

## Quotes

(Note: all the names are pseudonyms)

### 1. NEED FOR SOCIAL CONTACT

#### a) Longer visits

**Patient:** I've had enough... I've gone mad.

(..)

**Researcher:** But when your children are here, does that lift your spirits?

**Patient:** Yes, at the time...

**Researcher:** And at other times?

**Patient:** When they've gone? I'd like them to stay here longer.

[Field note, Norah]

#### b) Phone home

**Patient:** 'Telephone'.

**Researcher:** 'Do you want to use the telephone?'

**Patient:** 'Yes'.

**Researcher:** Who do you want to call?

(...)

**Patient:** 'Home'.

**Researcher:** 'Why?'

**Patient:** 'To say they have to come.'

[Field note, Zacharia]

#### c) More communication with staff

**Researcher:** So there aren't many people you can talk to?

**Patient:** Here in hospital?

**Researcher:** Nods, uh huh...

**Patient:** No... They don't answer you...

**Researcher:** Who?

**Patient:** The nurses [...] They came when I had almost gone mad.

**Researcher:** And why?

**Patient:** I don't know.

**Researcher:** And what do you think about that?

**Patient:** Leave the hospital.

[Field note, Norah]

#### **d) Misconceptions of staff towards patients' language proficiency**

When I come in the patient, a dark-skinned man, is writing, along with his daughter Barbara. I notice that he is already able to write better than in the previous days during which he wrote a lot of indecipherable signs on the paper. He points to me and writes 'NAME' on the paper. So he is asking my name. Then he points to his daughter and writes 'Barbara' on the paper. I say my name and then write my name on the paper.

[...]

During the change of nursing shift, the following is said about the patient:

'The patient wants to write all the time'. A nurse remarks: '*But he writes in Arabic!*' (...). Annoyed, the nurse continues, saying: '*I'm not going to learn Arabic so that I can understand him! We can never get anything right*'. (...) The nurse storms angrily out of the meeting. Some of the other nurses look shocked but they continue with the meeting. Another nurse asks: '*How can he write? He can't even hold a glass, talk ...*'

However the patient does not know any Arabic and can talk French, an official language in Belgium.

Apparently the nurse wrongfully believed that the patient could only talk a foreign language because he has a different skin colour and has been writing a lot of unreadable signs lately.

[field note, Quintus]

#### **e) Infrastructural constraints**

**Patient:** *Is there a sick person over there?*

The patient lifts her head a little and looks curiously at the bed in the distance that is diagonally opposite her bed. She can only catch a glimpse of that bed ...

**Patient:** *She has been ill for a week ...*

**Researcher:** *There are six beds here ...*

[...]

**Patient:** *Six in intensive care... Is it serious?*

**Researcher:** *Some are more seriously ill than others...*

[Field note, Norah]

## 2. NEED FOR NON-MEDICAL INFORMATION EXCHANGE WITH HEALTHCARE PROFESSIONALS

### a) Practicalities

The doctor gives a medical explanation to the patient. (...) During the doctor's explanation, the patient looks questioningly at the doctor. She asks the doctor: *'When can I go to the room?'* (Meaning: The patient asks the doctor when she can leave the ICU and go to a room in another ward). The doctor says: *'today'*.

[Field note, Norah]

### b) Family

I try to talk about his medical situation with him (patient) a bit and say: *'Your cannula has gone'* and point to his throat. He says bluntly: *'I'm not interested in that'*. I'm shocked by what he says. I ask what does interest him. He says: *'My wife'*.

[Field note, Zacharia]

### c) No communication from staff

The patient is lying with his eyes open. He has to gasp for air the whole time, is looking around which makes him seem very frightened (...) A nurse comes to aspirate the phlegm. He simply carries out his task and does not speak to the patient.

[Field note, Zacharia]

### d) Time pressure and workload

**Researcher:** Erm, how did you experience your care for the patient? (..)

**Nurse:** Very difficult! Erm, not always easy. Erm. He wasn't always easy to deal with himself. The patient. Which is sometimes understandable, of course, if you are that ill. Erm, but because of the, the pressure of work we're actually under, sometimes you can erm, with him, not as much, I mean sometimes we couldn't give him as much time as we would like to. Erm and sometimes I find that the most difficult part of your job, that you do want to stay in a room longer sometimes to, well, to be able to talk to your patient a bit more, or take your time a bit more with everything, but that sometimes that's not possible because you've got other things to do and you have to say "No, I have to go!" and, erm, yes, that's pretty much that. If I just look at the patient themselves, I mean.

