

“So you think I’ll survive?”: a qualitative study about doctor-patient dialogues preceding high-risk cardiac surgery or intervention

M A Schaufel,^{1,2,3} J E Nordrehaug,^{2,3} K Malterud⁴

¹ Department of Public Health and Primary Health Care, University of Bergen, Norway; ² Department of Heart Disease, Haukeland University Hospital, Bergen, Norway; ³ Institute of Medicine, University of Bergen, Norway; ⁴ Research Unit for General Practice, Unifob Health, Bergen, Norway

Correspondence to: Dr Margrethe Aase Schaufel, Department of Public Health and Primary Health Care, University of Bergen, PO Box 7804, N-5020 Bergen, Norway; margrethe.aase@isf.uib.no

Accepted 7 April 2009
Published Online First
29 April 2009

ABSTRACT

Objective: To explore doctor-patient interactions and decision-making processes before high-risk cardiac surgery or intervention with special attention to existential challenges.

Design, setting and participants: We conducted a qualitative study with data drawn from doctor-patient dialogues preceding high-risk procedures. The study setting was the cardiac department of a university hospital with 24-hour emergency service. We recruited a purposive sample of 10 patients and eight doctors. The patients were categorised as high-risk patients in accordance with EuroSCORE and established angiographic procedural high-risk criteria. Transcripts from the dialogues were analysed with systematic text condensation, inspired by discourse analysis.

Main outcome measure: Accounts of doctor-patient interaction reflecting existential aspects of the decision-making process.

Results: The main existential concerns identified in the doctor-patient interactions were surviving uncertainty, negotiating responsibility and trusting the doctor’s proficiency. When handling uncertainty, doctors imparted complex information about risk, warnings and recommendations, while patients sought and trusted the doctors’ advice. Though the decisions were made in asymmetrical power relations, they were based on a shared responsibility discussed and defined throughout the dialogues. The patients expressed a profound confidence in the doctor’s ability to get them through the high-risk treatment and give the best help possible.

Conclusions: Uncertainty, mortality, responsibility and trust are fundamental existential issues concerning both patients and doctors before high-risk procedures, with an impact on decision-making processes. Increasing focus on underlying existential conditions, ethical reasoning and power relations in medical education may improve the quality of shared decision-making and informed consent related to high-risk treatment.

Though modern Western medicine parades numerous health improving innovations, it has been criticised for lacking basic qualities and adequate competence when faced with the suffering patient.^{1–2} As a consequence, research has gradually focused the challenges of clinical communication and care beyond the biomedical aspects,^{3–4} including existential dimensions.^{5–7} Existential philosophy provides conceptual tools for understanding vital dimensions of the clinical interaction. Existentialism is the philosophy of the 19th and 20th century describing and exploring the concrete, basic and universal conditions of human existence.

Yalom emphasises, for example, death, freedom, isolation and meaninglessness as the main existential concerns in psychotherapy,⁸ while Vetlesen includes mortality, vulnerability, dependence, existential loneliness and relational fragility among his basic conditions of human existence.⁹

Existential distress is a complex phenomenon that may be difficult to distinguish from spiritual and psychological issues. The clinical relevance of existential distress has been acknowledged in caring for terminally ill cancer patients,¹⁰ end-stage heart failure, amyotrophic lateral sclerosis and dementia.^{11–13} Existential perspectives may enhance understanding of patients with HIV infection, stroke and heart attack.^{14–16} Yet, doctors and nurses encountering the challenges of life and death may find it difficult to address such themes.

To develop knowledge about challenges related to clinical interaction involving existential issues, we have studied medical situations where life/death aspects are particularly present. We wished to combine our experiences of treating critically ill patients at a cardiac department (JEN and MAS) and in general practice (KM) with our interests in dialogue and existential philosophy.

OBJECTIVE

We set up a study to explore existential challenges of doctor-patient interaction and decision-making processes before high-risk cardiac surgery or intervention.

METHODS

We conducted a qualitative observational study based on dialogues between patients with serious heart disease and their doctors.

Study setting

The study took place at the cardiac department of a university hospital with interventional and surgical expertise, performing approximately 1500 percutaneous coronary interventions (PCIs) and 650 open heart operations a year. Participants in the study were enrolled among patients who were eligible for high-risk percutaneous coronary intervention or cardiac surgery. Decisions of offering high-risk treatment are usually taken at a daily meeting between highly experienced interventional cardiologists and cardiothoracic surgeons. The doctor informing the patient represents this forum where alternatives, probable outcome and risk have been discussed. There are no standard information procedures concerning high-risk treatment, but either the operator, the doctor in charge on the

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ward, or both, inform the patient. Patients who are considered competent for consent are expected to accept or decline the offered treatment, and some of them are even recommended to write their testament.

