Symptoms of anxiety and depression in family members of intensive care unit patients: Ethical hypothesis regarding decision-making capacity

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Objective: Anxiety and depression may have a major impact on a person's ability to make decisions. Characterization of symptoms that reflect anxiety and depression in family members visiting intensive care patients should be of major relevance to the ethics of involving family members in decision-making, particularly about end-of-life issues.

Design: Prospective multicenter study.

Setting: Forty-three French intensive care units (37 adult and six pediatric); each unit included 15 patients admitted for longer than 2 days.

Patients: Six hundred thirty-seven patients and 920 family members.

Interventions: Intensive care unit characteristics and data on the patient and family members were collected. Family members completed the Hospital Anxiety and Depression Scale to allow evaluation of the prevalence and potential factors associated with symptoms of anxiety and depression.

*Measurements and Main Results:*Of 920 Hospital Anxiety and Depression Scale questionnaires that were completed by family members, all items were completed in 836 questionnaires, which formed the basis for this study. The prevalence of symptoms of anxiety and depression in family members was 69.1% and 35.4%, respectively. Symptoms of anxiety or depression were present in 72.7% of family members and 84% of spouses. Factors associated with symptoms of anxiety in a multivariate model included patient-related factors (absence of chronic disease), family-related factors (spouse, female gender, desire for professional psychological help, help being received by general practitioner), and caregiver-related factors (absence of regular physician and nurse meetings, absence of a room used only for meetings with family members). The multivariate model also identified three groups of factors associated with symptoms of depression: patient-related (age), family-related (spouse, female gender, not of French descent), and caregiver-related (no waiting room, perceived contradictions in the information provided by caregivers).

Conclusions: More than two-thirds of family members visiting patients in the intensive care unit suffer from symptoms of anxiety or depression. Involvement of anxious or depressed family members in end-of-life decisions should be carefully discussed. (Crit Care Med 2001; 29:1893–1897)

KEY WORDS: anxiety; depression; intensive care unit; Hospital Anxiety and Depression Scale; family; information; decision making

The intensive care unit (ICU) is one of the places in a hospital where family members suffer most, yet it is also in the ICU that they are most likely to be asked by physicians to make difficult decisions about their relatives (1). It has been shown that in 50% of cases, family members visiting the patient in the ICU (considered as persons having either familial or friendly relations and/or direct concern for the patient) fail to understand what doctors say about the prognosis, diagnosis, and treatment of the patient they represent (2), and the prevalence of emotional disorders in family members has been the focus of only very few publications (3). Symptoms of anxiety and/or depression may result in relatives overestimating the risks of treatment or underestimating its benefits (4) and also could

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impair comprehension and decision-making capabilities (5). Family members are asked to participate in decisions or discussions about treatment withdrawal or withholding for about 7% to 12% of patients admitted to ICUs; moreover, in end-of-life decisions, family members are consulted in 65% to 90% of patients who die in ICUs (6–9). Consensus statements recommend that family members participate in end-of-life decisions about the patient they represent (10–12). Characterization of anxiety or depressive symptoms in family members should have major implications for the ethics of involving family members in end-of-life decisions about ICU patients.

The aim of this prospective multicenter study was to determine the prevalence and factors associated with symptoms of anxiety and depression in family members of ICU patients.

METHODS

An invitation to participate in this study was sent to 72 directors of French intensive care units, all of whom were members of the French Society for Critical Care Medicine. The ICUs were equally distributed between university and community hospitals.

The following characteristics of the ICUs that agreed to participate in this study were recorded: number of beds, existence of rooms with two beds or more, number of senior physicians, nurse-to-patient ratio, existence of a waiting room, existence of a room used only for meetings with families, and whether nurses and physicians met regularly to discuss patient and family needs.

Patients. All patients admitted after December 7, 1998, were included. For each patient, the following information was recorded: age, gender, geographic origin, marital status and occupation (for adult patients), reasons for ICU admission, and clinical status at admission including the Simplified Acute Physiology Score II calculated within 24 hrs of ICU admission (13).

Family members were defined as all individuals who visited the patient in the ICU, regardless of their relationship to the patient. All family members who entered the patient's room were informed that a study focusing on their needs was ongoing and that they could participate in the study by completing a questionnaire between the third and the fifth day after admission. Those who accepted were offered a seat in a quiet place and were asked to complete the questionnaire themselves, anonymously. A caregiver was available to answer any questions.

