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Hope Work in the Care of Seriously Ill Patients

Anssi Perakyla

The interactional practices through which staff members and patients shape their medical identities as the patient approaches death in hospital are examined in this article. A recurrent conversational activity, whereby the medical identities of the patient and the staff are explicated in terms of the hopefulness of the situation, is identified and defined as "hope work." Hope work has three variants: in curative hope work, the patient is defined as "getting better"; in palliative hope work, he or she is defined as "feeling better"; and in the work to dismantle hope, the patient is defined as being "past recovery." Conflicts arise when different parties employ different types of hope work. All variants of hope work are linked to the maintenance of the legitimacy of medicine in relation to the death of the patients.

The work of Strauss and his colleagues (Corbin & Strauss, 1988; Fagerhaugh, Strauss, Suczek, & Wiener, 1987; Strauss, Fagerhaugh, Suczek, & Wiener, 1985) has broadened our under-

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408

standing about the scope and dimensions of medical work in several ways. First, they pointed out that such work consists of multiple types of activities, and they have extensively analyzed machine, clinical, safety, comfort, sentimental, and information work. Second, not all of these activities are traditionally considered as "work" by the participants or by the general public, and much of the work remains implicit and unrecorded, such as important aspects of sentimental work (Strauss et al., 1985, p. 141). Third, medical work is done not only by professionals but by kin and by the patients themselves who also contribute to the management of illness. Fourth, medical work always has a particular temporal context. The totality of medical work results in the shaping and management of "illness trajectories."

More than 23 years ago, Sudnow (1967), using different terminology, made some important observations related to the management of the end of illness trajectories. He reported that in the modern hospital "death must be made to seem an outcome of 'dying' " (p. 95). "Dying" was not a phenomenon directly determined by observation of the biomedical facts in a patient's body; rather, it was a socially constructed transitory period instituted by the medical profession's withdrawal of their active intervention and interest from the patient and through a shift into "palliative" or "terminal" care. Its timing depended on various social variables, such as the social status of the patient and the activities of relatives.

Another aspect of the management of the end of illness trajectories focuses on a particular type of medical work, usually implicit, which nevertheless seems to be essential in the management of serious illness. Staff members and patients are often engaged in intensive interactional work, which may result in a shared interpretation of the manageability of the patient's condition and the possibility of its being medically controlled.

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This interactional work, leading either to the establishment of hope or to its orderly dismantling, is called "hope work" in this article.

A key notion in the forthcoming analysis is identity, conceived as an interactional rather than psychological category. As the work of Goffman (1974) and Strong (1979, 1988) emphasized, participants in any organized interaction ascribe to each other a whole range of implicit qualities, rights, and duties. These vary according to the type or "frame" of the interaction. In this article, I analyze a frame of interaction in hospital in which the patient's identity is defined by his or her body and its processes and, respectively, in which staff members' identities are related to knowing and controlling these processes. This medical frame is applied in many everyday examination and treatment practices and conversation related to these. The identities implied in the medical frame are, of course, the core of the traditional medical version of reality, the ideal typical "biomedical model" (Mishler, 1984).

The argument is twofold. First, I wish to show how hope work is a pervasive and important aspect of hospital life. Despite the scientific and objectifying attitudes embodied in the medical frame (Mishler, 1984, p. 114), a moral dimension in the form of hope work is powerfully present in the interactions related to that frame. Second, I argue that in spite of their apparent polarity, the practices that assert hope and those that dismantle it serve the same purpose in maintaining the legitimacy and credibility of the medical version of reality.

METHOD

Data Collection

The following research results originate from an ethnographic study into the social meanings of death in hospital. Data were collected during a 10-month period of participant observation in a university hospital in southern Finland. Because the preliminary data analysis and memo writing were also undertaken during this period, the actual observation time was approximately 6 months. During that time, I spent approximately 30 hours a week on three different hospital wards. I was regarded as a staff member, and I wore the appropriate clothing (a white protective coat). My research topic (the social meanings of death) was disclosed to the staff on the wards. Patients were informed about my role as a researcher exploring the interaction between patients and staff, but they were not told about the specific topic. My daily routine as a researcher included participating in the ward rounds and in staff meetings, informally chatting with staff members and patients, and helping the nursing staff with simple auxiliary tasks.

Data were usually recorded in handwritten notes while on the wards and in the hospital library; these notes fill 1,706 pages. Some of the conversations were recorded as they took place and others within one hour. Staff meetings and formal interviews with the staff members were also sometimes recorded on tape, but these are not used in this report.

The three wards observed (leukemia, medical, and emergency) were chosen before the beginning of the observation period, in accordance with the administrative personnel who granted permission. The aim was to secure access to as wide a variety of patterns of serious illness management as possible. The leukemia ward was observed first, followed by the medical ward, and then the emergency ward.

Data Analysis

Data analysis began as soon as data were collected. The first questions about hope work (not using the term) arose in the early memos written during observation on the leukemia ward. This directed my attention to parallel phenomena on the other wards.

The final analyses of the data were undertaken after the fieldwork. The data analysis process followed an inductive pattern, not far from the "grounded theory" approach (Glaser & Strauss, 1967), and entailed a movement from single observations toward more general concepts. Hope work emerged as an underlying and recurrent theme in the observations and notes. However, theoretical concepts like "frame" and "identity," although not originating from the data, were applied alongside the concepts arising solely from the data.