Participants

Ten patients were recruited; two of them women, all categorised as high-risk patients in accordance with established guidelines and scores. We set logistic EuroSCORE (operative mortality) of >10% as cut-off for high-risk surgery.^{17 18} In addition, patients undergoing percutaneous coronary interventions ($n = 4$) had to fulfil at least one procedural risk criterion: LMS (left main stem) disease, proximal LAD (left anterior descending artery) lesion and/or EF (ejection fraction) <35% if intervention on main artery not supplying infarcted myocardium.¹⁹ A purposive sample aiming for diversity was searched for, regarding patients as well as doctors. Logistic EuroSCORE varied from 9.4% to 33%, and was above 20% in six patients. A man with score of 9.4% was also included because there was consensus among the doctors that he was a high-risk patient despite a value below 10%. Nine patients had present, recent or previous acute coronary syndromes, five had left main stem disease, all had multivessel disease, six significant valve disease and seven peripheral or cerebral artery disease with previous ischaemic attack. Eight patients were aged between 70–80 years. A relative was present during one conversation. The doctors informing the patients were either residents or specialists in general cardiology, interventional cardiology, cardiothoracic surgery or internal medicine. They were aged 30–60 years, one of them was a woman, and two of them participated in two different conversations.

Data collection

Qualitative observational data from dialogues preceding decision about treatment were collected from October 2007 until July 2008. The conversations lasted 6–16 minutes and were situated at the bedside, in an examination room or in a doctor's office. When a high-risk patient was admitted to the department, information about this was obtained from the doctor, from operation lists or through discussions at a daily meeting between the cardiothoracic surgeons and the interventional cardiologists which MAS attended as a resident. The purpose of the subsequent conversations was to inform patients about treatment options and elicit consent for the intervention agreed upon by patient and doctor. Patients who had been thoroughly informed earlier during their hospitalisation were excluded. All the patients had been examined by coronary angiography before this dialogue, and were either informed by the operator or the doctor in charge on the ward. Informed consent was obtained from all participants. All dialogues were audiotaped and transcribed verbatim. Data collection was closed when saturation was achieved, in the sense that new main issues did not appear in subsequent dialogues. Approval had been obtained from the Regional Committee for Medical Research Ethics and the Norwegian Data Inspectorate.

Analysis

Qualitative analysis was performed in collaboration by the authors. Supported by existential philosophy, we looked for patterns of existential basic conditions identified in the dialogues from this specific clinical context. Existential basic conditions are universal characteristics of human life,

comprising fundamental phenomena we cannot avoid or escape as human beings.^{8 9}

Discourse analysis^{20–23} and pragmatic linguistics²⁴ provided perspectives and tools for regarding talk as action and exploring how this action can constitute reality. Discourse analysis is a multidisciplinary tradition with a wide range of approaches, here applied as an analytical perspective focusing how ways of talking about a matter can inform us about the cultural context of the actual matter, such as which kind of issues are legitimate themes, or what kind of action the words perform. Nessa developed a procedure for analysis of clinical interaction based on pragmatic linguistics.^{25 26} Nessa's procedure consists of a systematic review and interpretation of the speech acts in a medical discourse—what is done by what is said—in the transcript, condensing the full transcript to a synopsis.

Our analysis started by making a Nessa synopsis of the first five dialogues obtained where the main verbal activity and speech acts were identified, keeping the existential basic conditions in mind. Main categories were then developed from the synopsis following the procedures of systematic text condensation.^{27 28} We proceeded through four stages: reviewing the whole text to identify themes, coding units of meaning, abstracting the meaning and finally summarising the content within the coded groups to generalised descriptions and concepts. Before coding, MAS and KM separately read the synopsis bracketing previous preconceptions, identifying six relevant issues (worry, support, uncertainty, exposure, gambling and responsibility). The categories used for coding were then elaborated, and finally a summary of the descriptions and concepts reflecting the most important phenomena observed was developed. Analysis was done stepwise with new conversations supplementing the sample in full text transcription. We used an editing analysis style²⁹ where categories were developed from the empirical data, not in a theory-driven template analysis style from predefined theoretical concepts.²⁹ Our findings reflected patterns of existential basic conditions relevant for this special context.

