, if there are enough members of staff to allow the patients to go out and if there are activities on offer. After all, it's our responsibility to make sure that conditions are good."

The chair of the supervisory commission said that there is no clear definition of what is meant by "good":

"The nature of it means that what you're looking at is whether it's an OK place to be, in so far as you can be OK in a place where you're receiving compulsory treatment."

The chair of the supervisory commission said that "... the building is what it is", but that the commission had nevertheless reported some inadequacies to the hospital, including that one patient had to use the toilet in the room of another patient. Ukom found that there wasn't a system for checking whether this kind of feedback was dealt with and the matters were rectified.

Approval of institutions providing compulsory mental health treatment

In 2001, the hospital applied for approval for its wards and tasks at the time. At that time, the Norwegi-

INFORMATION

Patient welfare inspections

Section 6-1 of the Norwegian Mental Health Care Act requires the supervisory commission to perform the inspections it considers necessary to safeguard patient welfare. These inspections are referred to as "patient welfare inspections". The law states that this duty only applies "to the extent that it is possible". The preparatory works to the act describe patient welfare inspections as a "secondary task in relation to the decisions for which the supervisory commission is responsible". The supervisory commission's authority in relation to general patient welfare inspections should be limited to raising matters with the people responsible and, if appropriate, with the chief county medical officer.

Patient welfare inspections can cover inspection of the institution's provisions for day-to-day activities, personal activities, visiting, personal integrity, how the premises work and the patients' surroundings.

an Board of Health Supervision was responsible for granting approval to psychiatric institutions. Ukom has been shown a long list of named departments that were approved back then, sent by the Norwegian Board of Health Supervision to the Norwegian Directorate of Health. The hospital has since undergone alterations and been reorganised several times. The intensive care ward where Hanna stayed has changed name and moved in recent years, and it cannot be identified in the approval. The Directorate of Health has informed us that missing paperwork in its archives makes it hard to match up the approval given in 2001 with the intensive care ward in operation today.

Interviews with hospital managers revealed that alterations were carried out in conjunction with a merger. After an application process, the new premises were approved.

In the letter of approval, which is more recent, the Directorate of Health refers to the fact that the hospital had applied for approval for four named wards. The relevant intensive care ward is not mentioned in the letter. The Directorate of Health deci-

ded to give a general approval for the whole hospital.

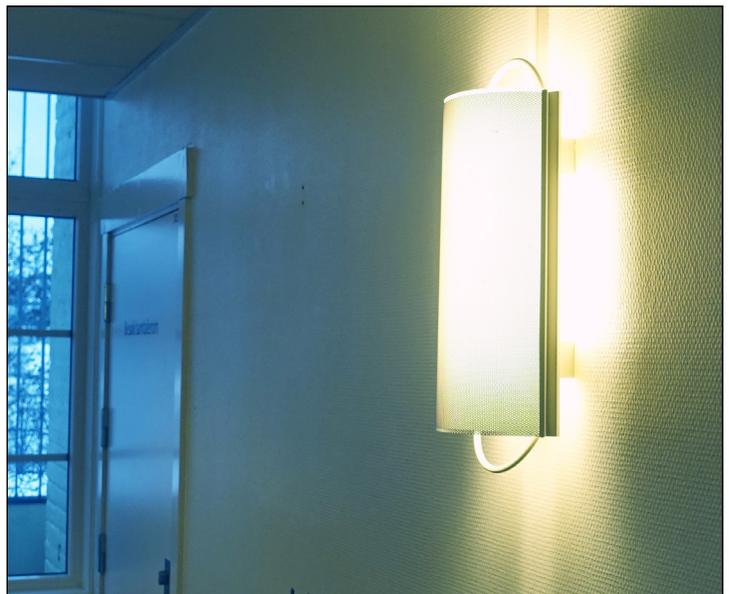
Ukom has been unable to determine whether the intensive care unit where Hanna stayed, in its current location and layout, was covered by the approval given by the Norwegian Board of Health Supervision in 2001. It wasn't assessed in conjunction with the more recent approval, which was a general approval for the whole hospital.

Maintenance and cleaning

At psychiatric intensive care wards, there is a need for frequent maintenance and replacement of furniture and furnishings. In their despair and frustration, patients may destroy furniture or make holes in the walls, ceilings and elsewhere. A lot of cleaning is also needed.

The intensive care ward where Hanna was hospitalised showed signs of inadequate maintenance and cleaning.

The windows were dirty from various liquids, such as soft drinks, coffee, milk and so on, which had been thrown out of windows on the floor above. The management explained



This is a broken lamp in the corridor. On the right side is how its supposed to be. (Photo: Ukom)

that it was hard to clean them on account of the patients on the ground floor.

Several of our interviewees suggested that the reason why conditions like this are accepted at the seclusion unit is that people become so accustomed to them that they stop noticing how bad they really are. Staff develop “institutional blindness”, as some of our interviewees put it. This also applies to the supervisory commission, which said the following:

“It’s really unpleasant, there’s no doubt about that. I guess the supervisory commission hasn’t focused enough on that side of things because there’s a feeling that the furnishing should be pretty basic, essentially.”

One nurse said:

“It makes me sick how ugly it looks, and how soon you become blind to it ... The last time I was there, I said to a colleague: These walls make me feel ill.”

Ukom’s assessment of the physical environment at the seclusion unit

Hanna was put into crowded and unpleasant surroundings, which probably heightened her agitation. Her agitation led to greater use of restrictions and medication. Eventually, her overall medication reached very dangerous levels.

The decision-making processes and mandate for performing repairs to the physical environment seem cumbersome and to some extent unclear. This can lead to inadequate maintenance and to damaged furniture not being replaced.

Ukom notes that the supervisory commission’s patient welfare inspections at this hospital didn’t fulfil their

intended purpose. The reasons for this may include its weak mandate and insufficient training on what the right kind of physical environment is. This may be due to a lack of adequate technical guidelines on the physical environment at seclusion units in mental health services. The Norwegian Directorate of Health may also find it difficult to communicate its advice. Another reason may be the way in which the Directorate of Health discusses what to include in patient welfare inspections in its circulars. The wording implies that the scope and nature of the inspection is left to the discretion of the individual supervisory commission.

Ukom has identified several possible reasons for the physical environment being in the state described above. There is an approval scheme for facilities used to provide mental health services. This approval scheme did not ensure that the physical environment at the hospital department under investigation was of an adequate standard. It is, in fact, unclear to what extent the premises were approved. The health trust that runs the ward is getting a new hospital. In that situation, repairs to existing buildings are often given low priority. A backlog of maintenance can more easily occur and be accepted. The decision-making processes and mandates for performing repairs also appeared cumbersome and unclear. We also found that patient welfare inspections were inadequate in their scope and nature.

Institutional blindness amongst hospital staff and the supervisory commission may mean that maintenance requirements are not noticed and reported to the management.

Our interviewees were highly critical of the state of the premises. They also said that some of the issues at the seclusion unit have been reported in the past, but this has not led to

any significant improvements. At the same time, they acknowledged that institutional blindness may mean that staff don't notice maintenance requirements and report them strongly enough to the hospital management.

Since our investigation, the hospital management has carried out several improvements (see Section 13). The management stressed that the investigation's external perspective had been an important eye-opener with respect to conditions at their own hospital.



Illustration photo

Ukom is aware that criticism has been directed at seclusion practices in mental health services. During the period 2015-2018, the Parliamentary Ombudsman's prevention unit visited 12 hospitals where patients were undergoing compulsory mental health treatment. These visits are summarised in the report "Seclusion in mental health care – risk of inhumane treatment" (1). A consistent finding from the visits was that the seclusion premises and units did a poor job at safeguarding patients' dignity.

In a literature review from 2015 (4), Norvoll, Ruud and Hynnekleiv show that the practice of seclusion is not backed up by much research, and that the term is imprecise and is used to describe a variety of approaches and actions. Few efficacy studies or randomised trials have been performed in relation to seclusion. Many patients react negatively to seclusion. Norvoll, Ruud and Hynnekleiv argue that seclusion raises legal and clinical questions that need to be discussed.

In 2016, the government appointed a legislative committee that carried out a general review of the rules on coercion in the health and care services. The committee came to the conclusion that current legislation on seclusion is unsatisfactory and suggested implementing universal rules on the design of facilities (2). Experience tells us that it will take a long time to adopt any changes to legislation.

This investigation shows that bad physical conditions at seclusion units can pose a serious threat to patient safety. This means there is a need for extensive improvements at several levels. We will draw up our recommendations with respect to this.