Data analysis was conducted solely by the author. Reliability was controlled through rigorous hypothesis construction (Silverman, 1989). Using a sample of data as a point of departure, hypotheses were constructed at the final stage of analysis. Every effort was then made to falsify or reformulate these hypotheses, with reference to a careful reading of the bulk of the data.

RESULTS

Maintenance of Hope in the Leukemia Ward

The general atmosphere on the leukemia ward is one of great optimism and determination. When I arrived on the ward, my first impression was like joining a high-spirited and wellorganized troop that was determined to put up a fierce resistance to this evil force, this illness and the pain and suffering it causes, and, ultimately, to death itself. Everyone had their own place in this struggle—the nurses, the doctors, and the patients.

This atmosphere of hope and resistance is most obvious when the doctor is on rounds. As a part of the daily routine, the junior doctor on duty in the morning, either alone or together with a senior colleague, sees all the patients on the ward, going from room to room and from bed to bed. The doctor is usually accompanied by the ward sister or a specialized nurse. The following excerpt describes a typical conversation between the doctor and a patient on the leukemia ward:

The physician superintendent opens the conversation: "The situation seems to be more or less under control now."

A little later, the doctor and the patient exchange the following words:

The doctor says, "It won't be long till the cell count increases,2 then the medication can be withdrawn."

"So when the cell count increases, my sore throat will be better as well, won't it?" [The patient has long been suffering from a sore throat.]

"Yes, that's right," the doctor responds.

This conversation invokes the medical definition of reality. They are talking about the patient's body and its processes. The patient's identity is defined in medical terms, with the focus being on one aspect of the biological organism, the cell count, which is soon expected to increase again. But there is something very important about the way in which this medical identity is portrayed here: There are expectations of a positive development in the patient's condition. Soon, his cell count will increase, the doctor will be able to withdraw the medication, and even the sore throat will get better.

Positive interpretations abounded in conversations held during the ward rounds on the leukemia ward. The doctors frequently used such phrases as "We're doing very well," "Considering the situation we started from, we've made some very promising progress," "The situation is now under control," "If we can keep up the good work . . . ," and "We're feeling better today." The doctors seemed to mention all favorable medical developments. The patient has less symptoms, there is a clear improvement in the patient's blood count, and so forth. Although this positive attitude was by no means a rigid rule without exceptions, it dominated the conversation in the majority of the leukemia cases.

The atmosphere of hope and optimism on the leukemia ward was created and reproduced through these daily interactions, during which the patient's medical identity was constructed in a positive way from an optimistic angle. The key assertion "We are getting better" usually translated into an improved blood count and reduced symptoms, but there were also references to the more distant possibility of being completely cured:

The patient [a 30-year-old woman who had recently contracted leukemia] is talking about her job and at one point says, "if I get better." The doctor intervenes and says, "No, listen, it's always going to be when you get better."

The doctor, a nursing student, and myself are leaving the room of a male patient in his early 20s. The doctor turns around and says to the patient, "You'll be cured. You have my word for that." The patient thanks the doctor for his encouragement.

The optimism displayed by the medical profession is very often supported by the patient. In the first excerpt, the patient made the spontaneous comment that his sore throat would probably also get better when his cell count increases. All the doctor had to do was confirm this assumption. Mr. K, a patient in his 60s, also took an active part in this process:

Ward rounds, Mr. K's room. We have been talking about various things, and then the consultant explains what they still have to do. He says that on the basis of the patient's cell count, the patient could actually be discharged from the hospital, but there is still the bone marrow sample they have to examine. It will all depend on that

Mr. K asks. "So things are looking good?"

The consultant replies, "As far as the cell count is concerned, yes. Let's hope that the results of the bone marrow examination are just as good."

The patient's relatives may also play an important part in the strategy for maintaining hope. A patient preparing for a bone marrow transplant has had various unexpected complications in her treatment. After the doctor has explained what will happen during the transplant, the patient's husband, who is present in the room, takes the initiative:

"She's been doing quite well now, hasn't she? She's been a bit tired, but that's quite normal after chemotherapy and radiotherapy." The doctor confirms this, saying that many patients suffer from severe nausea at this stage of their treatment.

However, in some cases, the doctor will receive no outside support in this task of building up a positive medical identity for the patient. L is a 17-year-old boy suffering from acute leukemia:

The doctor is asking the patient about his symptoms. She takes a close look at his skin and listens to his lungs. She tells the ward sister that the medication and nutrition infusion will have to continue. Finally, she says to the patient, "Things are looking much better now. And you're feeling much better as well, aren't you?"

L responds, "Yes, I am."

The doctor then states, "But we still can't let you go home, not yet."

This patient is reluctant to take an active part in the building up of an optimistic identity for himself. In this case, it remains the sole responsibility of the doctor, who actually has to suggest that L must be feeling much better, adding the tag question "aren't you?"³

On the leukemia ward, this process of constructing an optimistic medical identity for the patient was largely based on selective references to the time span involved. The core practice seems to be to assure the patient either that his or her present condition is much better than it used to be at certain times in the past or that the present condition is bound to improve within a certain space of time. The inevitable conclusion is that the patient is getting better, however poorly he or she may be feeling at the moment or however anxious he or she may be about next week's chemotherapy. The doctors were obviously using this strategy while talking to a young male patient who had recently had a bone marrow transplant:

When leaving the patient's room, the physician superintendent turns around at the door and says, "I know it's been no merrymaking for you, but we're only doing what's best for you."