RESULTS

The main existential concerns identified in the doctor-patient interactions were surviving uncertainty, negotiating responsibility and trusting the doctor's proficiency. When handling uncertainty, doctors imparted complex information about risk, warnings and recommendations, while patients sought and trusted the doctors' advice. Though the decisions were made in asymmetrical power relations, they were based on a shared responsibility discussed and defined throughout the dialogues. The patients expressed a profound confidence in the doctors' ability to get them through the high-risk treatment and give the best help possible. Quotations illustrating the findings are presented from the full-text transcripts.

Surviving uncertainty

Uncertainty and worries concerning survival were expressed both by the patients and the doctors. Assessing and communicating the risk of death and other complications with or without treatment constituted a substantial part of the dialogues, and both sides had to deal in different ways with the related uncertainty. While patients were facing the possibility of losing their life, doctors had to cope with the risk of taking or harming the life at stake when trying to save it. The interaction in handling these dramatic aspects consisted of the doctor's extensive and complex information about the patient's

medical condition, risk and possibilities leading to an agreement often based on the doctor's recommendation:

Sam (doctor): "All in all this means that you've got a risk of getting serious complications undergoing surgery."

Vincent (patient): "During surgery?"

Sam (D): "Yes, during and after surgery, meaning you can die from it and you can get other serious stuff, with long-lasting respirator treatment and stroke and bleedings and dramatic stuff."

Vincent (P): "Mm."

Sam (D): "Our basic judgment is that your risk of dying within not too many months or years untreated is greater than the risk regarding an operation."

Vincent (P): "Ok."

Sam (D): "So that's why we're basically clear regarding the recommendation."

No guarantees of a positive outcome could be made, and the patients' conditions were life threatening and for some of them unbearable. The doctors weighed and balanced the different arguments back and forth, illustrating the dilemma to the patient. Yet, when the doctor warned against refusing the offered treatment and at the same time carried out the obligation of warning against the recommended surgery or intervention, the patients' choice and uncertainty seemed even more difficult to handle. The meaning of risk was then elaborated on, and the doctors tried to explain the different aspects to the patients. These assessments were not easy to understand, though, illustrated by a woman with severe aortic stenosis who was facing high-risk surgery:

Helen (P): "So you think I'll survive?" (laughter)

Luke (D): "Yes. Like I said, we think so and hope so. But the risk that something happens exists, it sure does."

Helen (P): "Yes, no, it's—"

Luke (D): "As mentioned, stating percentages, it's somehow like—it's of good use to us, because then we know how to categorise, but to each individual patient it's difficult to get a percentage of risk."

Helen (P): "Yes, yes."

Luke (D): "But the risk is high."

Helen (P): "Exactly."

Luke (D): "But as I said, the risk is absolute if we don't do anything."

When the doctors were unsure of what to do and expressed uncertainty, warnings and hesitation, some patients revealed a steady belief in surgery or intervention despite the uncertain outcome and unclear recommendation. The choice of using the best means available instead of just watching the situation getting worse seemed apparent, but on the other hand the risk of death and complications related to high-risk procedures was considerable. In some situations the desperate call for action overshadowed the uncertainty of outcome and operative mortality, like with this patient who actually died before even reaching the operating room:

Jonathan (D): "The case is, we don't have any alternatives if we're going to help you."

Neil (P): "No."

Jonathan (D): "We can't say that medical treatment is just as good, because it isn't."

Neil (P): "No, I guess it's not" (...)

Jonathan (D): "So we've got our back against the wall, you could say. (...) Because we don't know—There are two things that are most uncertain. One: how strong is your heart—is it capable?"

Neil (P): "Yes."

Jonathan (D): "Two: there is a risk of stroke connected with these operations." (...)

Neil (P): "Yes, well, I think I'll immediately say yes to a heart operation, or a valve operation."

Negotiating responsibility

Another main theme in these dialogues was the interaction on responsibility. Who was to be in charge of the crucial decision and of the uncertain consequences was not always clean-cut. The negotiation between patient and doctor was affected by how concurrent their choice of action would be and how the participants handled the power relation. Some of the patients explicitly said that the doctors should decide, because they had the knowledge to make the proper choice. The doctors, on the other hand, gave the responsibility back to the patients and made it clear that they had to make up their own mind even though the issues were difficult and complex, illustrated like this:

Luke (D): "But we cannot make that decision for you, because there is a great risk that the operation might not go well." (...)

Helen (P): "Yes, no, you decide, I won't say anything."

Luke (D): "No, it is a difficult—"

Helen (P): "It's got to be the ones who understand it." (...)

