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So I'm down to this
I'm down to walking on air
And you're here by my side

Complex – Gary Numan

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Complexities in euthanasia or physician-assisted suicide as perceived by Dutch physicians and patients' relatives

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ABSTRACT

Background

The practice of euthanasia and physician-assisted suicide (EAS) is always complex, but some cases are more complex than others. The nature of these unusually complex cases is not known.

Aim

To identify and categorize the characteristics of EAS requests that are more complex than others.

Methods

We held in-depth interviews with 28 Dutch physicians about their perception of complex cases of EAS requests. We also interviewed 26 relatives of patients who had died by EAS. We used open coding and inductive analysis to identify various different aspects of the complexities described by the participants.

Results

Complexities can be categorized into relational difficulties — such as miscommunication, invisible suffering, and the absence of a process of growth toward EAS — and complexities that arise from unexpected situations, such as the capricious progress of a disease or the obligation to move the patient. The interviews showed that relatives of the patient influence the process toward EAS.

Conclusion

First, the process toward EAS may be disrupted, causing a complex situation. Second, the course of the process toward EAS is influenced not only by the patient and his/her attending physician but also by the relatives who are involved. Communicating and clarifying expectations throughout the process may help to prevent the occurrence of unusually complex situations

INTRODUCTION

The international debate surrounding euthanasia and physician-assisted suicide (EAS) primarily focuses on whether the performance of EAS is ethically acceptable. The pros and cons are defended in ethical discussions, and the general public in Western Europe is becoming more and more accepting toward the justification of EAS in certain situations and under specified conditions.(1) In The Netherlands, if a case meets the due care criteria (Box 1), the physician will not be prosecuted for granting the patient euthanasia (by administering lethal drugs) or physician-assisted suicide (by providing lethal drugs).

Box 1 Dutch due care criteria for the performance of EAS(2)

1. *The attending physician has to come to the conviction that the request from the patient is voluntary and well considered.*
 2. *The attending physician has to come to the conviction that the suffering of the patient is unbearable and without the prospect of improvement.*
 3. *The physician must inform the patient about his/her situation and prospects.*
 4. *There are no more reasonable alternatives for the patient.*
 5. *The physician must consult at least one other, independent physician.*
 6. *The physician must terminate the patient's life or provide assistance with suicide with due medical care and attention.*
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Since this law became effective in 2002, the frequency of EAS has remained at around 1.7-2.8% of the total deaths.(3) In addition to wondering whether EAS should be allowed, it is also necessary to study what complexities may occur within the handling of requests for EAS. What are the characteristics of EAS cases that are more complex than others? Do such complex cases raise new practical and ethical challenges? Research has shown that EAS in itself can be emotionally burdensome for the physicians.(4-5) Although we do not pretend to be able to relieve this burden, insight into the particular complexities of EAS may help physicians to improve care in difficult cases.

Regarding issues that can be more complex than others, public debate has focused on patients suffering from dementia or a psychiatric illness, or people who are 'tired of living.' These topics have been explored in previous research(6-12), but these studies mainly focused on decision making and judgment of the requests, and not so much on the problems or complexities that may arise. There is also research conducted re-

garding problems that occurred during the actual performance of EAS.(13-14) Instead of studying one specific topic or one moment in the process, our study explored the range of complexities that may occur. We studied the entire process leading to the performance of EAS by identifying complexities that may arise from the moment someone requests EAS.

The following research question was addressed: according to the physicians and relatives, what are the characteristics of the complexities that can arise from the moment someone requests EAS?

METHODS

Study Design and recruitment

This study was part of a nationwide study into the trends in the end-of-life decision-making practices.(15) As our research was of an exploratory nature and we were interested in people's experiences and ideas, we performed in-depth interviews with physicians about their perception of complex cases of requested EAS. We did not define the word "complex": this term was used as a sensitizing concept in the analysis. Thus, complex cases were those that were perceived as such by the physicians themselves.

We recruited physicians in two ways. First, we e-mailed Support and Consultation for Euthanasia in The Netherlands (SCEN) physicians and asked them to put us in contact with physicians who had experienced an unusually complex case. The SCEN physicians are specially trained in offering a second opinion in cases of EAS as independent physicians — one of the due care criteria (Box 1, Point 5). We recruited nine respondents this way. Second, we recruited physicians who had completed the questionnaire that was part of the nationwide study and had indicated that they were willing to elucidate their experiences in an in-depth interview. Here, we mainly selected physicians who had received an EAS request from someone suffering from dementia or a psychiatric illness, or who was 'tired of living', as these are cases that are often regarded as complex. This resulted in the recruitment of 18 physicians. In addition, there was one physician who had heard about our study and asked to be included.