CHAPTER 4

Organizing

Staff qualification and the number
of staff Hanna encountered

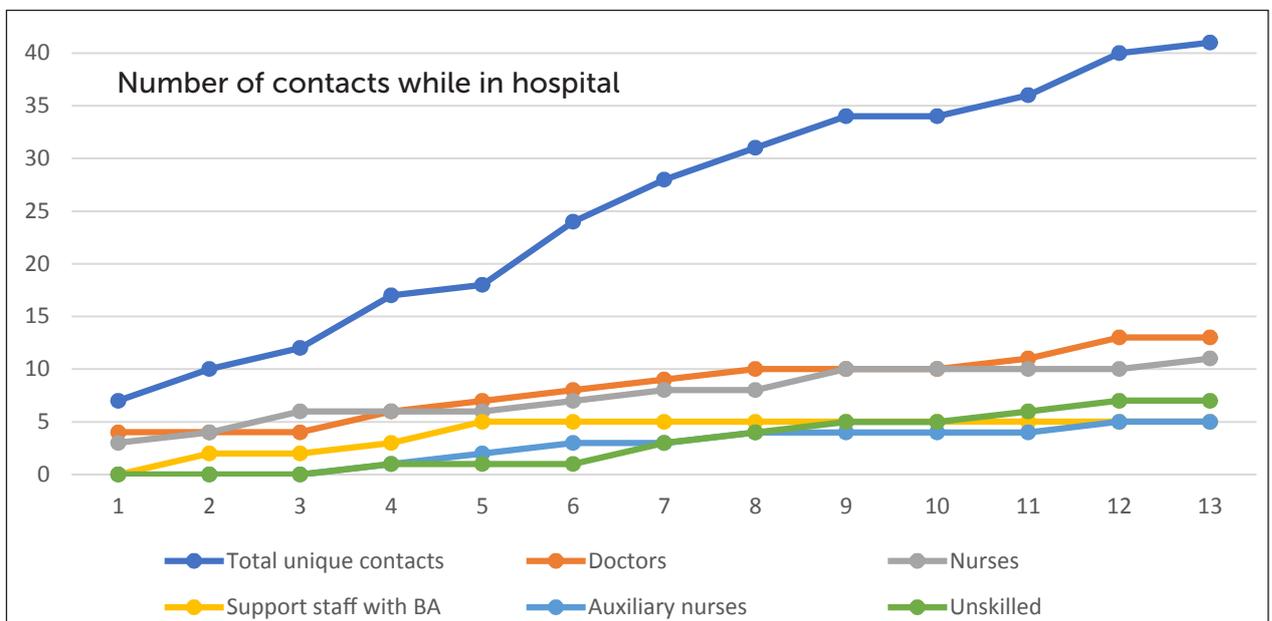
Staff qualifications and the number of staff Hanna encountered

In this section we describe our findings with respect to the number of staff members that Hanna had to interact with while she was in hospital. A few quotations have been included to exemplify some of our findings. Our key findings are:

- Doctors, nurses and support staff stress the importance of staff and patients knowing each other, but Hanna was constantly having to deal with new, unfamiliar faces.
- The organisation and allocation of nursing and support staff was done at each change of shift. There were frequent changes during shifts.
- Some interviewees told us that it was stressful for Hanna to have to deal with so many members of staff.

Hanna met new nursing and support staff and doctors almost every day, every day.

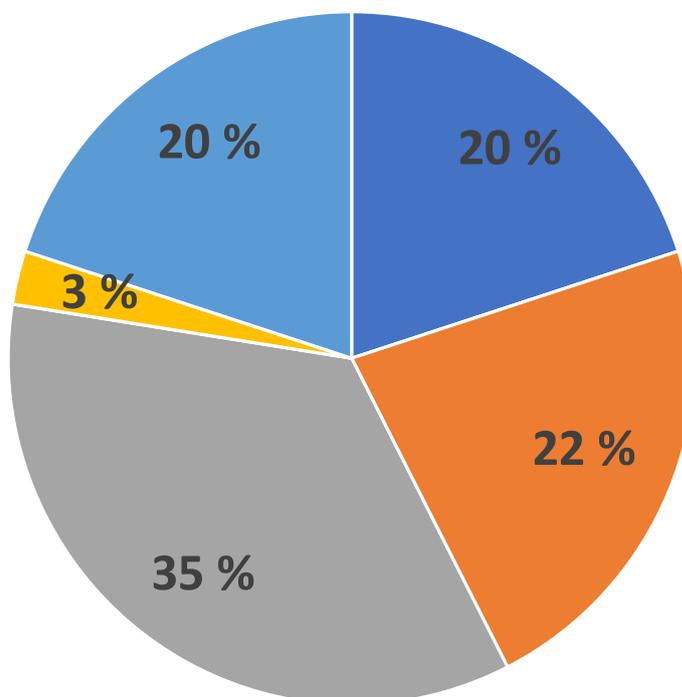
Hanna met new, unfamiliar nursing and support staff almost every shift. Hanna was transferred from the short-stay assessment unit to the seclusion unit on her fourth day in hospital. The short-stay assessment unit is part of a different hospital department. As such the transfer also involved a change in doctors, nurses and support staff. Due to the limits on its investigation, UKOM has not interviewed staff at the short-stay assessment unit. Consequently, the descriptions of our findings and our analyses do not apply to the short-stay assessment unit. Nevertheless,



The figure shows growth in the cumulative number of contacts. Hanna met 13 different doctors and 11 different nurses, and including other health care professions a total of 41 people were responsible for her over the course of 12 days.

Staff qualifications

- Unskilled
- Auxiliary nurses
- Nurses
- Learning disability nurses
- Support staff with BA



The figure shows the qualifications of Hanna's contact people for day, evening and night shifts during the 12 days that she was hospitalised.

we have included the health care workers she met there in our count, as it is the total number of people that is relevant to the patient experience.

Our conclusion is that the way contact people/patient responsibility was organised did not meet the need for stability and continuity. Hanna rarely had a contact person whom she knew from a previous shift. Moreover, the contact person frequently changed during shifts. Several interviewees admitted that the constant staff changes were stressful for Hanna.

We asked an experienced nurse if there were aspects of the seclusion regime that made it hard for Hanna to calm down:

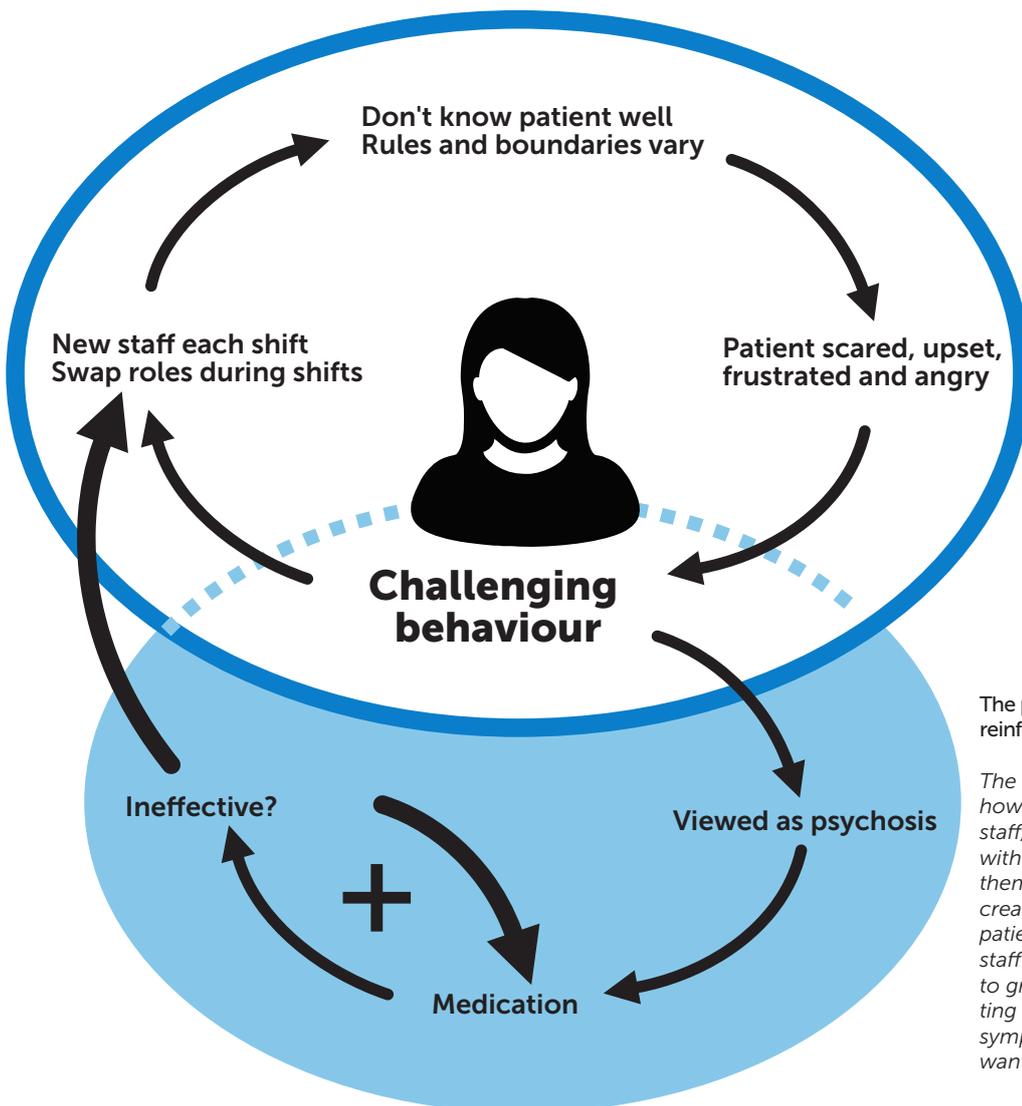
"Yes, I would think so. Dealing with 11 different nursing and support staff in the space of 24 hours must have been

challenging for her.

The figure above doesn't include changes during shifts. These were sometimes frequent. One nurse said: "There were '5-minute' swaps. Or we swapped once an hour. You agree that in advance. Some people have more energy to keep on going than others."

"You're treading on each other's toes a bit. The sickest patients really wear you out, so we took turns a bit. We were happy to swap."

"I remember that some staff got fed up with her behaviour, which is only natural. So that was really why I chose to be with her. It was better for me to be with her than someone who was fed up. She was really unwell."



The process has self-reinforcing feedback loops

The figure is a visual representation of how attempting to reduce stress on staff, by not giving them several shifts with the same patient and allowing them to swap roles during shifts, creates a stressful situation for the patient. This is because it leads to the staff knowing the patients less well and to greater variability in boundary-setting and rules. This can exacerbate symptoms, which in turn leads to staff wanting to swap roles.

Nevertheless, several of the interviewees stressed to Ukom the importance of stability and continuity. We haven't found any plans or structures in place to ensure that this existed at the seclusion unit.

Qualifications of the staff who helped look after Hanna

Our interviews revealed that the hospital management has focused heavily on recruiting and retaining

staff with qualifications in health and care services.