And the junior doctor adds, "You can think of it as an eve of merrymaking."

The selective reference to the time span here involves defining the present moment as an "eve of merrymaking." The implication is that a reward waiting for him in the near future will compensate for the patient's present poor condition.

When leukemia is treated with modern chemotherapy, the patient typically alternates between periods of severe symptoms and their complete absence. In most cases, therefore, the

conclusion that the patient is getting better can be based on the sound evidence of standard medical knowledge. There will obviously be better times somewhere in the future, and worse times can be found somewhere in the past. All the doctor has to do is choose a suitable time span as the basis of the comparison. But there are also situations in which the maintenance of hope in face-to-face interaction seems to depart from the definition of reality based on standard medical knowledge. The following note describes a visit to a female patient who was expected to die in the very near future (and this, in fact, happened):

The doctor says, "When you get better. . . ." [He answers the patient's question.]

"Aren't you giving any treatment for the leukemia now?"

asks the patient.

The doctor replies, "We'll have to talk about that with J [the consultant] once we get the thrombocyte count up again. Then we can start your treatment again."

Here, the basic pattern of conversation is very much the same as in the earlier cases when patients were at a less advanced stage of the disease. The doctor assures the patient that she is getting better and even talks about the treatment she will be getting. What makes this case different from most of the other cases of the maintenance of hope is that the hospital staff strongly expected that this patient was soon going to die.

The exchange of words between the doctor and the dying patient shows that the maintenance of hope is not a straightforward function of medical knowledge. In this extreme case, as well as the routine ones, shaping the patient's identity in positive terms is accomplished through negotiations between staff and patients. The patient-as-getting-better identity is produced on the spot, so to speak.

The Doctor Is in Control of the Situation

In the interactions in which an optimistic medical identity is constructed for the leukemia patient, we also find a tendency to construct an identity for the doctor and for the hospital staff 416

that is compatible with the one ascribed to the patient. The doctor's identity consists of his or her ability to control the situation, to cure the patient, or at least to alleviate the patient's symptoms.

The reciprocity of the identities of patients and doctors is implied in all the cases of maintenance of hope, and it is particularly visible in some cases. To show this reciprocity, I will first reexamine two cases already described, in which the participants explicate the doctors' identities along with the patients' identities. Then, I will present two cases that focus mostly on the doctors' identity. I begin by looking again at the first excerpt presented here, in which the physician superintendent opens the conversation by saving, "The situation seems to be more or less under control now." A little later, the doctor tells the patient, "It won't be long till the cell count increases, then the medication can be withdrawn." In his opening comment that the situation is more or less under control, the doctor is referring to his own identity; it is he and his colleagues who are in control. The same would seem to apply to what he says next: "The medication can be withdrawn." This statement implies that the doctors will soon be able to decide that the patient no longer needs any drugs.

Another earlier excerpt that we can examine from this new perspective was that in which the doctor, a nursing student, and myself are leaving the room of a male patient in his early 20s. The doctor turns around and says to the patient, "You'll be cured. You have my word for that." Here, the doctor gives his word that the patient is going to be cured, which implies that he knows how the patient's condition is going to develop in the future. The doctor is not only foreseeing but committed to bringing about the cure.

Sometimes, it is more important to stress the control aspect than the prospects of recovery. By implication, the conversation will then focus more on the doctor than on the patient. This was the case when the physician superintendent, on leaving L, the 17-year-old leukemia patient mentioned earlier whose condition had recently deteriorated, says to him, "We have to keep a close eye on how things go now." Rather than constructing a

positive patient identity, the doctor is referring directly to himself and his colleagues. We is the voice of the medical team (Silverman, 1989); it is not only this physician who is monitoring the situation but the whole team. It is up to the medical profession to keep the situation under control. Under the circumstances, this was an understandable move, as the patient was obviously reluctant to take an active part in the construction of a positive outlook, and his condition was worsening. So, instead of describing the patient's identity, the doctor concentrated on his own and his colleagues' role and identity.

Hope Work as Specification of Identities

After having examined a number of cases of the maintenance of hope in the leukemia ward, we are now in a position to summarize our findings. The construction of hope involves specification and explication of the medical identities of staff members and patients in their conversation. The patient becomes one who is getting better, and the doctor becomes one who is in control of the situation and helping the patient to recover.

Hope work, therefore, can be defined as an interactional process whereby the medical identities of the patient and the staff are explicated and specified in terms of the hopefulness of the situation. Conversation is the most important tool in hope work, and hope work is an important part of the doctors' and other staff members' jobs as well as an essential component in the work of patients and relatives.