We interviewed the physicians about a complex case in which the patient had requested EAS. The performance of EAS in these cases was not a criterion, so we also included cases in which the request was rejected (Table 1). Interviews lasted 37-97 minutes.

Table 1 Characteristics of the interviewed physicians and the cases they discussed

Code	Sex	Age	Specialty	Illness of the patient	Outcome
P01	Female	51-60	Family physician (and SCEN consultant)	Dementia	Euthanasia
P02	Male	61-70	Family physician (and SCEN consultant)	Cancer (lung)	Natural death
P03	Male	61-70	Family physician (and SCEN consultant)	Cancer (brain)	Rejected and patient switched doctor (unknown outcome)
P04	Female	61-70	Elderly care physician (and SCEN consultant)	Cancer (breast, metastasized)	Euthanasia
P05	Male	61-70	Family physician	Conditions of old age and depression	Euthanasia
P06	Female	51-60	Family physician (and SCEN consultant)	Cancer	Euthanasia
P07	Male	51-60	Family physician	Psychiatric illness	Rejected; patient went to nursing home later (unknown outcome)
P08	Female	41-50	Family physician	Conditions of old age	Euthanasia
P09	Male	61-70	Family physician	Conditions of old age	Euthanasia
P10	Male	61-70	Family physician	Parkinson's disease and dementia	Rejected; patient went to nursing home later (unknown outcome)

Table 1 Characteristics of the interviewed physicians and the cases they discussed (continued)

Code	Sex	Age	Specialty	Illness of the patient	Outcome
P11	Male	51-60	Family physician	Dementia	Physician-assisted suicide and euthanasia
P12	Male	51-60	Family physician	Parkinson's disease and dementia	Euthanasia
P13	Male	51-60	Family physician	Cancer (intestinal, metastasized)	Euthanasia
P14	Female	41-50	Family physician	AIDS	Euthanasia
P15	Male	41-50	Family physician	Conditions of old age	Euthanasia
P16	Male	41-50	Family physician	Heart failure	Referred patient to colleague physician, who performed euthanasia
P17	Male	51-60	Family physician	Cancer (lung)	Physician-assisted suicide
P18	Female	31-40	Family physician	Cancer (intestinal)	Euthanasia
P19	Female	51-60	Family physician	Multiple sclerosis	Euthanasia
P20	Male	61-70	Family physician	Dementia	Euthanasia
P21	Male	51-60	Psychiatrist	Psychiatric illness	Physician-assisted suicide
P22	Male	51-60	Family physician	Cancer (esophagus)	LAWER ^a
P23	Female	51-60	Family physician	Dementia	Physician-assisted suicide

Table 1 Characteristics of the interviewed physicians and the cases they discussed (continued)

Code	Sex	Age	Specialty	Illness of the patient	Outcome
P24	Female	51-60	Family physician	Cancer (ovary, metastasized)	Euthanasia
P25	Male	41-50	Elderly care physician (and SCEN consultant)	Cancer (breast)	Euthanasia
P26	Male	51-60	Elderly care physician	Parkinson's disease, depression	Euthanasia
P27	Male	51-60	Internist/oncologist/hospice physician	Cancer (brain)	Euthanasia
P28	Male	31-40	Lung specialist	Cancer (lung) and psychiatric illness	Euthanasia

SCEN = Support and Consultation for Euthanasia in The Netherlands; EAS = euthanasia or physician-assisted suicide.

^a LAWER: Life-terminating acts without the explicit request of the patient. In this particular case, the physician and the patient had had conversations about EAS and there was a request from the patient albeit a non-persistent one.

As a part of the nationwide study, we also performed in-depth interviews with the relatives of patients who had requested EAS. We recruited seven relatives through the interviewed physicians: after we had interviewed a physician, we asked whether he/she was willing to ask a relative of a patient who had died by EAS to participate in the study. We also placed a notice in the *Right to Die-NL* magazine, asking relatives of patients who had died by EAS to contact us if they wanted to participate in the study. This resulted in 15 additional interviews.