Six out of the seven unqualified staff members were studying to become auxiliary nurses or other kinds of health care workers. One of the 11 nurses was a specialist psychiatric nurse. Four members of the support staff had a relevant Bachelor's degree, which could include having trained to be a police officer, teacher or occupational therapist, and one of them had additional relevant training. There was one learning disability nurse (who is included under support staff with a relevant degree in the figure above).

Two out of the auxiliary nurses had taken additional training, in nursing and psychiatric health care respectively. Most of these members of staff were Hanna's contact person on one occasion while she was at hospital.

In the case of the nurse who was on duty the night she died, it was her first shift with Hanna, although she knew her from previous hospitalisations.

Importance of relationships

One of the doctors who treated Hanna after she was admitted to hospital answered our questions about the admission process itself:

"Discontinuities in relationships are harmful and hinder the recovery process. So we should try to minimise them, and we try to give that high priority when admitting patients and deciding which ward they should go to."

The doctor also stressed the importance of the nursing and support staff to the therapeutic process:

"It is the nursing and support staff who have continuous, long-lasting contact with the patient. Who can sit beside a patient holding their hand. Who can listen to them and comfort them, in other words. That side of the treatment is important."

Everyone Ukom interviewed emphasized the importance of knowing the patients. One assistant put it like this: "It was important for her to have one person. Whom she trusted. I felt she needed to feel safe. I tried to be there for her."

Changes in the staff looking after and treating her

The physical environment, with little daylight and high noise levels, as well

as the patients' medical conditions, made for a challenging working environment for staff. As a result, it was decided that nursing and support staff should alternate between spending a month at the seclusion unit and a month on the rest of the ward. Our interviewees also reported an almost daily need for extra staff, due to illness or because more people were needed on duty.

A contact person, who the patient should go to if they need something, was chosen at each change of shift. A nurse or learning disability nurse decides who will be the contact person for each individual patient. Staff can express their preferences at the start of their shift.

The interviews made it clear that arrangements to help staff cope with the stress were given high priority in the unit. The idea is that the patients will benefit from being looked after by staff with enough energy. That may explain why at each shift a new person was designated Hanna's contact person. In addition, staff often took turns at being the contact person during shifts. Many of them became worn out by Hanna's struggles.

The reason why 13 doctors were involved in treating Hanna over the course of the 12 days she was in hospital was that the nurses contacted different ward physicians and doctors on duty to ask them to prescribe medicines at different times of day. Hanna was allocated a responsible clinician, but it is unclear whether this doctor was present.

The ward had been reorganised a little while before her death. Consequently, many members of staff were reassigned. Several of them were unhappy about this. Approximately 30 trained staff members left this ward over a twelve-month period. It was a chal-

lenging year, and there was a heavy focus on retaining and recruiting staff. This may have contributed to the hospital management not realising that Hanna came into contact with so many different members of staff.

Ukom's assessment of the organisation of the ward

There was a relatively good number of trained health care workers on Hanna's ward. However, very few of them acted as her contact person for more than one shift while she was there. The staff at the unit kept changing. All of the evidence suggests that this lack of continuity was very stress-

ful for her. It is overwhelmingly probable that this increased her agitation, anxiety and frustration. Her agitation led to her being given medication over and above her regular medicines.

It can be challenging to interact with a patient with a serious psychosis and an impaired ability to self-regulate. As the figure below shows, the self-reinforcing feedback loops must be broken by staff creating stability for the patient. This requires staff to be highly professional and very robust, and the right systems must also be in place. Over time, a systematic therapeutic approach may improve the patient's condition. There must be a plan in place to ensure staff continuity.

CHAPTER 5

Milieu therapy

Milieu therapy

This section describes our findings with respect to the milieu therapy Hanna received and its efficacy. Quotations have been included to exemplify some of our findings. Our key findings are:

- The nursing and support staff reported that Hanna received standard milieu therapy, but that it was not sufficiently effective. The staff resorted to restrictions and reprimands in order to deal with her agitation.
- The nurses, support staff and doctors all said that it was a priority for Hanna to get peace and rest, but the nurses and support staff found that they were helpless without the use of medication. They couldn't manage to get her to sleep.

Planned milieu therapy

The interventions described in the patient record, apart from medication, were milieu therapy involving support, structure and limiting stimuli. According to the treatment plan, Hanna could go outside if she was accompanied. This was done twice during her hospital stay.

The interviews carried out by Ukom make it clear that the nursing and support staff tried to transmit a sense of calm and security. There was a lot of emphasis on talking and behaving calmly and on being patient. Some staff said that they tried performing calming activities, like combing her hair and allowing her to listen to music. In her good periods, Hanna used to draw, and she was given reassuran-

ce and a cloth to put on her forehead to help her become peaceful and sleep.

The nurses, support staff and doctors told us that Hanna sometimes spoke in her mother tongue, which most of them couldn't understand. That made communication challenging. There were one nurse and one doctor who spoke Hanna's mother tongue. Both considered that what she said was disjointed and devoid of meaning.

The staff felt that sleep was an important part of her treatment. They tried to keep her in her room, so that she could calm down and rest.

They often felt that whatever they did was insufficient. A lot of the time, Hanna was agitated and active.

Rules and boundaries

Hanna was asked to stay in her room, in spite of the fact that she could express clearly that she didn't want to be there. This was mainly done for the sake of the other patients, but it was also supposed to shield Hanna from stimuli. Sometimes Hanna accepted this and calmed down in her room, but at other times she attempted to force her way out. "She was pushed into her room on repeated occasions", according to her patient record. Several interviewees reported that she was confined to her room, but that this was against the regulations. Moreover, it didn't help her to calm down and sleep.

In the interviews, we were told that Hanna made noise with her bed. This is also reported in the patient record for the eighth day that she was in hospital. After that date, the problem is not referred to. The bed was

removed from Hanna's room. Several interviewees assumed that this was done because she made noise with it, but that there could also have been other reasons. They said the bed was high and narrow, and Hanna might have felt unsafe sleeping in it.

The staff tried to implement structured milieu therapy. According to the patient record, this included Hanna only being served food at set times. Several interviewees reported that she sometimes reacted negatively to that kind of boundary-setting, by getting angry and lightly hitting the nurses and support staff.

Establishing rules and boundaries didn't promote peace and sleep; on the contrary, it often increased her agitation. The question of medication therefore came up often. One assistant put it like this:

"Getting her to calm down was a challenge. I ran out of options. I had to reset myself. We gave each other advice. Swapped patients. I joined in the discussions about medication, or mainly just listened. I would ask the

nurse 'can you do something', but not 'can you give her that'.

As short-term solutions, the staff tried to deal with challenging behaviour by exhortations and setting boundaries. They continued to do this although Hanna responded negatively to it. They also tried to build on any good moments. The same assistant also gave the following answer when asked what he was conscious of trying to do when dealing with Hanna:

"If she was being silly, I was silly back to her. Tried to have a good relationship. But there also needed to be boundaries. For example, in relation to food and changing clothes; she wanted to change what she was wearing the whole time. You can't always go along with that."

Why did rules and boundaries vary?

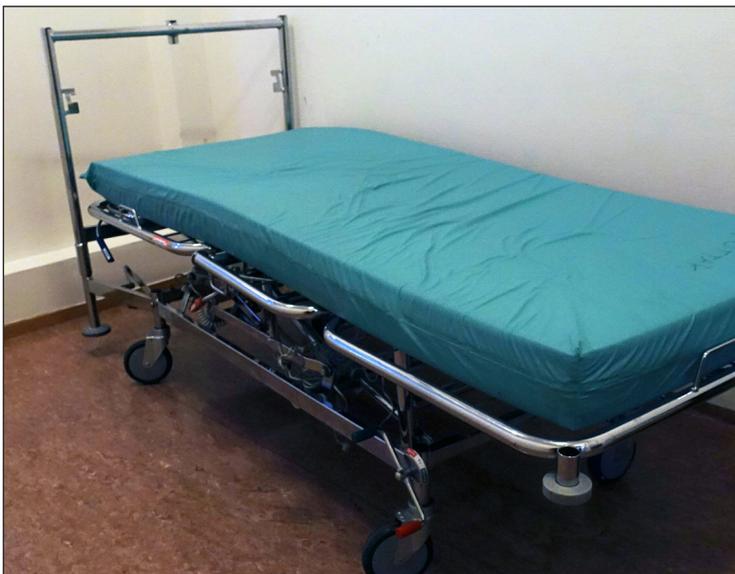
Our analysis shows that the variation in rules and boundaries was mainly the result of her contact person constantly changing. This greatly limited the amount of experience-ba-



sed adaptation. New members of staff repeated rules and boundaries that caused her stress. Ukom did not find any evidence either that there was a forum for planning and discussing milieu therapy activities, or for discussing which kinds of rules and boundaries to establish. Some of the staff did not attend the ward's regular meetings. Staff doing relief/extra shifts and night shifts didn't have these meetings in their rota.

The beds that were used at the seclusion unit were made of steel and could be used to make noise. Ukom was told that they could be dangerous if a patient wanted to self-harm, as well as being narrow and high, which meant the patients felt unsafe lying in them.

The senior management was not aware of the issue with these beds, nor with the fact that patients therefore ended up sleeping on the floor. The fact that the nurses and support staff took the bed out of Hanna's



This is a bed from the seclusion unit which is equivalent to Hanna's. It was taken away from her since she used it to make noise. (Photo: Ukom)

room is not noted down in her patient record. Nor was it defined as a non-conformity. As a result, the information was not passed on.

The supervisory commission assumed that patients slept on mattresses on the floor because they might use beds for self-harming, and they never questioned it when they observed it. The commission never met Hanna.

Our interviews revealed professional disagreement about the appropriate boundaries, particularly with respect to how reasonable they were, but this was not discussed or agreed at meetings or in the treatment plan.

Ukom found that the ward didn't have clearly defined areas of responsibility for structuring the milieu therapy. Seclusion is generally intended as a short-term measure.