[Interview with nurse Vanessa]

#### **e) Language differences**

The nurse comes into quarantine without saying anything to the patient. She looks at the medication and does several things on the PC. The patient looks at the nurse and says: '*tranquil*', relax. I deduce from this that the patient wants to talk to the nurse. The nurse doesn't react to the patient's words. Then she pours the patient's urine into a plastic bottle. The patient asks me: '*What is she doing?*' I say to her: '*He's asking what you're doing*'. She replies in Dutch, a language the patient doesn't understand: '*I'm pouring his pee into a bottle*'. Then she leaves quarantine.

[Field note, Zacharia]

### **3. NEED TO INCREASE COMFORT AND ALLEVIATE PAIN**

#### **a) Mistrust and irritation**

10 minutes later, the patient is shivering with cold. He points to the blanket. He wants an extra blanket, but there are no nurses nearby. I leave quarantine again and go and ask the nurses for a blanket. One of them says: '*Now he's messing us around. I was with him just a moment ago.*' There was no response to his request.

[Field note, Abdallah]

### **b) Language differences**

I sit down at the nurses' table. The patient sees us and calls out to us in Arabic. The nurses stay where they are and say: *'It is annoying, though, that we don't understand them'* (...). Apparently these carers feel powerless. The patient continues to call out and complain, and waves her arms in the air. She also bangs her arms against her head. Clearly she is trying to tell us something. None of the carers go over to her.

[Field note, Fadila]

### **c) Misconceptions of staff towards patients' language proficiency**

I ask the nurses who are checking the parameters shown on the monitor by the patient's bed: *'Does he speak French?'* One nurse answers: *'Yes, because French is an official language in Algeria, isn't it.'* However the visitor told me that the patient only speaks Arabic. The patient is very distressed. 2 nurses stand around his bed after visiting hour and ask him in French: *'Can you breathe properly? Are you comfortable? Bilal, Bilal, are you comfortable?'* The patient is still very distressed and every time the nurses say something to him, he moves his head from left to right. (...) The carers therefore assume that this patient understands them on the basis of their presuppositions.

[Field note, Bilal]

### **d) Quiet comfortable patient**

During the nurses' meeting in the unit, the patient's situation was discussed. Among other things, he is said not to be a difficult patient: *'He doesn't cause trouble, he's not in pain and he doesn't complain'*. It strikes me that the patient has little opportunity to 'complain' given that he had a cannula that rendered him unable to speak. Besides, according to the visitor, he does not speak Dutch, French or English, so he cannot speak to the nurses. It is also strange that the nurses decide he has no pain purely on the basis of the absence of verbal communication between the patient and the carers.

[field note, Bilal]

### **e) Wish to leave the ICU**

**Patient:** I'm not going to stay in intensive care, this place is death.

**Researcher:** Why?

**Patient:** I don't like it...Nobody comes, nobody listens... Even the nurses, one in ten glances your way for a moment, that's all ...(...) *'I can't manage yet, when I'm done'*...Anyway, I don't like it.

[...]

The patient looks sad and dejected. She says to her daughter that she wants to be moved because her back hurts. She says the nurses aren't friendly to her and that they don't often come when she asks them to.

Suddenly she starts to cry.

[Field note, Norah]

#### **4. NEED TO EXPRESS DESPERATION**

##### **a) Wish to give up treatment and leave the hospital**

**Patient:** Nothing has changed...

**Researcher:** How does that feel?

(Silence; she's thinking)

**Patient:** It doesn't change anything.

**Researcher:** You don't think it changes anything? And why do you think that?

**Patient:** I'm disgusted with life.

**Researcher:** You're...?

**Patient:** Disgusted with life.

**Researcher:** Disgusted with life ... And that means?

**Patient:** I've no more hope.....I want to leave the hospital...

[Field note, Norah]

##### **b) Tranquilizers**

The nurse says that the patient is nervous and that that is why she is giving her a Xanax. The nurse speaks to the patient in Dutch, asking: *'Why are you nervous?!, You have to do your best, you know!!'*. I have the impression that the patient doesn't understand the nurse. (..) The patient says in French: *'Don't understand.'*

[Field note, Norah]

**c) Hopeful relatives**

I hear from the nurses that the patient gets panic attacks, hyperventilates and that his heart rhythm has increased (...) During visiting hour the patient says to his wife: *'it's fucked,'* to which the wife replies hopefully: *'You'll get through it, you'll get better. The infection has gone down'*. The patient rolls his eyes at this.