In the interviews, we asked these relatives to describe the period from the moment of the EAS request up to the death of the patient. Although relatives do not have a formal role in EAS, in practice they are often present at important moments in the process of (requests for) EAS. We analyzed the relatives' interviews to determine whether they told us anything about possible complexities the relatives had faced. By including relatives, we added another perspective to the perceived complexities, which made it possible to compare the complexities raised by the physicians with those raised by the relatives. In response to the notice in the *Right to Die-NL* magazine, we also received responses from relatives of patients whose request for EAS was rejected. Again, we included these cases (Table 2). The interviews lasted 42-118 minutes.

Interviews were conducted by M.C.S. and D.G.v.T., both of whom are trained in qualitative interview methods. All participants signed an informed consent form. As the interviews were not burdensome and did not pose risks to the participants, the study was not reviewed by the medical ethics committee. This is in accordance with relevant Dutch legislation.

Table 2 Characteristics of the interviewed relatives and the cases they talked about

Code	Sex	Relation to the deceased	Patient characteristics	EAS or other? ^a
B01	Female	Spouse	≥ 81 y, male, dementia	Euthanasia
B02	Female+ Female	Daughter and spouse	61-80 y, male, cancer (throat)	Euthanasia
B03	Male+ Female	Neighbors	61-80 y, male, cancer (lung, metastasized)	Euthanasia
B04	Male	Spouse	≥ 81 y, female, cancer (intestinal)	Euthanasia
B05	Female	Spouse	61-80 y, male, cancer (esophagus)	Euthanasia
B06	Female	Spouse	61-80 y, male, cancer (prostate, metastasized)	Palliative sedation ^b or euthanasia? ^c
B07	Female	Daughter	61-80 y, female, cancer (lung, metastasized)	Palliative sedation
B08	Female	Spouse	≥ 81 y, male, amyotrophic lateral sclerosis	Euthanasia
B09	Female	Friend	≥ 81 y, female, cancer (intestinal, metastasized)	Euthanasia
B10	Male+ Female	Son and daughter-in-law	≥ 81 y, female, heart failure ≥ 81 y, male, cancer (prostate, metastasized)	Physician-assisted suicide (both)
B11	Female	Daughter	≥ 81 y, male, cancer (lung) ≥ 81 y, female, cancer (intestinal)	Physician-assisted suicide (male) Euthanasia (female)
B12	Female	Cousin	61-80 y, female, dementia	Physician-assisted suicide
B13	Female	Daughter	61-80 y, male, cancer (pancreas)	Euthanasia
B14	Female	Spouse	61-80 y, male, cancer (breast)	Euthanasia

Table 2 Characteristics of the interviewed relatives and the cases they talked about (continued)

Code	Sex	Relation to the deceased	Patient characteristics	EAS or other? ^a
B15	Female	Spouse	61-80 y, male, cancer (esophagus, metastasized)	Palliative sedation, although with the attention of shortening life
B16	Female+ Female	Sibling and parent	≤60 y, female, psychiatric disease	Self-inflicted death by means of collecting medication in a lethal dose
B17	Female	Daughter	≥81 y, male, chronic obstructive pulmonary disease	Euthanasia
B18	Male	Spouse	61-80 y, female, cancer (intestinal, metastasized)	Euthanasia
B19	Female	Spouse	61-80 y, male, dementia	Self-inflicted death by means of collecting medication in a lethal dose
B20	Female	Daughter	61-80 y, male, cancer (lung)	Physician-assisted suicide
B21	Female	Spouse	≥81 y, male, dementia	Euthanasia
B22	Female	Daughter	Age not registered, female, cancer (leukemia) and heart failure	Euthanasia

EAS= Euthanasia or physician-assisted suicide

- ^a Not all requests led to the performance of EAS. All patients who were discussed in the interviews had persistently and explicitly requested EAS and had talked about it with their attending physician. The grounds on which their requests had not been granted were 1) the due care criteria could not be met according to the physician or 2) the physician was unwilling to perform the euthanasia in this specific case.
- ^b Palliative sedation is a medical intervention at the end of life aiming at symptom control by deliberately lowering a patient's consciousness. This is intended to treat refractory symptoms without prolonging or shortening the life of the patient.
- ^c According to the bereaved, euthanasia had been performed. The description of the case, however, showed more resemblance to palliative sedation.