The patient record does not set out which rules and boundaries were set, why they were needed or the justification for them. No assessment was made as to why Hanna was deteriorating.

The patient record mainly describes Hanna's condition and episodes of agitation and unwanted behaviour. For example, it states that she threw her food on the floor, but not that this was due to her frustration about not getting melted cheese like she had asked for. This detail was only uncovered by our conversations with the nursing and support staff.

Ukom's thoughts on milieu therapy

The agitation felt by insecure patients can be combated by creating systems to ensure continuity in their milieu therapy, so individual staff members are not left to their own devices. It is important to provide nurses and support

staff with systematic support and guidance. Patients whose behaviour is particularly challenging must be met with understanding and a broad analysis of the reasons for expressing themselves as they do.

Our impression is that rules and boundaries varied from shift to shift, which was challenging for both Hanna and staff members.

Another reason why rules and boundaries were not continuously reassessed may be that Hanna's behaviour was largely viewed and interpreted as being a symptom of psychosis. Disruptive behaviour and tantrums can be due to relational causes, even in psychotic patients.

In the national guidelines on the diagnosis and treatment of bipolar disorders, setting boundaries is not explicitly mentioned as an element of treatment. However, the guidelines do point out that manic people often need structure and stable frameworks in order to avoid uncritical and dangerous behaviour (3). They do not specify what this means in practice. Setting boundaries is mentioned once in the national guidelines, but as a reason why manic patients may respond aggressively.

A review article about seclusion at psychiatric intensive care wards (4) makes it clear that boundary-setting has traditionally been one aspect of seclusion. It should be noted that recent professional development projects put less emphasis on control, physical power and pacification during seclusion, favouring instead approaches based on recognition and dialogue.

Ukom notes that Hanna's treatment largely involved setting rules and boundaries. This was apparent from our interviews, and the notes in her patient record frequently refer to



Illustration photo

the fact that Hanna didn't respond to reprimands. We consider that a treatment regimen based on rules and boundaries is not in line with modern milieu therapy. This kind of practice may reflect the fact that it takes time to bring a treatment culture into line with new knowledge. It may also be because staff found Hanna particularly challenging, and there was a pressing need for peace and quiet, for the sake of other patients. The nurses and support staff resorted to the "tools" available to them. Staff were not given any specific training or guidelines before becoming a contact person for Hanna. Several staff members became worn out and didn't know what to do in the face of her challenging behaviour. Their natural response was to resort to boundary-setting and exhortations to calm down.

The fact that she was lying alone on the floor of a bare room may have made her more agitated and made it more difficult for her to sleep.

At seclusion units, as in all other places, it's inevitable that a treatment culture will develop – "this is how we do things here". That becomes a problem when highly invasive actions are part of that culture and tradition. This is a kind of "cultural blindness".

Even if the general impression is that boundaries and rules were the main tools used by the nurses and support staff, our interviews and the patient record also show that some staff were patient, stoical and willing to give things time.

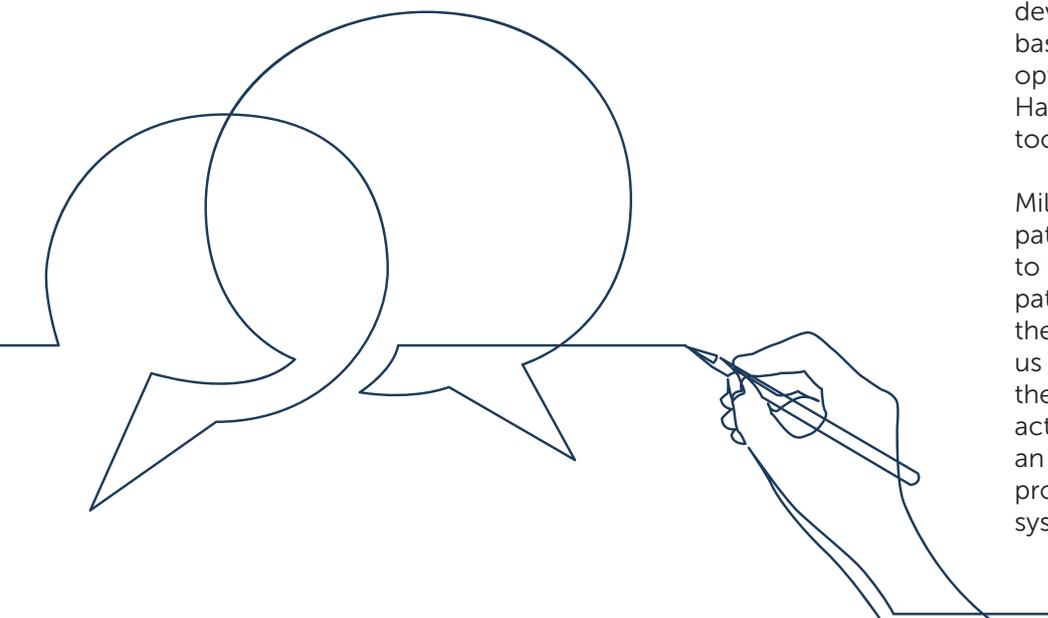
Hanna was from an ethnic minority background. When a patient speaks a language that the staff don't understand, which Hanna sometimes did, there is a strong need to interpret and understand non-verbal signals. Psychosis often disturbs patients' ability to think and communicate. They may experience disturbances in their ability to understand language or speak, which also applies to patients who are native speakers of Norwegian. Patients suffering from psychosis are often chaotic in their use of language. Their use of language may change, be distorted or completely disappear. How these disturbances are dealt with during hospitalisations,

including the challenges and consequences for both patients and staff, are described in more detail in the research article Tap av språk ved psykose ("Loss of speech during psychosis") (5).

Using a patient's mother tongue can play a big role in maintaining their level of function and integrity as much as possible. It is a well-known fact that language problems can be a barrier to equitable provision of health services (6). Language barriers and other communication difficulties can lead to misunderstandings. There are also cultural differences in how illnesses present themselves. Many patients who do not have Norwegian as their mother tongue would greatly benefit from an interpreter in their conversations with health care workers.

However, we believe that it is unlikely that the language difficulties experienced by Hanna in conjunction with her manic psychosis could have been solved by using a professional interpreter. This is something that must be assessed on a case-by-case basis and in consultation with patients' families. Using a professional interpreter should be tried at treatment meetings with the patient before concluding that their speech is chaotic and devoid of meaning. Our impression, based on our interviews, is that this option was considered when treating Hanna, and that the immediate family took part in that assessment.

Milieu therapy is important to the patient's experience of, and ability to benefit from, hospitalisation. The patient is in a vulnerable situation, and the staff may have to deal with serious challenges. In their relationships, there is a high risk of unacceptable actions. This can be counteracted by an individual, planned milieu therapy programme with good systems for systematic evaluation and reflection.



CHAPTER 6

Treatment and intellectual disability

Hanna was particularly vulnerable

INFORMATION

Intellectual disability

Being diagnosed with an intellectual disability implies having permanently impaired cognitive ability, but also varying degrees of difficulty with motor skills, language, social skills and coping with everyday life. Those affected are generally categorised as having a mild, moderate, severe or profound intellectual disability based on the level of challenges they face. Intellectual disability makes people vulnerable to developing illnesses or disorders. The way in which the person's environment recognises their challenges and helps them to overcome them is the key to whether they develop additional problems.

In this section we describe our findings in relation to the fact that Hanna had a congenital condition that made her particularly vulnerable and meant that she needed her treatment and care to be specially adapted. Quotations have been included to exemplify some of our findings. Our key findings are:

- Hanna had been diagnosed with triple X syndrome and a mild intellectual disability. Several of the nurses and support staff were unaware of the fact that she had this congenital condition. The diagnosis was not taken into account in her treatment plan, nor were any special supportive measures implemented in light of it.

Little is known about how this kind of congenital disorder may have affected the medication and milieu therapy received by Hanna.

Hanna's congenital vulnerability

Hanna was diagnosed as having triple X syndrome as an adult, and she was subsequently found to have a mild intellectual disability. That diagnosis was based on the results of a neuropsychological test. A neuropsychological test is an extensive assessment involving conversations, observations and testing to study various skills and brain functions.

On average, people with triple X syndrome have lower cognitive ability than the general population, but this varies greatly (6). A significant number have emotional problems.

One nurse told us the following:

"...she was a very challenging patient, but of course she had an intellectual disability as well as being diagnosed with a psychiatric disorder. She was very agitated, and that may have meant that many of the people who worked with her were simply worn out by her behaviour."