The consistency and intensity of the explication of the participants' identities make hope work a distinct interactional activity of its own. In the ordinary encounters between people, an *implicit* understanding of participants' identities usually prevails (Strong, 1988). The obligations, rights, and qualities that are ascribed to the participants are not spelled out in an explicit manner; instead, they are taken for granted. Only very dramatic deviations from the expected identities are given attention (see Goffman, 1974). This is obviously the case in much of the routine medical interaction in hospitals: The expectations that the

418

doctor attends exclusively to the patient's body and has the knowledge to control body processes and to help the patient are taken for granted (Perakyla, 1989; Strong, 1979). But in the interactions described earlier, these identities were consistently made explicit and specified.

Why, then, is it necessary to explicate and specify the identities implicitly contained in the medical frame? Why are the implicit assumptions not sufficient, just as they are in normal encounters between people? Apart from the reasons that have to do with modern medicine in general (which will be discussed at the end of the article), the explanation can be found in the special characteristics of the leukemia ward as a social setting.

First, leukemia is a severe disease, and its treatment is a very difficult and distressing experience for both the patients and the staff. Most of the symptoms that the patients suffer from are caused by the treatment itself. Chemotherapy, the main form of treatment, makes the patients particularly susceptible to various kinds of infections; in fact, these infections keep most of the patients in the hospital. Second, the chances of recovery from leukemia are not good. Despite recent improvements in treatment programs, most patients die within the space of a few years. Consequently, the social reality of the leukemia ward is very much inclined to suffer from legitimacy problems (Berger & Luckmann, 1966). It is always possible to question the meaningfulness of all these efforts, and these kinds of doubts were often brought forth in informal contexts, especially by the nursing staff. If the parties concerned are willing to continue their work within the given medical frame, then it is necessary to continually reinforce that social reality and its plausibility. This is achieved by the hope work: specifying the patient as "getting better" and the doctor as being "in control of the situation."5

Curative and Palliative Hope

Thus far, we have confined ourselves merely to one particular social setting, the leukemia ward. During the research pro-

cess, the phenomenon of hope work was initially encountered there; however, it was also observed in other situations and other wards. Given that the illness trajectories and their management differ greatly according to the ward, it is reasonable to assume that we will also find marked differences in the hope work.

The hope work done by the staff and patients on the medical ward is occasionally very similar to that done on the leukemia ward. In daily conversations, the staff members and the patients often reassure each other that "we're soon going to get better." However, this is neither as frequent nor as systematic as on the leukemia ward. There also occurs a very different type of conversation, both between the staff and the patient and in other interactions. The following is a good example of a different type of talk. This example occurred on the medical ward during the daily rounds. The ward sister, a consultant, the junior doctor, and I were visiting Mr. N. a patient in his 70s:

Before we enter the room, we stop for a moment in the corridor. The consultant and the unior doctor exchange a few words about what has been said to the patient's relatives. The junior doctor has spoken with the patient's wife almost every day; no one has seen the patient's children, who are from the patient's previous marriage. The ward sister says that his daughter phoned this morning, and she'll be phoning again at 10 o'clock to speak with the doctor. The patient's son lives in Germany; the daughter will phone him as soon as she's spoken to the doctor. He'll travel to Finland :: the situation gets serious. The junior doctor says she had told the wife that there's not much hope, as the patient's condition is critical. The consultant asks whether she had already mentioned to the wife about their suspicions that the patient may be suffering from cancer. I seem to remember the junior doctor saving, "Not yet." The junior doctor says that the wife had wanted them to do a CT scan [a sophisticated X-ray method for detecang changes in the patient's body]. The junior doctor and the specialist doubt whether this is a good idea. They are agreed that the possibility of cancer of the liver should be taken seriously. But whether or not this is the case, there is very little they can do to help the patient, as excretion of urine is quite low. The consultant asks his doctor once more what she would suggest. She says, "There's nothing we can do to cure this patient. We won't be doing a CT scan. Besides, the patient couldn't even cope with that at the moment. It would do him no good at all." Finally, the specialist asks the junior doctor whether anyone has told the patient himself about the suspected cancer. "No," she says, "no one."

A few minutes later, the doctors and the ward sister enter the patient's room. They examine the patient and discuss his medication. As we are leaving, the consultant puts his hand on the patient's shoulder and says to him, "We're going to give you some new medicine that might make you feel a bit better." We are already at the door when the patient asks someone to turn him over. The consultant says that the nurses will soon be round to take care of him. In the corridor, we stop once more to discuss the patient's situation. The consultant says, "What we're going to do now is change his medication. His condition is critical—he may die within a couple of days. I think we should contact his relatives [children] and explain the situation to them."

The junior doctor asks, "Should we also talk to the patient himself?" and adds that perhaps he already knows. The consultant feels that this is a good idea as he might still want to say something to his children. A few more words are exchanged on whether the patient really knows he is dying. It is agreed that he probably does

In this episode, the staff members obviously expect that the patient is going to die, but nevertheless, references to a positive outlook are not altogether missing from it. However, there is clearly not the same kind of determination here as we saw on the leukemia ward. It is admitted—and even the admission is phrased in the conditional—that all the staff can do is make the patient feel a bit better. When the doctor is leaving the room, he says to the patient (creating at the same time a sense of closeness by putting his hand on the patient's shoulder), "We're going to give you some new medicine that might make you feel a bit better." The identities of the doctor and the patient are thus specified: They are now defined as "doctor who helps the patient feel better" and "patient who begins to feel better."