Analysis

All interviews were recorded and transcribed verbatim. Analysis was supported by the use of ATLAS.ti 6 (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). We used open coding and inductive analysis to identify various aspects of the complexities described by the participants; the codes were based on the content of the interviews. M.C.S. and D.G.v.T. independently coded the same five interviews, compared codes and notes afterward, and developed a code schema that fit both physicians' and relatives' interviews. The rest of the interviews were coded based on this code scheme, which was adapted if M.C.S. and D.G.v.T. found an important aspect that was missing in the initial scheme. Saturation was reached when no new aspects of complexity were found. After all interviews were coded, a third researcher coded five interviews with the final coding scheme to increase the (internal) validity of the coding.

RESULTS

Between November 2011 and April 2012, we conducted 28 interviews with Dutch physicians and 22 interviews with relatives (Table 1, Table 2). The interviews showed that both physicians and relatives had often experienced comparable complexities, although some complexities were more group specific. Complex situations can be divided into relational complexities and complexities that arise from the occurrence of unexpected situations.

Relational complexities: absence of the process of growth

EAS was referred to by both physicians and relatives as a process of growth in which physician and patient grew together toward the final decision to perform EAS. As one of the interviewed physicians said: “[EAS] is not an act, it's a process towards which we both grow” (P03, family physician and SCEN consultant).

The interviews indicated that relatives also played an important role in this process of growth. Although a few physicians stated that their only objective was to care for the patient, rather than the patient's family, most explained the importance of involving the relatives in the process toward EAS.

“I told her I that wouldn’t perform euthanasia if I didn’t get the feeling that her children could cope with it. [I told her:] “Your children take precedence over your wish.” That’s my point of view.”

(P04, elder care physician and SCEN consultant)

“I think I should take part in supporting the partner. I don’t mean directing the partner towards the decision. I think euthanasia is part of the treatment relationship. Almost always in this relationship, you relate to the partner too.”

(P27, oncologist and hospice physician)

The importance of the process of growth was emphasized in the interviews, and complex situations arose when this process was disrupted or absent, for instance when a patient asked a physician for EAS while there had been no previous care relation between them. In one case, this happened when the family physician was on holiday and the patient’s condition suddenly deteriorated, resulting in an urgent EAS request to the locum physician.

“I will not push an EAS request through within a week. You just can’t do that. You don’t know the patient. People aren’t always understanding [when I tell them this]. Well, so be it. But as a locum physician you have to explain that it’s a process, not some sort of piecemeal policy whereby we satisfy every request.”

(P15, family physician)

In another interview, the locum physician mentioned that he rejected the EAS request as a consequence of the absence of the process of growth.

The interviews showed that the process of growth was also important for the coping of relatives:

“He [the patient] wanted to arrange the euthanasia, although his request wasn’t persistent at that moment. But his wife just wasn’t ready for it, to say the least. (...) I could understand his decision, but I think it was important he showed some consideration for his wife. I think it’s my responsibility to see them through this process and to try to work it out together. (...) It’s certainly not a criterion for performing EAS, but rather an important point of interest.”

(P06 family physician and SCEN consultant)

Relational complexities: miscommunication

Complex situations in the relationship also were caused by miscommunication, which regularly stemmed from different yet implicit expectations.

“They [the parents] talked with their family physician about their euthanasia directives. And they told us that he [the family physician] would not grant a request. (...) At that point, the family physician said: “They misunderstood me completely; that’s not what I said to them”.”

(B11, daughter)

Physicians frequently mentioned feeling pressured by the patient or the relatives to perform EAS. The latter most often happened when the patient was no longer able to express his/her request. This frequently also stemmed from a difference in expectations: patients and relatives did not understand why EAS was not or not yet an option.

“Perhaps at some point there was some sort of moral pressure. The moment he [the patient] said: ‘If you won’t perform EAS, I might go to a railway line or climb a high building.’ (...) And I thought: that’s verging on blackmail, isn’t it?”

(P01, family physician and SCEN consultant)

“[The patient] said something like: “I want it [EAS]; soon I’ll no longer be able to handle it [the disease] and you can’t let me down.” He had a friendly smile, but I found it hard to sympathize with him: he had little consideration for the position he put me in. (...) Problems arise when you’re not yet ready [to perform EAS] while the patient is.”

(P17, family physician)

Relational complexities: invisible suffering

Complex situations also occurred when the patient’s apparent condition seemed a lot better than it really was, when there was incongruence between the medical state of the patient and his/her appearance or the story he/she told. The interviews showed that relatives and sometimes even physicians failed to notice how severe the patient’s suffering was. In these situations, the patient’s request for EAS could take the people involved by surprise.