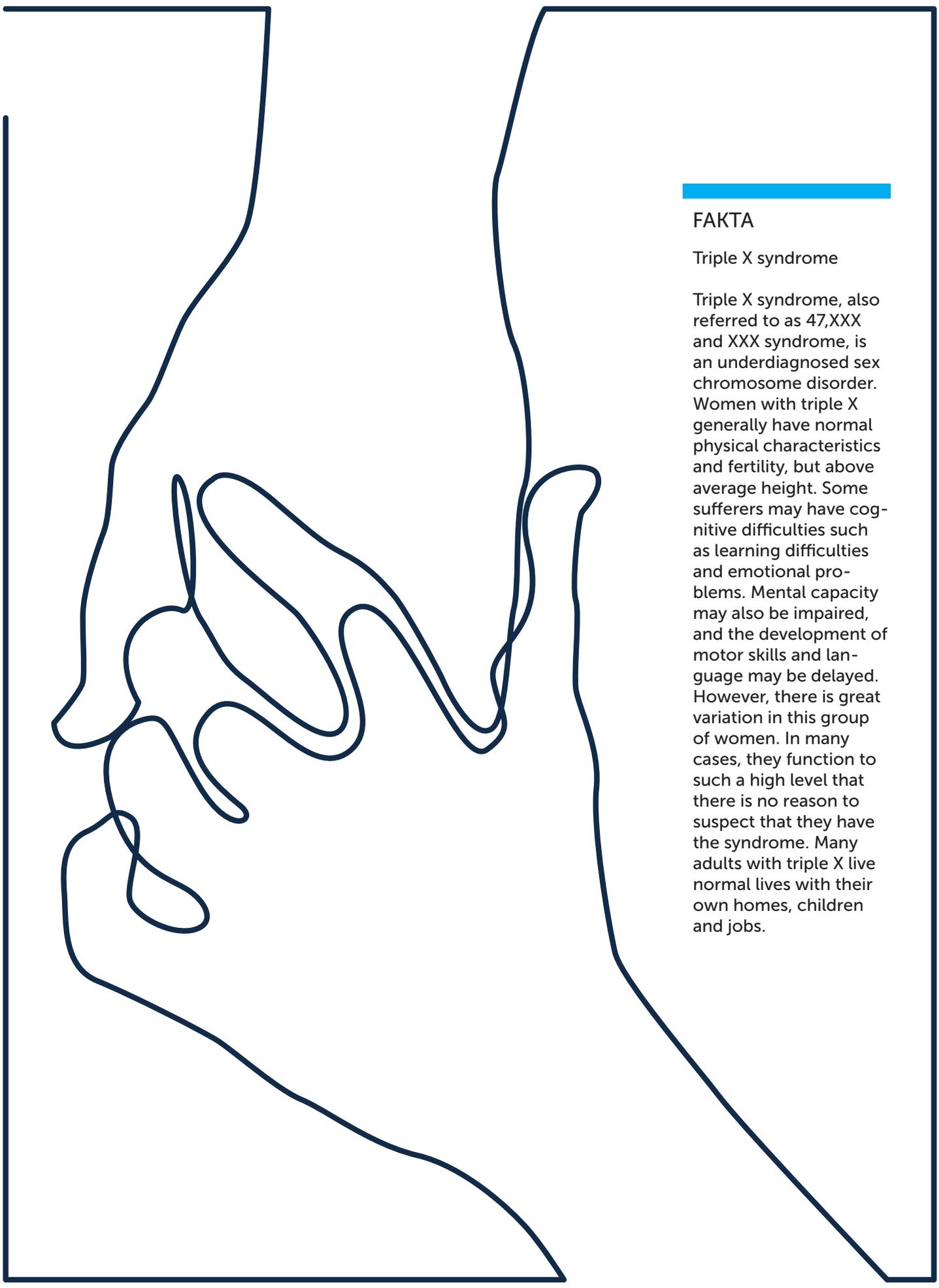
The specialist psychologist who examined Hanna told us that for people with intellectual disabilities it is extra important to give simple messages, provide structure and avoid confusion, and for the patient to have a regular, safe person to spend time with.

"Changes will often increase stress, exacerbate symptoms, and cause anxiety and agitation. Stability is important", he said.

One of the doctors at the hospital said that Hanna was probably vulnerable to developing psychosis, and that she needed support in her day-to-day life:

"... she had been diagnosed as having an intellectual disability. She needed extra support during the day. Socially and in her work she wasn't at the same level as other people of her age."

Several of the nurses and support staff were not aware that she had been diagnosed as having a mild intellectual disability. No individual guidelines were established, and no special support measures were introduced to reflect her condition. One nurse put it like this:



FAKTA

Triple X syndrome

Triple X syndrome, also referred to as 47,XXX and XXX syndrome, is an underdiagnosed sex chromosome disorder. Women with triple X generally have normal physical characteristics and fertility, but above average height. Some sufferers may have cognitive difficulties such as learning difficulties and emotional problems. Mental capacity may also be impaired, and the development of motor skills and language may be delayed. However, there is great variation in this group of women. In many cases, they function to such a high level that there is no reason to suspect that they have the syndrome. Many adults with triple X live normal lives with their own homes, children and jobs.

"I thought she might be intellectually disabled, but I wasn't told that she had been diagnosed as such. She was highly active and difficult to handle. She was infantile and had a childish way of talking. She seemed afraid and wanted to feel safe."

Fatal outcomes associated with medication

Our interviews and the notes in the patient record do not indicate that the use of medication took into account the fact that Hanna had an intellectual disability. According to the Norwegian Pharmaceutical Product Compendium, patients with mental retardation are over-represented amongst fatalities associated with the antipsychotic zuclopenthixol (Cisordinol).

The national centre of expertise for intellectual disabilities and mental health says it is difficult to generalise about how intellectual disabilities affect medicinal treatment. People with intellectual disabilities (including mild ones) find it hard to explain the effects and side-effects of medicines, which is another reason to exercise greater caution.

Her diagnosis was not widely known

The patient record system is the main way that relevant information about the patient is communicated. In an extensive patient record, it can be time-consuming to find the results of previous examinations with information about the patient's difficulties and need for adaptation. A few people were aware of Hanna's congenital disorder from previous hospital stays, but for most members of staff she was a new patient. The significance of

triple X syndrome and a mild intellectual disability was not discussed at treatment meetings.

Ukom's thoughts on dealing with patients with intellectual disabilities

People with psychoses may behave erratically. For Hanna it was particularly difficult to express, explain and justify herself in a way that was easy for other people to understand. She may have expressed her needs, desires, insecurities and anxiety through her behaviour.

All patients at mental health institutions benefit from stable relationships, but some patients will suffer more if this stability is lacking. The latter group includes patients with intellectual disabilities.

It is well known that patients with intellectual disabilities do not have as good access to mental health services as the rest of the population. The health authorities have recognised that the examination, diagnosis and treatment of mental disorders in people with intellectual disabilities and/or autism is an area of weakness.

That is why the national centre of expertise for intellectual disabilities and mental health was established in 2019. The centre is based at Oslo University Hospital Health Trust. The primary target group for the centre of expertise is people working in mental health care within the specialist health service. Habilitation services in the special health service will in many cases be a resource, particularly for people with more severe intellectual disabilities. Patients will often have had previous contact with this service, which has expertise on various syndromes.

CHAPTER 7

Medication

Medication

In this section we describe our findings with respect to the medication received by Hanna. Quotations have been included to exemplify some of our findings. Our key findings are:

- Hanna was given additional medication involving intramuscular injections of antipsychotics and benzodiazepine because she was agitated and sleeping too little.
- Both the patient record and our interviews gave the impression

that medication was considered the most important treatment for Hanna.

Hanna’s regular medicines were insufficient

Prior to being hospitalised, Hanna was taking lithium 83 mg + 125 mg (mood-stabilising) tablets and perphenazine 12 mg + 12 mg (antipsychotic) tablets as preventive measures. It is possible that Hanna wasn’t taking

	Medicines prescribed by ward physicians (daily dose in mg of tablet)		One-off prescriptions by ward physicians	One-off prescriptions by on-call doctors (in mg of tablet)
Day 1	Perfenazin 24, Litium 208, Olanzapin 15	Zolpidem 5		
Day 2	Perfenazin 24, Litium 208, Olanzapin 15	Zolpidem 5, Oksazepam 30		
Day 3	Perfenazin 24, Litium 208, Olanzapin 15	Zolpidem 5, Oksazepam 30		
Day 4	Perfenazin 24, Litium 208	Zolpidem 5, Oksazepam 30	Lorazepam 2 mg tablet	Zolpidem 5
Day 5	Perfenazin 24, Litium 208	Zolpidem 5, Oksazepam 30		
Day 6	Perfenazin 24, Litium 208	Zolpidem 5, Oksazepam 30		Diazepam 10
Day 7	Perfenazin 24, Litium 208	Zolpidem 10, Oksazepam 15, Diazepam 20		Diazepam 10
Day 8	Perfenazin 16, Litium 208	Zolpidem 10, Diazepam 30	Injection of Zuclopentixolacetat 100 mg	
Day 9	Perfenazin 8, Litium 208	Zolpidem 10, Diazepam 30		
Day 10	Perfenazin 8, Litium 208	Zolpidem 10, Diazepam 30		
Day 11	Perfenazin 8, Litium 208	Zolpidem 10, Diazepam 30		Diazepam 5
Day 12	Perfenazin 8, Litium 208	Zolpidem 10, Diazepam 10	Injection of Zuclopentixolacetat 100 mg Injection of Diazepam 10 mg	Diazepam 20

Table 1: The table shows Hanna’s medication while she was at hospital

her medicines regularly before she was hospitalised. Her serum level of lithium on the day she was hospitalised was 0.3 mmol/l. On the fourth day of her hospital stay that had risen to 0.9 mmol/l. In hospital, Hanna was given lithium and perphenazine every day. On the first three days, she was also given daily olanzapine 15 mg (antipsychotic) tablets.

Hanna was given benzodiazepines as relaxants while she was in hospital. Initially she was given 2 x oxazepam 15 mg (relaxant benzodiazepine). This was replaced with 3 x diazepam 10 mg (Stesolid) tablets from the seventh day onwards. Hanna was also given 5-10 mg of zolpidem (sleeping pills) in the evening.

Her condition gradually deteriorated, and on the seventh day Hanna was given an intramuscular injection of zuclopenthixol acetate 100 mg (Cisordinol-Acutard). Her perphenazine dose was reduced.

On day 12, Hanna was given the following medication (orally unless otherwise stated):

09:00 lithium 83 mg + perphenazine 4 mg + diazepam 10 mg
 13:00 zuclopenthixol acetate 100 mg + diazepam 10 mg (both as intramuscular injections)
 18:55 diazepam 10 mg
 20:30 lithium 125 mg + perphenazine 4 mg
 22:40 diazepam 10 mg + zolpidem 10 mg

Hanna was injected with antipsychotics and benzodiazepines.

Her patient record states that Hanna was psychotic, slept little, was agitated and sometimes tried to hit and kick the nurses and support staff.