Luke (D): "If I understand you properly, then you are willing to undergo surgery if we think it's medically—"

Helen (P): "Yes. Exactly. You are the ones to decide."

Luke (D): "Yes—we can only give advice and recommendation."

Helen (P): "Yes, yes, of course."

Luke (D): "And in the end it's for you to decide."

Other patients were more aware of their responsibility and right to choose or not to choose a potentially dangerous treatment. Several patients had experienced loss of physical abilities, meaning, energy and identity. With no prospects of other effective treatment like for instance medication, they were willing to risk their lives for the chance of health improvement. They stated that if something could be done, let it be done, and the doctors were asked in clear terms to make this choice possible by carrying out the treatment, like this man in his 70s, who said:

William (P): "The torments are so immense; I cannot even climb the 12–13 steps in my basement staircase."

Ryan (D): "Yes, we understand that. And like I said, you're conscious about this and you're a sensible man and can choose for yourself. And if you choose to undergo surgery, we'll do it."

William (P): "Yes, if I don't get surgery or become better, then I'll quite simply fade away."

Ryan (D): "Yes, that's clear, good words."

William (P): "I'll quite simply fade away."

Ryan (D): "Yes, that's clear words."

William (P): "Because sitting in an armchair watching TV and be reluctant to go outside when there's a strong breeze, that's not who I am."

The doctors were willing to offer and perform potentially life-threatening treatment and even recommending it in situations where the patients were critically ill and presented an attitude favouring surgery or intervention and understanding of risk. They themselves also had to be convinced there was a fair chance of success. These prerequisites made it possible to carry out the tough and risky task in a responsible way. Thus, the patients were in charge of wanting and the doctors were in charge of informing about and carrying out the high-risk

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treatment in a very asymmetrical interaction of responsibility, illustrated like this:

Jack (D): "But I do have to say that the complication I was talking about might cause a big heart attack, which can lead to a long hospital stay or that you perhaps won't make it."
 Philip (P): "You ask me what I want to do?"
 Jack (D): "Yes, if you are willing to take that risk."
 Philip (P): "Yes."
 Jack (D): "You are?"
 Philip (P): "Yes." (...)
 Jack (D): "We are willing to carry out the intervention, but the prerequisite is that you are willing to take a somewhat greater risk than normal."
 Philip (P): "I'll sign right away."

Trusting the doctor's proficiency

Most of the patients in this study expressed a fundamental confidence in the doctors, their competence and their intentions. They listened carefully to the professional advice and were ready to accept the recommended option, convinced that the best solution was pointed out for them. The basic interaction handling the uncertain and threatening aspects of the situation was the doctors suggesting a deliberate plan and the patients entrusting themselves to it, like this man in his late 70s:

Kevin (D): "You've got what we call a dangerous heart disease that consequently can reduce your expected lifetime."
 George (P): "Yes."
 Kevin (D): "And maybe we can do something about that, but what we primarily think we can do is to relieve some of your torments in terms of breathlessness, by means of stenting. Then we'll have to see if a heart starter is recommended in addition. I think we'll have to take that discussion afterwards."
 George (P): "Ok, that's fine."
 Kevin (D): "Have we reached an agreement, then, me and you?"
 George (P): "Yes, I believe in you."

As a contrast, a few patients were a bit more sceptical or reluctant to accept right away what was presented to them, both facts and recommendations. Since there were no straightforward answers to what should be done in many cases, the solution to the patient's problem as well as the confidence and alliance between patient and doctor had to be evolved throughout the conversation. Yet, exposing their worries, doubts and vulnerability in front of a professional whom they barely knew demonstrated the patients' trust and the doctors' competence providing a confidential atmosphere, like this woman in her 70s confiding in her female doctor:

Veronica (P): "Because I've been thinking: imagine if something goes wrong, and that I'll turn out as a vegetable afterwards, right?" (...)
 "Yes, I've been terribly frightened of that, because today it's still functioning, and I'm still working."
 Melanie (D): "Yes."
 Veronica (P): "Yes. And it would be terribly sad to become sitting."
 Melanie (D): "Yes, exactly."
 Veronica (P): "That my grandchildren would say: 'Shall we go visit the cabbage head?'" (laughter)
 Melanie (D): "Yes, we'll have to try avoiding that." (more laughter)

DISCUSSION

Studying dialogues between patients and doctors preceding high-risk treatment, we found that both sides had to cope with

and communicate uncertainty and responsibility in different ways. Below, we discuss the strengths and limitations of the study design and the impact of our findings.