“And when there were visitors, he acted ... well ... just like always. Even towards my brothers. It was unbelievable. For a long time, they hadn’t seen how sick my father really was. When they came over, my father would be in bed, joking and just chattering away. And when my brothers left, he’d collapse ... I said: “Dad, do not just show it to us, show it to the others, too!” But he didn’t ... Not until the Monday evening [the evening before euthanasia was performed].”
(B02, child and spouse)

In the interview extracts above, the invisible suffering made it harder for the people close by to empathize and come to terms with the patient’s request and his/her death.

The problem concerning the invisibility of the patient’s suffering was even more noticeable in patients who suffered from a disease that is not physically manifest: it was harder for an outsider to understand and see the suffering of a patient who suffered from a psychiatric condition or dementia. Two relatives of a psychiatric patient phrased it like this:

“He [the psychiatrist] was really upset. It actually surprised him a bit. Because Elisa, well, she can fool the whole world. She was really smart. She could ... She was very good at keeping up appearances.”
(B16, parent)

In this case, the invisibility made the physician uncertain about assessing the due care criteria, although he was a psychiatrist — someone who is expected to be specialized in psychiatric suffering.

A psychiatrist who talked about another case of psychiatric suffering put it like this:

“I was talking with an intelligent man, who appeared to be fairly healthy, and I wondered, as an outsider: “How severe is his suffering?” I think that is what made it complicated: “How unbearable is his suffering really?””
(P21, psychiatrist)

Complexities related to the occurrence of unexpected situations

The points mentioned above all have a connection to the relationship between the people involved. The following set of complexities has less to do with this relationship, and more with the occurrence of unexpected situations and the need for control.

The capricious progress of a disease sometimes created a sense of haste and the idea of being overtaken by the disease: the patient's condition was rapidly deteriorating, which complicated the procedure and/or the assessment of the due care criteria. From that moment on, the performance of EAS was no longer possible.

“At a certain moment, you might get outrun by the disease. In fact, that’s what happened. (...) It became very difficult for me when we could no longer communicate [our ideas] clearly. That’s what happened here. Tuesday he sort of dozed off. You could hardly reach him.”

(P02, family physician and SCEN consultant)

“I was once caught out by the disease at a weekend. It was a young woman who was severely ill, and we’d talked about her request for euthanasia. I decided to sedate her, because of her bad condition. I realized at that point that I was ignoring her request for euthanasia. I just felt I couldn’t organize everything that weekend.”

(P23, family physician)

Another event that created a complex situation was the unexpected necessity to move the patient to another place to perform EAS. One of the interviewees talked about a patient who was staying in a hospice where it was against policy to perform EAS. The transfer of the patient to a nursing home on the day of euthanasia led to a complex situation in the context of the setting.

“Another difficulty that emerged was that it [euthanasia] couldn’t take place in the hospice, so we had to organize something for that. Yeah, I thought that was kind of difficult. (...) That was quite an obstacle, that I couldn’t perform it right there.”

(P18, family physician)

DISCUSSION

The aim of this study was to gain insight into the characteristics of the complexities that can arise from the moment someone requests EAS. Physicians regarded something as complex if it hindered the (decision-making) process toward EAS. The results show that complexities can be categorized into relational difficulties — such as the absence of a process of growth, miscommunication, and invisible suffering — and complexities

that arise because of unexpected situations, such as the capriciousness of a disease or the necessity of moving the patient.

Relational complexities

The relational complexities described above most often became manifest in the period preceding the actual performance of EAS. This suggests that when it comes to complex situations, the process toward EAS is more important than the event of EAS. Decision making in cases of EAS needs time; time to grow, develop or deepen the relationship, and to balance the different options. A recent study on decision making in requests for euthanasia supports this finding: building relationships is described as a crucial part of the process and one of the five consecutive phases that constitute the decision making.(16)

Another finding of our study is the importance of the role of relatives in the process of EAS. The process is not only influenced by the physician and the patient but also should be seen as a triangle among physician, patient, and relatives. If the physician is afraid that the relatives will not be able to cope with death caused by EAS, this can even be a reason for him to reject a request for EAS. Therefore, when investing in the relationship with the patient, the relatives should not be overlooked. The interdependence of physician and relatives is recognized(17-18) but remains largely overlooked in guiding documents(19), which focus mainly on the conversation between patient and physician. Relatives are mentioned only briefly by the Royal Dutch Medical Association as one of the environmental factors that should be taken into account when handling an EAS request.(20) The association recognizes that ignoring the relatives can disturb the decision-making process or cause trouble after the performance of EAS, but this is an underestimation of the substantial role that relatives play in the process.