This same pattern of specification of identities in hope work was abundant in the staff's interactions with patients whose condition was seen as deteriorating. The staff repeatedly pointed out that they were doing this or that in order to make the patient

feel more comfortable. Sometimes, the staff would exchange similar comments among themselves, especially during ward rounds: "Although we can't do anything to stop the disease," they said, "at least we can help to make the symptoms less distressing."

This leads us to elaborate the notion of hope work. A distinction can be made between *curative* and *palliative* hope. Curative hope work leads to the specification of the identities of the patient and staff as "patient who is getting better" and "staff who are in control of the situation." In palliative hope work, they are specified as "patient who is beginning to feel better" and "staff who help the patient to feel better."

The distinction between curative and palliative hope is, of course, an ideal-typical characterization. In actual cases, the types of hope work often overlap. A palliative component is often included in the curative hope work. On the other hand, the curative aspect can be entirely withdrawn when the patient deteriorates so that the hope work becomes exclusively palliative.

Work for Dismantling Hope

In the case of Mr. N, the identities of the parties involved were specified not only through the reference to making the patient feel better but in another, very different way. Before they went to see the patient, the two doctors agreed that whether or not the patient is suffering from cancer, there is nothing they could do to help the patient; the junior doctor adds that there is no medical cure. Once they are back in the corridor, the specialist repeats his opinion: "His condition is critical—he may die within a couple of days. I think we should contact his relatives [children] and explain the situation to them."

In all the exchanges between the two doctors, the identities of both the patients and the doctors themselves are specified. But now the patient is defined as one who is past recovery, and the doctor is defined as one who cannot do anything to help this patient; he cannot prevent the patient from dying.

Conversations like this, which lead to the conclusion that there is nothing to be done, also explicate the identities of patients and staff in terms of the hopefulness of the situation. In this sense, they involve hope work but hope work of a very different kind in comparison to palliative or curative hope work. The participants are now engaged in *dismantling hope*. This is the third variant of hope work.

Work for dismantling hope is usually done regarding the curative hope, although dismantling palliative hope is also possible. Work for dismantling curative hope is undertaken at some point during the career of most critically ill hospital patients. When it is done, the doctors, family members, and sometimes the patient communicate to each other that there is nothing more that can be done to prevent the patient from dying.

The fact that palliative hope work and work for dismantling curative hope were done in the same conversation in the preceding extract was no coincidence. These two kinds of hope work are empirically and logically compatible: When curative hope is dismantled, palliative hope can be maintained. However, as speech acts, they assert different propositions and, accordingly, can stand separately and be considered as two different types of activities.

The Different Contexts of Hope Work

Hope work, in all its varieties, takes place in several different contexts: in conversations between the patients and the hospital staff, in those between the patient's relatives and the staff, and in those among the hospital staff. There is every reason to believe that it also occurs in those interactions that could not be observed in this study, namely, in conversations among the patients and between the patients and their relatives.

Curative and palliative types of hope work are much more common in the interaction between the staff and patients than in the interaction among staff members. Work for dismantling hope, then, is clearly more typical of the interaction among staff members and in their conversations with the patient's relations. However, this is merely a general tendency, for all types of hope work can appear in any context.

Conflict in Hope Work

The very existence of different types of hope work is also a potential source of conflict between the hospital staff and the patient. It is not always the case that the participants collaborate in curative hope work and thereafter move in consensus toward palliative hope work and work for dismantling curative hope. Instead, the patient or his or her family may want to pursue a different line from that of the staff. In the following brief excerpt, an elderly female patient, chronically ill with multiple diseases, describes her situation to me. She complains that she feels awful and that there is nothing anyone can do to help her, and with this sentiment, she contradicts any curative or palliative hope:

I enter the room where Mrs. H is staying. She's complaining about several conditions. Apparently, she can't breathe very well. She says that she wants to die, that hers is a pointless

Mrs. H was a determined and dramatic patient, and from the very beginning, the staff considered her a great pessimist and a difficult patient. One day, she stripped naked, arranged all her belongings in a neat pile, and then told the staff she was ready to die. At first, the staff did not want to take her seriously. The following conversation ensued during the ward rounds:

The consultant goes over to the patient and says to her, "We're feeling much better now, aren't we?"

The patient complains, "No, I'm not feeling good at all." She reports all kinds of problems: something's wrong with her eye, etc., etc. In the end, she says that her husband won't have her at home. He wants her to stay in hospital.

The doctor here starts out with a positive approach. She defines the patient as "patient who is beginning to feel better," but the 424

patient rejects this. Eventually, Mrs. H manages to get the upper hand with her own pessimistic definition of the situation, a control that is clear from the comment made by a junior doctor to the nurses on the ward: "As far as Mrs. H is concerned, we're giving you a free hand. You can try sorcery if you like—there's nothing medicine can do." Here, the doctor is doing work to dismantle hope, not so much with regard to the identity of Mrs. H as with regard to his own identity as a member of the medical profession: In his capacity as a medical doctor, there is nothing he can do to help this patient. Mrs. H died on the ward a couple of months later.