It does not describe any concerns about Hanna's physical health, although our interviewees informed us that it was a concern. Several of them were afraid that Hanna would collapse. One doctor put it like this:

"We thought rest was important because her agitated state meant that her brain and body were exposed to incredible stress in the shape of stress hormones, which we produce much more of when we're agitated, and that put strain on the rest of her body like her heart and blood pressure."

One registrar and two consultants were involved in the final decision to administer intramuscular injections. The patient record states:

"Unable to answer with meaningful sentences. However, cooperates with medication. Repeatedly grabs hold of the hands and clothes of the doctors.

On a couple of occasions she hits out into the air and lightly at the support staff.

High levels of psychomotor agitation. Responds to some extent when reprimanded on this.

Appears to be suffering from auditory and visual hallucinations."

Hanna was then given intramuscular injections of zuclopenthixol acetate 100 mg and diazepam 10 mg at 13:00. Shortly afterwards she slept for a while. In the afternoon she was agitated again, but the on-call doctor felt that Hanna had been given enough medicines overall.

On her last day, Hanna was given the following benzodiazepines: Diazepam 30 mg and zolpidem 10 mg (tablets) and diazepam 10 mg (Stesolid) intramuscular injection. It should be noted that she was given diazepam 20 mg and zolpidem 10 mg (tablets) over the course of three and a half hours the evening before she died.

INFORMATION

Antipsychotics:

Antipsychotics are medicines that can help to control psychosis. These medicines cannot cure the illness, but that they eliminate many of the symptoms and make them milder. In some cases they may also shorten the duration of a bout of illness. There are many different types of antipsychotics, which are also referred to as neuroleptics.

They work by blocking dopamine receptors, thereby reducing communication between neurons in the brain. This may have an antipsychotic effect, but due to the many functions of dopamine, and the fact that antipsychotics affect other receptors as well as dopamine receptors, the vast majority of patients also experience tiredness, sedation, increased appetite, reduced cognitive function and various other symptoms.

Antipsychotics are primarily used therapeutically, but in exceptional circumstances they may be used to prevent patients from injuring themselves and/or other people.

Ukom's assessment of the medication given and risk management

With respect to treating Hanna's mania, the national guidelines on the diagnosis and treatment of bipolar disorders ([link to the guidelines](#)) have the following to say:

"Mania and mixed episodes are serious psychiatric conditions that require rapid treatment to eliminate the symptoms and allow a return to the patient's normal level of function. Medication is the cornerstone in the treatment of mania. Medicines generally work quickly and effectively. Clinical experience suggests that it is reasonable to reconsider the treatment regimen if no improvement is seen within a week. Patients who do not respond sufficiently to antimanic drugs are often given combination therapy involving several medicines (258). The best documented combinations are second-generation antipsychotics administered together with lithium or valproate." (3)

According to the guidelines, it is good practice to combine lithium and one antipsychotic. However, Hanna was given more medicines than this. Ukom is aware that patients suffering from mania are often given several different medicines to reduce their symptoms. The guidelines say nothing about how benzodiazepines should be used in the treatment of mania. The guidelines do not discuss the risk level associated with this treatment or any special observation requirements in relation to physical health.

The guidelines say that medication should be tailored to the patient's ethnic background. This is because drug absorption and efficacy can vary between ethnic groups.

In clinical practice, variation is often observed in how patients respond to psychiatric medications. This variation is related to a variety of factors such as age, sex, ethnic background and genetic makeup (pharmacogenetics). In some cases, there is a link between ethnic background and genetic differences. These important genetic variations lead to differences in drug metabolism (how the body transforms and uses drugs), which in turn determines both the therapeutic effects and risk of side-effects. This is the context for the recommendation to tailor medication to ethnic background.

The cytochrome P450 system is responsible for metabolising a large number of medicines, including antipsychotics. The prevalence of genetic variations in this system differs between ethnic groups. Zuclopenthixol acetate is a psychopharmaceutical that is metabolised by the isozyme CYP2D6, and a lower prevalence of slow CYP2D6 metabolizers has been observed in the Asian population (1%) than in Caucasian or African populations (5-10%). This means that the risk of excessive levels of zuclopenthixol acetate varies between groups. Hanna was given a pharmacogenetic test several years ago. The results of that test came back normal.

We believe that zuclopenthixol acetate injections of the kind administered to Hanna are relatively widely used in mental health services. It is an intensive and to some extent risky treatment that is used in the most serious cases of manic psychosis.

Zuclopenthixol acetate injections are slow-acting. In the Norwegian Pharmaceutical Product Compendium, the company that makes the drug states that a significant effect begins to be seen four hours after injection, with a slightly stronger effect after 1-2 days, after which time the effect dimi-



Hanna received injections antipsychotics and benzodiazepines. (Photo: Ukom)

nishes rapidly. The Maudsley Prescribing Guidelines in Psychiatry state that the initial sedative effect begins to be seen after around two hours, and that it takes around 12 hours for the maximum effect to be reached. If you are not very aware of this, it may be hard to judge the efficacy of the medicine and how strongly the patient is affected. If it is administered at 13:00, the maximum effect will only be reached in the night at 01:00.

The Maudsley Prescribing Guidelines (8) mention a number of precautionary measures that should be taken with these kinds of injections. Link to the Maudsley Prescribing Guidelines – Zuclopenthixol Acetate injection. In our view, these are two of the most important ones:

- Zuclopenthixol acetate should not be administered at the same time as other medications as this may lead to oversedation (excessive sedation which can leave the person numb or unconscious).
- Zuclopenthixol acetate should not be used if the patient can take tablets.

Combining it with relatively large doses of diazepam and benzodiazepine-like substances may constitute an additional risk as they can lead to breathing difficulties and reduced consciousness.

The National Health Service (NHS) in England has introduced its own guidelines on the use of zuclopent-

INFORMATION

Capacity to consent

Capacity to consent is a prerequisite for making your own choices and giving valid consent to treatment. The health care workers with responsibility for providing treatment decide whether a patient has the capacity to consent. Capacity to consent requires:

- the ability to express a choice
- the ability to understand information that is relevant to making a decision on treatment
- the ability to acknowledge information about your own situation, particularly in relation to your illness and the possible consequences of the various treatment options
- the ability to weigh up alternative treatment options by making a reasoned assessment of relevant information

hixol acetate for seriously ill patients. They include guidelines on observation practice after the patient has received the injection (9). http://www.oxfordhealthformulary.nhs.uk/docs/Acuphase%20Guidelines%202014_Final.pdf

According to those guidelines, the so-called National Early Warning Score should be used when giving patients injections. This kind of scoring system is widely used in physical health care services as a tool for systematically monitoring the vital signs of hospital patients. It increases the likelihood of early identification of any deterioration in the patient's clinical condition during the hours/days after administering this kind of injection (9).

Was Hanna able to consent to her own medication?

According to the patient record, Hanna had taken medication to treat her mental health problems for many years. On several previous occasions, Hanna had been given injections of zuclopenthixol acetate 50 mg. On those occasions, it was given as involuntary treatment. The patient record does not state that Hanna was to be given involuntary treatment involving zuclopenthixol acetate, nor that she lacked the capacity to consent to her medication. In the patient record and in their conversations with Ukom, the staff described sporadic difficulties with getting her to cooperate. While in hospital, Hanna continued to take her regular medicines.

In hindsight, doctors and managers at the hospital have said that Hanna did not have the capacity to consent with respect to the medication for her mental illness.

A letter from the Norwegian Directorate of Health (11) states that if a

patient lacks capacity to consent, any medication used to treat mental illness in mental health services cannot be considered voluntary. Without valid consent, the rules in Sections 4-4 and 4-8 of the Act on the provision and implementation of mental health care apply.

The nurses, who were responsible for Hanna, told us they had an acute need for medication to help her rest and sleep. The doctors supported their assessment and believed that it was urgent. That sense of urgency may have been one of the reasons why no formal administrative decision was taken at that time. The fact that patients can appeal against administrative decisions on compulsory treatment has been highlighted as an issue that may delay treatment:

"It takes a week from when I take the decision until the chief county medical officer comes back to us with a lawyer to help the patient with their appeal. Sometimes, if the patient is as sick as Hanna was, I take the decision with immediate effect. Because we can't wait a week."

This doctor went on to explain that Hanna cooperated with taking zuclopenthixol acetate, but that she did not have the capacity to consent. "If I had had a bit more time, I probably should have taken a Section 4-4 decision based on the need to promote sleep."

The doctor says that diazepam (Stesolid) cannot be given based on an administrative decision on compulsory treatment:

"Sometimes you take a Section 4-4 decision and give a depot injection, which starts to work after 3-4 weeks, but in the meantime you may also need to use faster-acting medicines. So then the question is ... You're not



Illustration photo

really allowed to use Stesolid as a treatment, but to prevent harm, you can give a Stesolid injection based on a Section 4-8 decision rather than a Section 4-4 decision.”

The doctors and hospital management reported that Hanna was not in a condition to understand the risks associated with the injections, but that they were considered necessary and that she did not resist the treatment. Several of our interviewees made the point that cooperation is generally considered to be a kind of consent. It is considered unhelpful to read out all of the side-effects or risks of the medicine to the patient. These medicines are given daily.

For the doctors it was a challenging situation, with lots of expectations,

considerations and dilemmas to weigh up when deciding whether to inject medicines on the final day. It appears that their way out was to rely on the consent given, even if they weren't sure that it was valid.

In mental health care, the requirements relating to informed consent became stricter after Norway ratified the Convention on the Rights of Persons with Disabilities in 2013 (12), and subsequently through the introduction of the capacity of consent model in the Act on the provision and implementation of mental health care (13). This has led to greater awareness of the right of patients to make their own decisions and the legal rights of people with serious mental health issues. Our investigation shows that this is a challenging and time-consuming area that requires hospitals to have good management systems in place.