Although cases that are usually seen as complex in the public debate — such as dementia, psychiatric illness, or people who are ‘tired of living’ — do not actually cause complexities to arise, our study indicates that these cases have a greater likelihood of turning into complex situations, because the conditions in which complexities may occur — both relational complexities and unexpected situations — are more frequently present in such cases.

Unexpected situations

Unexpected situations occur just before the actual performance of EAS. These situations can even lead to the rejection of an EAS request at the last moment if the due

care criteria can no longer be met. Factors associated with the refusal of a request include the patient not being (fully) competent, and unbearable suffering “to a lesser extent.”(21) These factors typically occur when the patient’s disease suddenly progresses, for instance when a patient lapses into a coma or when dementia suddenly takes a turn for the worse, making the patient no longer competent.

Strengths and limitations

We interviewed both physicians and relatives to gain information from different perspectives and to obtain a fairly complete insight into the complexities that can arise. By including cases in which the patient’s request for EAS had been rejected, it was possible to arrive at an understanding of the complexities that can potentially lead to the rejection of an EAS request. This further insight into possible reasons for rejection is important because many euthanasia requests are denied.(15)

The recruitment of relatives as respondents might have been a limitation, as most had experienced EAS only once. This implies that they had no frame of reference for EAS, so it was hard for them to estimate the weight of the complexities they had experienced. On the other hand, they represent the lay view, which should not be neglected.

The selection of atypical cases — such as dementia, psychiatry, and ‘tired of living’ — raises the question whether our findings are representative of the general population of patients who request EAS.

Ethical considerations

The results of our study also raise ethical questions. We have seen physicians reject cases because of the complexities. Should we say that these cases are just too difficult and that physicians should not get involved in them? But then, a case often becomes complicated when a physician is already involved and then cannot simply ignore the patient’s EAS request. Most often it is not possible to distinguish beforehand which cases will become more complex than other cases. If the process toward EAS is so important, one may wonder who should be involved in this process: is it ethically justifiable for a physician — or perhaps even the patient — to leave close relatives out of this process, when we have seen that relatives play such an important role? The notion of autonomy that is now present in the euthanasia debate is closely linked to the strict individual autonomy of the patient. Yet, in practice, a more relational form of autonomy seems to be at work. The performance of euthanasia often is the result of a decision shared by the patient, the physician, and the relatives involved. Perhaps we should think about a notion of autonomy that is more shared and equal. What does this entail: should review committees also evaluate the role of relatives? Should we be

worried about relatives gaining too much influence over the course of the process? When miscommunication emerges, at least two parties are involved. Can we hold both of these parties responsible when the process is disrupted?

Physicians do not perform EAS often, so they do not easily develop their own way of dealing with complex cases of EAS or are unaware what to expect. It would, therefore, be advisable if physicians take the complexities that might arise into account beforehand. This could be done individually by personal reflection or in deliberation with other physicians in a form of group counseling during which each of the participants could share experiences and thoughts. This would ensure that physicians are aware that certain complexities might occur and can prepare themselves, insofar as they might consider what they think is an appropriate reaction in these situations. Current networks (SCEN, Support Group Psychiatrists) that offer support for physicians often do not support the physician during a longer period. It could be a supplement of their tasks if they incorporated a role as coach or supervisor to advise the attending physician along the way.

As a part of a more shared notion of responsibility, the role of relatives could be made more explicit, and the attending physician could actively involve them in the process as they form a part of the situation.

Conclusion

First, our study adds a new dimension to the already known complexities that can occur during the actual performance of EAS. Although previous studies focused on the difficulty of EAS as an event, we have shown the importance of the process toward EAS. Complexities most often occur in this period. Second, the course of the process toward EAS is influenced not only by the patient and his/her attending physician (as the current rules seem to take as a starting point) but also by the involved relatives. By regarding EAS as a process instead of an isolated event, the role of relatives becomes more apparent.

Further quantitative research could enrich our findings by showing how often these unusually complex situations occur and whether there is a need for additional education or guidelines to handle these complex aspects.

Although handling an EAS request will always be a complex task, communicating about expectations and clarifying them throughout the process for all the people involved may help to prevent the unnecessary occurrence of complex situations.

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