In the following case, the roles of the patient and staff are reversed. A junior doctor was telling me about the attitude of one of the patients to his own disease. This patient was mentioned earlier: He is Mr. K, who was on the leukemia ward and defined both his own identity and that of the doctors in optimistic terms. However, the treatment of his leukemia had not been successful, and he was suffering from serious infections as a result of chemotherapy. He is now on the medical ward where the two parties fail to agree on how their respective identities should be specified:

R [junior doctor] then asks me whether I have spoken to Mr. K. I say, "No, not here on the medical ward, but I did see him earlier on the leukemia ward."

She tells me the following story about Mr. K: He s not willing to give up. The doctors, R herself and C, the junior doctor from the leukemia ward, have told the patient that there's very little they can do to help him. C explained to him that there's no return to the remission stage; R herself has put it more bluntly. But Mr. K doesn't seem to want to know: "Surely we're not going to give up at this stage," he keeps saying. Both C and R feel that the best thing to do in this situation is to stop all medication so that the patient could go home, or at least minimize the amount of drugs. But Mr. K insists on having treatment. He doesn't seem to be interested in going home like the other patients.

According to the doctor, this patient is absolutely determined to retain his positive self-identity and definition of the medical profession as being in control of the situation. He is doing

curative hope work. The doctors have tried to offer a different definition but with little success. The junior doctor is clearly concerned about the situation; later on in this same conversation, she asks me to go and see this patient and "sort things out with him."

Absence of Hope Work in the Emergency Ward

Each ward observed in this study had its particular profile regarding the prevailing type and intensity of hope work. In the leukemia ward, especially in the interaction between the patients and the hospital staff, the dominant type of hope work is clearly the curative kind. Work for dismantling hope was usually restricted to situations where the patient was expected to die within a matter of days or hours, and even then, it was primarily carried on among the staff.

On the medical ward, the emphasis was more on the palliative hope work and work for dismantling hope. Moreover, this was clearly of a less dramatic and emotional nature: When a patient was expected to die, the staff would usually voice their opinion in a rather dry, matter-of-fact sort of way.

The third setting observed, the emergency ward, differed from both the leukemia and the medical ward in that there was very little hope work of any kind done. In many situations, the emergency staff were reluctant to take any explicit stand on either the fate of their patients or even on their own chances of helping them. The following conversation between the doctor on duty and the relatives of an elderly female patient who was in critical condition and under intensive observation illustrates the somewhat reserved attitude of the emergency staff toward hope work:

After his rounds, the doctor goes straight over to see the relatives of this patient: her husband and two women, apparently the patient's daughters. They're standing in the corridor; I'm listening at a respectful distance. The doctor explains the situation to them: "Her condition deteriorated, and she had to be put back on the ventilator. The combined effects of heart failure and her lung condition were too much. Now that she's on oxygen, her condition is beginning to stabilize." The relatives want to know what is going to happen next. The doctor responds by stating, "It's hard to say. You can't keep the patient too long on oxygen because that may also cause problems. The first thing we have to do is try to wean her from oxygen."

The daughter asks, "So what you're saying is that she is not going to die from this?"

The doctor says he "cannot tell for sure. It is impossible to say that for certain."

The conversation continues for a while about the unpredictability of the situation. All the time, the daughters and the husband, in particular, listen attentively to what the doctor has to say. When the conversation is over, the husband thanks the doctor very politely. The doctor seems very composed and calm as he speaks.

In this conversation, the basic identities of the participants according to the medical frame seem to be taken for granted. The patient is equated with the processes of her body; the doctor knows these processes and is trying to control them. Nevertheless, there is a great deal of uncertainty in the air about the fate of the patient. Remarkably, this uncertainty does not lead the doctor to emphasize an optimistic or a pessimistic prospect. He does not give a definite answer to the question of whether the patient will survive. The participants' identities are not specified or explicated in terms of the hopefulness of the situation.

The reason for the scarcity of hope work on the emergency ward may be related to the exceptionally short time—usually no more than 1 to 3 days—that the average patient spends there. Given this high turnover, all questions and problems related to the staff's relationship with their patients are automatically solved as soon as the patient is discharged or transferred to another ward. Questions of hope do not easily arise in such a short time.

Hope Work and the Credibility of Medicine

As already shown, the need for curative hope work seems to be most urgent when the meaningfulness of a medical intervention is easily called into question, for example, in the leukemia ward. The medical version of reality can be legitimated by positively specifying the identities of the parties involved. The function of palliative hope work can be seen from the same angle: If the hospital is not able to cure the patient, its ability to ease his or her suffering nevertheless maintains the legitimacy of the medical version of reality.

Is not, then, the third type of hope work, the one dismantling hope, concurrently undermining the medical version of reality? The medical frame is based on a mutual understanding that the doctor knows what is happening in the patient's body and is capable of controlling those processes; work for dismantling curative hope, by contrast, points specifically to the lack of control on the part of the medical profession.

In some situations, the work of dismantling hope by hospital patients and their relatives will indeed undermine the credibility of the medical frame. This seemed to be the case in the example where Mrs. H contradicted the positive interpretation of the nursing staff. On the other hand, this kind of hope work, when done by the staff itself, generally serves to strengthen the credibility of the medical frame.6

The case of Mr. N illustrates how work for dismantling curative hope can strengthen the medical frame. Soon after the doctors and the ward sister had left his room, someone (apparently a relative) phoned the ward and asked how the patient was doing:

The junior doctor is saying that on the basis of some examination they are assuming that the patient has cancer of the liver and metastases in the lungs. He is "beyond treatment. . . . It would be good if you could come down to the hospital." The doctor says the patient is conscious.