Validity and transferability

The dialogues we studied took place as naturally as possible where the patients were situated on the ward. However, the audio-recorder and the preceding process of recruitment inevitably influenced the participants. Yet, our aim was not to evaluate the quality of authentic dialogues, but to explore existential issues that might appear in this kind of clinical interaction. Thus, we consider our data to be sufficiently relevant and valid for the purpose.

To ensure the recording of these kinds of dialogues be ethically justifiable, the quality of the informed consent process and confidentiality were of the utmost importance. The patients were immediately excluded from the study if they deteriorated right before or during the recording, which happened once. The doctors were asked to participate in a manner that was not always possible to conceal from their colleagues, and those who participated had to be aware of and accept that.

The dialogues were obtained from a cardiac department at one hospital, contained mostly men and had a patient sample of high age. Even so, the participants had a varied background of education and religion, and the doctors were of various ages. The fact that the doctors were recruited from as different positions as surgery, internal medicine, general and interventional cardiology, as well as residents and specialists, adds transferability to our sample. This indicates that our findings may be applied in other areas of medicine dealing with life/death decisions and high-risk treatment.

Unconditional trust under pressure

Our findings are consistent with previous research demonstrating the difficulties and challenges of decision-making in different areas of modern medicine like neonatal³⁰ and critical care.³¹ The communication of risk and uncertainty in medical practice has been investigated both theoretically and empirically,³²⁻³⁴ also regarding cardiovascular disease.³⁵⁻³⁷ Existential aspects on risk perception have been outlined,³⁸ illustrating the possible benefits of analysing underlying existential distress. Our study adds to previous knowledge by presenting empirically based descriptive aspects of the doctor-patient interaction regarding uncertainty, mortality, responsibility and trust. Approaching these phenomena from an existential point of view, we found that patients and doctors, respectively, made an effort trying to survive and defeat uncertainty and mortality. Through a short discussion patient and doctor seemed to agree on their separate but essential parts of responsibility, though it was not always easy to accept or define. Trusting the doctor's proficiency seemed to be of fundamental importance for the patients coping with their critical situations, and made them literally put their lives in the hands of the doctors.

Treating critically ill patients includes decision-making processes regarding life and death, which inevitably involve existential aspects. Communication about options, risks and benefits is essential, but challenging. The apparently unconditional trust expressed by the patient under pressure and the asymmetrical power relations deserve further considerations regarding the possibility of shared decision-making, a treatment decision-making model emphasising sharing information and building a consensus about preferred treatment based on

mutual agreement.^{31–39} The patients are totally dependent on well-considered and balanced accounts from the doctors when trying to understand their own complex situations and the best way ahead. Our data indicate that the possibility of a “truly” or “fully” shared decision-making in the complexity of modern medicine could be questionable, and that the patients have no other real option but to trust the doctor. Analysing the existential challenges of these conversations shows that both the patient’s and doctor’s perspectives are influenced by underlying existential conditions and that the decision-making process might be better understood and dealt with if some of these aspects are given attention and discussed.

Trust has been described as a basic condition of human existence, and the subsequent ethical demands have been underlined.^{40–41} When studying the ethical reasoning of health-care professionals, a core concept of “protective responsibility” has been suggested by Holm.⁴² This concept comprises the personal responsibility acquired through working in healthcare to protect the vulnerable patient against disease. Even though respect for autonomy is emphasised, the healthcare professionals see themselves as responsible and in charge of deciding what treatment is acceptable, revealing a subtle and perhaps inevitable trait of paternalism. Thus, the patients’ vulnerability and trust deserve awareness from the professionals regarding the ethical demand, “protective responsibility” and the power they possess and exercise. This calls for medical education and training to provide competence regarding power, roles and communication, specifically the impact of these issues on decision-making processes.

CONCLUSIONS

Uncertainty, mortality, responsibility and trust are fundamental existential issues concerning both patients and doctors before high-risk procedures, with an impact on decision-making processes. Increasing focus on underlying existential conditions, ethical reasoning and power relations in medical education may improve the quality of shared decision-making and informed consent related to high-risk treatment.^{43–44}

Acknowledgements: We would like to thank the patients and doctors who participated in this study, and the research network “Vulnerability as a Strength”.

Funding: This study was funded by the Western Norway Regional Health Authority.

Competing interests: None.

Ethics approval: Approval has been obtained from the Regional Committee for Medical Research Ethics and the Norwegian Data Inspectorate.

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