[Field note, Abdallah]

**d) Relatives hiding negative medical information for each other**

In the meantime, the patient's daughter tells me her brother talked to another doctor the previous evening and that it was a 'good' conversation. The patient was apparently a bit better and they would see how he was later in the week. This has clearly given the daughter more hope today. However I witnessed the conversation the day before between the doctor and the patient's son from a distance and the news the doctor brought was not good news. I deduce from this that the patient's son is hiding the confronting information the doctor gave him from his sister and giving her a rosier picture of the patient's situation so that she would continue to hope.

[Field note, Onur]

**e) Patient more positive towards relatives from his home country**

Then the uncle says: *'Will you fight for your children?'* The patient nods. The uncle continues: *'You came out of the coma, that's a sign that you want to continue, that you want to fight. Your face looks better.'* Then the patient shakes his head and lowers his eyes. (...) Then the patient's brother comes into quarantine. He flew over yesterday from Morocco. When he asks the patient how he is, the tone is more cheerful. The patient lifts his hand into the air and makes small, successive striking motions in the air, with which he means to indicate that his medical situation is improving. The brother laughs and says he saw him a while ago in a coma and that he is pleased he is now awake and eating. So he says to the patient that he sees clear progress. It is striking that the patient says to his brother who has flown over from Morocco that he is better, whereas he tells his wife and uncle that he is not doing well. [field note, Abdallah (died in the ICU)]

## 5. NEED TO PARTICIPATE IN END-OF-LIFE DECISION MAKING

### a) Verbal and non-verbal communication by patient

I ask him (the patient) if he is okay. He shakes his head, indicating 'no', then breathes in and out loudly. He looks like a fish gasping for air. He means by this that he has difficulty breathing, even with the machines. He points to the machines. He looks angry and very sad at the same time. (...) He strikes the air with his hand, a gesture that I believe means he wants to give up. He points to the machines again and says '*that's useless*'. (...) The patient sighs and looks really contorted. I ask in French if he is in pain. '*Vous avez mal*'? He nods and points to his chest.

[Field note, Abdallah]

### b) Patient seen as incompetent by staff

I see the doctor walking into the unit. I go over to him for a moment and tell him about the patient's panic attacks. He says: '*That is normal, because he has already been in here for three months... We can hardly tell his body it has to stop... And even if the patient or family wanted us to stop treatment, we couldn't comply with that....*' I ask him: '*Why not?*' He replies: '*The patient and his family are not competent to decide because they are in a phase of pain and emotion... If we say we are going to continue, we will continue...*

[Field note, Abdallah]

### c) Saving the patient as doctors' mission

**Nurse:** And I think he had indicated a couple of times himself that he had had enough.

**Researcher:** How did he indicate that?

**Nurse:** Yes, by actually, erm by saying, and by saying "It doesn't help, does it! Don't do that, it doesn't help!" He said that very often at the end.

**Researcher:** And who did he say that to then?

**Nurse:** He said it to me a couple of times. (...) He definitely said to me: "Just leave it like this, it's not going to, you know..." Erm, but even helping to decide "We're going to stop!" I don't think he did that. (..)

[..]

**Researcher:** Erm, and did you talk about that to other people, about the fact that the man told you he would prefer the treatment to stop?

**Nurse:** Yes. Yes. We do tell each other that. Yes, I did say it to my colleagues, and to the doctor as well, that he wanted, that those words had been said and that that... Well it's heartbreaking, isn't it, because, well, somehow you know he's right but, you still do it, don't you.

**Researcher:** Yes. And how did the doctors react to this?

**Nurse:** It wasn't easy. Because the doctor also had real difficulty with it, to take the decision to let him go. Yes. I think, well, at times like that, still not being able to admit it and saying anyway "We're going to keep going".

[Interview Nurse Vanessa]