As the doctors had agreed during their rounds, the patient's relative is told that there is nothing more than can be done. During their rounds, the doctors had been working to dismantle hope among themselves; now the junior doctor is doing that work in relation to the patient's relative. The expression she uses, "beyond treatment," gives a hint about the function of this work. It is a phrase often used in similar situations.

"Beyond treatment" implies that hospital patients fall into two categories: those who are considered to be within the boundaries of treatment, and those who are not. The former is, of course, the usual case, and here, the credibility of the medical frame will not be called into question. Patients who are "beyond treatment" represent a special case where the normal medical identities are not applicable. This does not, however, affect the applicability of these identities in the case of those patients who are not "beyond treatment." In other words, work that dismantles hope serves to strengthen the medical frame by specifying those patients to whom the regular medical identity is not applicable as being in a special category of their own.

In this connection, it is interesting to refer to the accounts that staff members gave about their emotional responses to the deaths of patients. In their descriptions of how they felt about death, the nursing staff repeatedly pointed out that they were far more upset by unexpected deaths than by expected ones. It is always a shock when a patient who has not been expected to die suddenly does die.

This experience, which was widely shared by the nursing staff, points also to the need to specially categorize the patients to whom the regular medical identity is not applicable. If a patient dies unexpectedly, the staff will usually not have categorized him or her as being "beyond treatment." Therefore, unexpected deaths form a serious threat to the implicit moral and cognitive order of the medical frame, which is used by the staff to understand what is happening in the patient's body and to feel in control of those processes. However, if there has been enough time to redefine the patient's and doctor's identities through dismantling curative hope, then the deteriorating patient will be seen as an exceptional case whose death is merely a logical consequence of the "publicly known" state of affairs.

Basically, then, the point of dismantling hope is that it helps the participants to collectively orient to the death of the patient before it actually happens. In this way, work for dismantling hope presents the patient's death as a social fact before the patient dies in the biological sense. When the social goes before the biological, then the biological, when it is time for it, can no longer threaten the social. Consequently, the medical frame, as a social arrangement, remains unchallenged.

Medicine and Mastery

Defining and redefining the identity of the dying person may very well be a part of death rituals in all societies (see Huntington & Metcalf, 1979). However, the very intensity of hope work in the modern hospital may also tell something in particular about the institution of modern medicine and contemporary society. It has been pointed out by several writers that in Western societies and in our system of medicine, there is inherent the principle of man's mastery over nature. Death is associated with "nature," and concurrently, health is seen as man's triumphant battle against death (Aries, 1982; Illich, 1977; Juul-Jensen, 1983; Vuori, 1979). For such medicine, dying can only represent a disruption in the expected course of events.

Tentatively, the wider function of hope work can be related to these characteristics of Western medicine. The disruption caused by dying can be minimized by active hope work. In a sense, curative and palliative hope work extend the area governed by the principle of medical mastery toward the area dominated by nature and death. They reestablish the principle of mastery once it has been called into question. Work for dismantling hope, then, has the function of demarcating the boundary vis-à-vis death: There are some patients who form exceptions to the principle of mastery. Work for dismantling hope appears as an orderly means of giving up these patients to "nature."

DISCUSSION

The analysis presented in this article complements those done earlier by Strauss and his colleagues (Strauss et al., 1985). An additional type of implicit work that is done by medical

professionals, patients, and their family members alike has been identified. More important, the foregoing analysis has shown the central place of conversation as a tool in hospital work (see Drew & Heritage, 1991). Most aspects of medical work require at least some use of language, written or spoken. What is particular to hope work is that it is accomplished solely through conversation.

In terms of the frame analysis, our results have identified an environment in modern society where there prevails a chronic "vulnerability" (Goffman, 1974) of an otherwise well-established frame. Hope work is needed to restore the stability of the medical frame in the face of death. In more technical terms, these results show how simple conversational devices are used to restore a shaken frame and how speech activities, which on the surface appear as contradictory (curative hope work vs. work for dismantling curative hope), can serve the same function in terms of the maintenance and reproduction of frames.

In relation to the classic observations by Sudnow (1967), I hope to have shown how the socially constructed transitory period between life and death extends beyond the final phase of "dying." Social anticipation of death involves more than mere withdrawal of the (medical) interest in the patient. Before categorizing the patient as "dying," there can be a period when the opposite categorization is reinforced through curative hope work.

Finally, in terms of the practical implications of this study, I hope to have shown how pervasively present the phenomenon of hope work is in the care of seriously ill patients in modern hospitals. It is an essential part of the job of doctors and nurses and other hospital staff; it is also a skill in the same sense as any other professional skill. Different types of hope work are typically done in different situations. It is part of the professional competence of the doctors and nurses to know when and where and to what extent any type of hope work is required. There are various relevant factors influencing decisions about this work: the type and the stage of the illness, the activities of the other parties involved, and organizational context.

However, there is a question of how thoroughly the staff members have recognized the pervasiveness of this phenomenon in their own activity. The observations on which this study is based cannot fully answer this question, but some comments can be made.