INFORMATION

Chapter 4 of the Act on the provision and implementation of mental health care provides for examinations and treatment being carried out without the consent of the patient. If coercive means are needed to carry out the examination or treatment, a separate administrative decision on this must be taken pursuant to Section 4-8.

Compulsory treatment is a serious and invasive action, and the purpose of the rules is to provide quality control and to allow a broad-ranging assessment that goes beyond purely medical questions, incorporating a range of informed opinions about the issue. Health care workers who know the patient and their situation well may possess valuable knowledge that can inform the assessment as to whether or not treatment should be given.

Autopsy findings and cause of death

When Hanna died, the cause of death was unknown. Several hospital employees told us that they suspected heart disease, in other words a heart attack. The police, who were called by the hospital, decided to order a forensic autopsy. The autopsy uncovered no signs of disease in the heart or other organs. The final autopsy report assumes that Hanna died as a result of combined drug intoxication. When we performed our investigation, several members of staff at the hospital were unaware of this conclusion.

Toxicological findings and expert opinion

It is difficult to interpret the toxicological findings of an autopsy, but the concentrations of medicines measured in a full blood sample after death are nevertheless indicative of the levels that were probably present in the patient's serum prior to death. In Hanna's case, a blood test was taken around 48 hours after she died. The

concentration of some medicines rises through a mechanism called redistribution, while other medicines are gradually broken down after death. With some medicines, both of these mechanisms occur in parallel. An expert on forensic toxicology helped us to interpret the forensic toxicology report that was published in conjunction with the autopsy.

In general, the prescribed medicines were found in quantities that could be consistent with the treatment received by Hanna on the final day before she died. The quantities of diazepam and zolpidem were consistent with what you would expect from the doses and time of administration. However, olanzapine was found in much larger quantities than expected.

The level of zuclopenthixol was also much higher than is normally measured in the serum of living patients. However, given that its concentration rises after death, the quantity was in line with what you would expect from the injections given to Hanna.

The level of perphenazine was below the detection limit for the analysis (the value was so low that it couldn't be measured accurately), which is not unexpected given the dose she received. The forensic toxicology department at Oslo University Hospital made the following comments:

"Given the significant variation in the serum concentrations that can be observed after a given dose, and the fact that there are 'traces' of the substance (albeit below the cut-off level, which explains why it is defined as "not detected"), the test results may be consistent with the specified dose/timing of administration."



Blood tests (Stockphoto)

Ukom later also ordered a lithium test. Based on Hanna's medication, the concentration found was as expected.

One unexpected toxicology finding

However, one toxicology finding in the autopsy report was unexpected, and has subsequently received particular scrutiny: Olanzapine was found at a level of 220 nanomol/l in a full blood sample. Olanzapine was only prescribed the first three days that Hanna was in hospital, and it was not prescribed the last nine days before her death. We asked the toxicology expert to comment specifically on this finding.

Based on the specified doses given, the olanzapine plasma concentration at the time of death should have been in the range 1-7 nanomol/l, in other words extremely low. The expert said that for the observed concentration to be consistent with the specified dose given nine days early, significant redistribution must have occurred after death; in other words, the medicine must have "leaked" back into the blood from the internal organs. He went on to say that the observed blood concentration was consistent with what you would expect to find in a patient given a normal therapeutic dose of olanzapine on the day of death.

Ukom's thoughts on the medication given and cause of death

An autopsy is a potential source of learning that is not, in general, widely used. When a sudden, unexpected death occurs at a healthcare institution, discussing the possible causes of death openly may promote learning and improve patient safety.



Illustration photo

There is a lack of knowledge and awareness about the side effects and deaths caused by medicines. In order to improve our understanding in this area, clinical practitioners must flag up these deaths. It is therefore important to define them as serious unwanted incidents and as side-effect deaths in the report sent to the Norwegian Medicines Agency.

Administering antipsychotics in combination with lithium and benzodiazepines can have complex, unpredictable effects, including a risk of acute cardiac arrhythmia and consequent risk of cardiac arrest. There are also risks associated with sedation, which can lead to the airways becoming obstructed. Simultaneous use of antipsychotics and benzodiazepines, whether taken orally or as injections, can constitute a not-insignificant risk of fatal side effects.

This case also shows that patients may have significant quantities of medicines in their bodies that the doctor treating them is unaware of. This will further increase the risks



associated with what is already a potentially risky treatment.

Medication errors are the most frequent cause of unwanted incidents and patient injury in the health service (14). Incorrect medication on account of, for example, unclear prescriptions or medicine lists, or errors in doses or distribution, are frequently implicated in these injuries (14). A lot of work is done in all health regions to reduce medication errors through the Norwegian Directorate of Health's project "In safe hands 24/7". Work to ensure safe medication practices is just as important in mental health care as in physical health care. With that in mind, Ukom recommends much better monitoring of patients who receive antipsychotic injections.

It was clear from Ukom's conversations with staff that there was a concern that Hanna would collapse and a fear that mania made her condition life-threatening. The dangers of not administering medication for mania are associated with delirium, which is not a clearly defined diagnosis.

The last doctor who examined Hanna said that she was relatively calm. Her condition was not considered life-threatening. Ukom cannot find any evidence that the patient's health condition as such was life-threatening, neither due to lack of sleep nor on account of mania.

CHAPTER 8

Recommendations

Recommendations

The aim of this report is to help prevent similar incidents in the future. The most important work on this must be done locally with individual patients. But there is no universal solution that would prevent medication-related deaths amongst hospitalised patients.

Hanna died of what is assumed to be drug intoxication. The sequence of events, contributing factors and causal relationships have been discussed in detail in this report. The report is relevant to all institutions that provide mental health services. For learning to take place, the health service will need to reflect on what happened and put in place improvement processes.

In conjunction with this investigation, Ukom has been in contact with professional bodies and stakeholder associations, as well as medical staff at psychiatric intensive care wards in Norway. The following topics have particularly been highlighted:

- **The physical environment at seclusion units and how milieu therapy is used in conjunction with seclusion (hereafter referred to as seclusion practice)**
- **Expertise on monitoring physical health in mental health services**



After our investigation was carried out, the hospital where Hanna was admitted has implemented a number of improvement measures. This section sets out the measures that relate to the seclusion unit and its expertise on monitoring physical health. We briefly discuss the experiences of the hospital, and as an extension to that we provide our general recommendations on areas for improvement.

Ukom's recommendations in this report apply to all inpatient mental health institutions in Norway. After concluding our work on this report, we will assess whether we should also provide separate recommendations to the competent authorities, administrative agencies or supervisory bodies, in relation to the areas for improvement uncovered by our investigation.

The physical environment at seclusion units and seclusion practice

Our investigation found that Hanna was put into a poorly maintained seclusion unit where there was just a mattress on the floor. It was difficult to see out of the window and the acoustic absorption was poor, which meant that at times it was very noisy.

During the period 2015-2018, the Parliamentary Ombudsman's prevention unit visited 12 hospitals where patients were undergoing compulsory mental health treatment. These visits are summarised in the report "Seclusion in mental health care – risk of inhumane treatment", which was published in December 2018 (1). The Parliamentary Ombudsman's findings coincide with those of Ukom. The ombudsman found that premises used for seclusion were generally sparsely decorated, and that both patients and staff described them as

having a prison-like feel. Rooms often lacked furniture, were painted white and sometimes had opaque windows that made it difficult or impossible to see out. The Ombudsman wrote that overall seclusion units did a poor job at safeguarding patients' dignity. The sparse decoration was often justified on the grounds of safety. The Ombudsman wrote that this kind of approach to safety is problematic and not supported by research (1).

A repeated finding was that wards had a culture based on boundary-setting and reprimanding unwanted behaviour, with lots of emphasis on structure, which can provoke conflicts and lead to a need for seclusion. The visits also uncovered a lack of activities and time outdoors, which could also lead to a need to impose seclusion (1).

Recommendation: There is a need for systematic inspections of the physical environment in seclusion units.

Ukom recognises that seclusion units are particularly likely to suffer wear and tear, damage and defects. This means there is a strong need to counteract "institutional blindness", which can prevent staff from observing their surroundings objectively. Although the furnishing and design must take into account safety concerns, the physical environment in seclusion units affects patients' first impression and their experience of staying there.

Our investigation found that this kind of "institutional blindness" was a factor. This may have led to the seclusion unit not being refurbished earlier. It may be the case that staff at seclusion units are more prone to becoming blind to a poor physical environment because people other than staff rarely have access. Family visits often take place in dedicated

visiting rooms. This kind of unit is referred to as a closed system (15). During our investigation, staff expressed that they had more or less given up on getting necessary repairs performed. No-one had the seclusion unit where Hanna died as their permanent place of work. It is normal for health care workers to take turns at working at seclusion units. Ukom believes that this increases the risk of conditions being accepted that would not normally be considered acceptable. The fact that patients are not supposed to stay for long may also promote acceptance of unsatisfactory conditions.

How can institutional blindness be avoided?

There are several tools that can help health care workers avoid stopping noticing the negative environment



There was poor maintenance on the furniture in the hospital. This can happen due to staff going blind about the environment. (Photo: Ukom)

and instead look at it from the patient's perspective. Here we would like to highlight two of them. .

"In the patient's footsteps"

"In the patient's footsteps" is a management tool whereby the chief executive of the health trust accompanies a patient/user and observes his or her encounter with the trust over the course of all or part of a day. By accompanying the user, the chief executive gets to see the trust from the point of view of the patient/user, and can listen to what that person needs in their dealings with the health service. This is then built on by drawing up improvement measures in cooperation with the patient/user, family members and staff, as well as systematic work on specific improvements. According to the patient safety campaign, health trusts have had positive experiences of doing this (16). The measure is more widely used in specialist physical health services than in mental health services. With appropriate planning and preparation, this is a measure that could also be implemented in psychiatric wards.

"The Fifteen Steps Challenge"

"The Fifteen Steps Challenge" is a simpler tool than "In the patient's footsteps":

"I can tell what kind of care my daughter is going to get within 15 steps of walking on to every new ward."

This is a quote from The Fifteen Steps Challenge. Quality from a patient's perspective; A mental health toolkit developed by the NHS in England (17). The methodology is based on the idea that taking 15 steps into a ward is enough to get an impression of what conditions are like.

The purpose of the programme is to identify necessary improvements by asking patients and their families to take 15 steps into a ward. “The Fifteen Steps Challenge” emphasises the importance of first impressions:

When we first arrive in a healthcare setting, does it inspire confidence in the care that we are about to receive? How can first impressions make us feel that we will be safe and cared for? What are the first clues to high quality care?

What does good care look, feel, sound and smell like?

“The Fifteen Steps Challenge” should be carried out by a small group that includes patients and their families, as well as other people who don’t normally work at the ward, staff in non-clinical roles and managers. This makes it possible to look at the ward with fresh eyes.

The results of structured inspections such as “In the patient’s footsteps” and “The Fifteen Steps Challenge” must subsequently be built on in order for systematic improvement processes to be successful.

Recommendation: Seclusion practice must be regularly discussed.

In our investigation, we found that Hanna did not receive a planned milieu therapy programme based on her needs, wishes and preferences. The nurses and support staff didn’t know what to do, so they tried setting boundaries and making demands, but this was neither based on a treatment programme nor systematically evaluated. It was largely up to the individual member of staff’s judgement to define the nature of the seclusion, including its rules and framework.

In a review of seclusion units in Norway, the Parliamentary Ombudsman found that seclusion is often implemented in accordance with very strict local rules that in practice involve isolation (1). The culture at these wards is characterised by boundary-setting, reprimands and a strong emphasis on structure.

It is important for individual wards to discuss their seclusion practice regularly and systematically, and to look at how this relates to individual patients. Discussions must be inter-disciplinary, with doctors, nurses and support staff all present. It is important for all members of staff to participate, so that practice doesn’t vary between shifts; for example, staff who work night shifts often don’t have these meetings in their rota.

How can we set up interdisciplinary discussion forums on seclusion practice?

Whiteboard meetings are a tool for establishing regular, interdisciplinary meetings about, and for monitoring, selected risk areas. They provide a forum for sharing information and opinions between specialist groups and for ensuring systematic monitoring. Whiteboard meetings are a practical tool for initiating improvement processes relating to specific risks facing patients and the ward. <https://pasientsikkerhetsprogrammet.no/forbedringskunnskap/Tavlemoter> (18)

Expertise on monitoring physical health in mental health services

The autopsy report concluded that Hanna most probably died of combined drug intoxication. Administering medicines can be risky. According to

the national guidelines on the diagnosis and treatment of bipolar disorders, it is good practice to combine lithium with one antipsychotic. During part of her hospital stay, that is what Hanna was given. However, Ukom is aware that patients suffering from mania are often given several different medicines to reduce their symptoms. The guidelines do not discuss the risk level associated with this treatment, nor do they set out any special observation requirements in relation to physical health.

We believe that the injections Hanna received, with either zuclopenthixol acetate alone or a combination of fast-acting (diazepam) and slow-acting (zuclopenthixol acetate) medicines, is relatively widely used by mental health services. It is an intensive and to some extent risky treatment. The Maudsley Prescribing Guidelines in Psychiatry, a guide that is widely used internationally, mention a number of precautionary measures that should be taken with these kinds of injections (8). The National Health Service (NHS) in England has imple-

mented its own guidelines on the use of zuclopenthixol acetate for seriously ill patients. They include guidelines on observation practice after the patient has received the injection (9).

Those guidelines specify that a structured scoring tool for the patient's vital signs – the so-called National Early Warning Score – should be used. This increases the chance of early identification of any deterioration in the patient's clinical condition during the hours/days following an injection. This kind of scoring system is widely used in physical health care services as a tool for systematically monitoring the vital signs of hospital patients. The tool is an important element of the systems for early detection of any patient deterioration (19).

Recommendation: The national recommendations on early detection of deterioration in physical health should be implemented at inpatient mental health institutions.

In the spring of 2020, the system for early detection of patient deterioration "In safe hands 24-7" was replaced by the national recommendations on the early detection of, and rapid response to, deterioration in physical health (20). The new recommendations are based on updated information and have a wider target audience. Whereas the previous measures were clearly aimed at physical health services, the target audience for the updated national recommendations has been extended to also cover mental health services. Ukom suggests that the national recommendations on early detection of deterioration in physical health also be implemented at inpatient mental health institutions.



Table meetings is a tool to conduct interdisciplinary meetings in a structured and clear manner. (Illustration photo)

How should the national recommendations be implemented?

All of Norway's health trusts have implemented various measures to increase their capability for improvement. Continuous improvement requires a systematic approach. There are models and tools to support the planning and execution of quality improvement processes. We recommend using the improvement guide, which provides simple instructions on how to implement improvement processes in the health service (21).

The hospital's own areas for learning and improvement

After our investigation, the management team at the hospital where Hanna was admitted went on an inspection of the seclusion unit. The following improvements and changes have since been performed:

- Acoustic panels have been installed on the ceilings of the rooms.
- Headphones (hearing protection) are now available for patients in the seclusion unit to borrow.
- Some of the walls have been painted in colours other than white.

In addition, the following improvements have been made to the ward:

- The office that was previously in the ward has been moved, and the room it occupied has been converted into an activity room with a ping-pong table and TV, where patients can also play video games.



Illustration photo

This has created more space for both patients and staff. The room is now used for conversations, visits, activities and meetings. After the unexpected death, the management has given training in NEWS2 throughout the hospital.

The management pointed out that a small thing like painting feature walls made the unit feel much more pleasant. It is a significantly bigger job to do something about the physical structure of the building, but the sound-absorbing panels have slightly improved the poor acoustics. The experience with providing headphones is that some patients borrow them, and that they work as intended.

The hospital management informed us that these improvement measures were not expensive. They emphasised that the conditions in and surrounding the seclusion unit have improved.



Illustration photo

CHAPTER 9

Methodology

Methodology/documentation

The purpose of our investigation and analysis has been to identify why so much medication was needed, uncover systemic safety issues and investigate how patient safety at seclusion units in psychiatric intensive care wards can be improved.

Our investigation has drawn on the following sources:

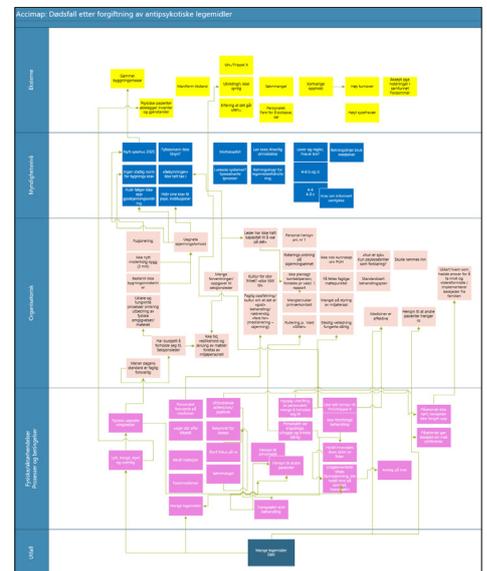
- interviews with a selection of employees who were directly or indirectly involved in the incident
- interviews with family members
- interviews and e-mail communication with experts
- interviews with members of the supervisory commission
- a review of the patient’s mental health records, medicine lists, autopsy report and police interviews
- a tour of the intensive care ward

Over the course of two visits, we interviewed a total of five family members and 15 members of staff at the hospital.

The interviews with staff members included nurses, assistants, auxiliary nurses, doctors and managers at various levels of the organisation. In addition, we spoke to the supervisory commission and a specialist psychologist. We have communicated by e-mail with the department of forensic

medicine at Oslo University Hospital, the national centre of expertise for intellectual disabilities and mental health, RELIS Vest (an independent source of information about medicines) and psychiatry specialists.

The topics we covered were based on our conversations, tour of the intensive care ward and document review. We supplemented the first round of interviews with a second set of conversations where we also discussed some of the topics of this investigation. This was done to gather information that was as detailed and accurate as possible, so that we would have a good basis for analysing our findings in the tool AcciMap, which is used to analyse accidents.



A screenshot of work processes with the analysis tool AcciMap

Analysis and causal relationships

The AcciMap analysis underpins the parts of the report that explain the causes and causal relationships. Several of these causes were raised during our interviews. The various causes of an accident are organised into a multilayer diagram. The accident is at the bottom and the causes branch out upwards.

The number and type of levels will depend on the kind of organisation where the accident occurred. We chose to split the causes into five levels. At the bottom, which we called the outcome, we entered "heavy medication and the death of the patient". The level above that we called activities and physical processes. This is where we put circumstances that directly affected the outcome, such as a lack of specific milieu therapy, lots of different staff members and so on. Level three, which was called organisational issues, explains the level below, such as restructuring, training and meetings. Level four, which we called the regulatory level, relates to matters outside the hospital's control, such as the obligation to accept patients. Level five covers issues and factors that are relevant, but which the clinicians cannot change through their decisions. We called this level "external factors". Triple X syndrome and psychosis are two relevant examples of this. The age of the buildings is another one.

We chose to use AcciMap because it takes a systematic approach to the causes of accidents. The AcciMap diagram shows how factors interact at several levels, far beyond the most immediate causes of the incident. The whole spectrum of factors contributed to the outcome, or failed to prevent it. AcciMap helps us to under-

stand how and why an accident occurred. The approach helps to move the spotlight away from the immediate causes (such as mistakes made by health care workers). By doing this, it reduces the temptation to put the blame on frontline staff. By broadening the search for contributing factors to the government, regulatory and societal levels, the approach also makes it possible to raise and address factors relating to the competent authorities.

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