As has been argued elsewhere (Labov & Fanshel, 1977), persons producing talk may not always be aware of all the delicate implications of their speech acts. This may be the case in much of the curative hope work: It is not necessarily always recognized as a distinct activity by the people who are engaged in it. They may consider themselves as talking merely about "facts," when actually their speech acts are doing the work of reinforcing curative hope. If this is left unrecognized, the curative hope work may continue even when the staff's own professional ethos would not accept it. In turn, this may lead to a confusion among patients and their relatives. Therefore, staff should become even more self-conscious and reflexive in their use of these linguistic practices and recognize them as an essential aspect of their professional conduct.

This article made some comparisons regarding the intensity and the type of hope work in different medical settings. A further analytical task would be to outline the differences between the hope work done by different professional groups. The differences between the official tasks and professional traditions would suggest that the nurses' contribution focuses on the palliative hope work, whereas the doctors concentrate in the curative one. However, this distinction remains to be examined.

NOTES

1. This is not at all to say that these identities apply to all interaction in hospitals. As I have shown elsewhere (Perakyla, 1989), other "frames" of interaction maintain psychological and "lay" versions of patients and staff members.

2. The increase in cell count refers to such improvements in the patient's blood count that will also bring an improvement in his or her general condition. The leukemia patient's cell count decreases during chemotherapy, which usually results in a high temperature and other similar symptoms. Shortly after this treatment, the cell count will start to increase again.

3. Note that in a Finnish conversation, the use of tag questions like this is not as commonplace as it is in English conversations. Thus this tag question conveys a much stronger invitation for the patient to agree than it would in English.

4 In this article, a distinction between different professional groups has not been made. Most of my observations on hope work concentrated on the doctor-patient

interaction, which is reflected throughout the article.

5. Silverman (1989) reported a "congratulatory mode" in the interactions between doctors and parents after a successful pediatric heart surgery. In the consultations analyzed by him, the doctors and parents regularly emphasized the child's excellent recovery and the competence of the medical team. The specification of the medical identities was then of the same kind as the one on the leukemia ward. But the function of the moral work in pediatric cardiology seems to be different from that done on the leukemia ward. According to Silverman, the mutual congratulations had a normalizing function: The child was moving away from the scope of the medical frame. In the leukemia ward, the moral work served to maintain the legitimacy of that frame.

6. In theory, of course, there is nothing to stop the hospital staff from using the work for dismantling hope to undermine the credibility of the medical frame, but in practice, there tended to be widespread consensus among the staff that when they resorted to such work, its function was to strengthen the medical frame in ways that are examined

in this article.

REFERENCES

Aries, P. (1982). The hour of our death. New York: Vintage.

Berger, P., & Luckmann, T. (1966). The social construction of reality. London: Allen Lane.

Corbin, J. M., & Strauss, A. (1988). Unending work and care: Managing chronic illness at home. San Francisco: Jossey-Bass.

Drew, P., & Heritage, J. (Eds.). (1991). Talk at work. Cambridge: Cambridge University Press.

Fagerhaugh, S., Strauss, A., Suczek, B., & Wiener, C. (1987). Hazards in hospital care. San Francisco: Jossey-Bass.
 Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies

for qualitative research. New York: Aldine.
Goffman, E. (1974), Frame analysis: An essay on the organization of experience

Goffman, E. (1974). Frame analysis: An essay on the organization of experience. Cambridge, MA: Harvard University Press.

Huntington, R., & Metcalf, P. (1979). The celebrations of death: The anthropology of mortuary ritual. Cambridge: Cambridge University Press.

Illich, I. (1977). Medical nemesis: The expropriation of health. Harmonsworth: Penguin.

Juul-Jensen, U. (1983). Det klinisk arbejds filosofi og videnskabsteori. Köbenhavn: Rhodos.

Labov, W., & Fanshel, D. (1977). Therapeutic discourse: Psychotherapy as conversation. New York: Academic Press.

Mishler, E. (1984). The discourse of medicine: Dialectics of medical interviews. Norwood, NJ: Ablex.

Perakyla, A. (1989). Appealing to the "experience" of the patient in the care of the dying. Sociology of Health and Illness, 11(2), 117-134.

Silverman, D. (1989). Telling convincing stories: A plea for cautious positivism in case studies. In B. Glassner & J. Moreno (Eds.), The qualitative-quantitative distinction in the social sciences (pp. 57-77). Dordrecht: Kluwer.

Strauss, A., Fagerhaugh, S., Suczek, B., & Wiener, C. (1985). Social organization of medical work. Chicago: University of Chicago Press.

Strong, P. M. (1979). The ceremonial order of the clinic: Parents, doctors and medical bureaucracies. London: Routledge & Kegan Paul.

Strong, P. M. (1988). Minor courtesies and macro structures. In P. Drew & A. Wootton (Eds.), Erving Goffman: Exploring the interaction order (pp. 228-249). Cambridge: Polity Press.

Sudnow, D. (1967). Passing on: The social organization of dying. Englewood Cliffs, NJ: Prentice-Hall.

Vuori, H. (1979). Lääketieteen historia—sosiaalihistoriallinen näkökulma [The history of medicine—A social history perspective]. Jyväskylä: Gummerrus.

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