For each family member, the following data were recorded: age, gender, relationship to the patient, and occupation. Family members were asked, by using a simple questionnaire with yes/no answers, whether they had received contradictory information, whether they were receiving support from their general practitioner, and whether they would like help from a psychologist. Symptoms of anxiety and depression were defined by using the Hospital Anxiety and Depression Scale (HADS), a 14-item, self-administered questionnaire developed by Zigmond and Snaith (14, 15) for detecting and classifying the severity of anxiety and depression (Appendix 1). The HADS was considered the most appropriate tool in this situation: It is simple, requires little time to complete, and has been proven sensitive as a screening tool. Although designed for outpatients receiving care in general hospitals, it has been used extensively in primary care settings. As compared with the General Health Questionnaire, the HADS has been reported to be more sensitive (90% vs. 49%) but less specific (86% vs. 96%) in primary care settings (14). The HADS has been validated in French (16–17). Each item is scored on a 4-point scale (ranging from 0 to 3). Seven items evaluate depression and seven evaluate anxiety. A cutoff score of 10 on the anxiety or depression subscale has been found reliable for discriminating between patients with and without the corresponding disorder and was used in this study.

We chose the HADS based on its simplicity and dimensional approach, on its easy application in general population, and because this questionnaire could reliably be proposed by physicians other than psychiatrists.

The study was approved by our Institutional Review Board.

Statistical Analysis. Results are expressed as medians and ranges. The exact Fisher test and the nonparametric Wilcoxon test were used for between-group comparisons of discrete and continuous variables, respectively. A multivariate logistic regression model was used to assess the effects of variables on anxiety and depression separately, as measured by the estimated odds ratio. Anxiety or depression (defined as a subscale score >10) was the dependent variable. The independent variables were the patient, respondent, and ICU characteristics. The Hossmer Lemeshow test was used to check goodness-of-fit of the logistic regression. Analysis was performed with the SAS software package (SAS, Cary, NC).

RESULTS

A total of 43 ICUs participated in the study (661 beds) and included a total of 637 patients. Eleven family members did not and 920 did agree to complete the questionnaire; 836 HADS questionnaires were evaluable.

Characteristics of the 43 ICUs. Six ICUs (14%) were pediatric. The ICUs had a median of 15 beds (range, 6–30), a median of four physicians (range, 1–8), and a nurse-to-patient ratio of 1:3 (range, 1:2–1:5). The median time allowed for daily visits was 150 mins (range, 15–1440). Thirty-five ICUs (81.4%) had a waiting room and 19 (44%) had a room used only for meetings with families. In 29 ICUs (67.5%), nurses and physicians met regularly to discuss patient and family needs.

Characteristics of the Patients. Median age was 59 yrs (range, 1 month to 93 yrs). Fifty-six (8.8%) patients received no visits from family members within 5 days after their ICU admission. There were 418 men (65.6%) and 217 women; 85 (13.3%) patients were not of French descent, 108 were unemployed (17%), 202 were single (32%), and 572 (65.5%) had a chronic disease. The median Simplified Acute Physiology Score II was 38 (range, 0–103), the median length of ICU stay was 9 days (range, 3–99), and ICU mortality was 18.5% (118 patients died).

Characteristics of Family Members Who Completed the Questionnaire. There were 611 men (66.4%), and the median age was 45 yrs (range, 13–90). Although 120 (13%) family members were not of French descent, only 28 (3%) had no knowledge of French; absence of knowledge of French did not lead to exclusion of any patients from this study, but for some patients only those family members who knew French were able to complete the questionnaire.

The relationship with the patient was as follows: 217 spouses (23.5%), 210 parents (22.8%), 227 children (24.7%), 84 siblings (9.1%), 99 other family members (10.8%), and 84 (9.1%) family members who were not relatives of the patient they represented. One hundred and thirty-five family members (14.7%) were relatives of a pediatric ICU patient.

One hundred and five (11.7%) family members reported receiving contradictory information, 492 (53.5%) did not know the specific role of each caregiver, 431 (46.8%) wanted help from a psychologist, and 439 (47.7%) were not receiving help from a general practitioner.

The prevalence of anxiety and/or depression in family members is reported in Table 1; 69.1% of family members had anxiety and 35.4% had depression.

Multivariate Analysis. Factors associated with symptoms of anxiety and depression are presented in Table 2. Anxiety was independently associated with one patient-related characteristic (absence of chronic disease), four family-related characteristics (spouse, female gender, desire for help from a psychologist, help being received by general practitioner), and two caregiver-related characteristics (no regular nurse-physician meetings, no room used only for meetings with families).

Factors associated with symptoms of depression included one patient-related factor (younger age), three family-related factors (spouse, female gender, not of French descent), and two caregiver-related factors (no waiting room, contradictions in the information given).

No differences in anxiety or depression were found between family members of pediatric and adult ICU patients. Moreover, a number of factors such as the nurse-to-patient ratio, the number of physicians, the Simplified Acute Physiology Score II, length of stay, and mortality rate also failed to correlate with anxiety or depression.

DISCUSSION

This is, to our knowledge, the first prospective multicenter study establishing that symptoms of anxiety and depression are common in family members visiting ICU patients. The HADS does not determine clinical syndromes for depression and anxiety but reveals the prevalence of symptoms. Family members of older patients were less likely suffer from symptoms of depression, and those of patients with a history of chronic disease were less likely to suffer from symptoms of anxiety, suggesting that sudden severe disease in a young individual produces a particularly massive emotional upheaval. Nevertheless, our results failed to find any differences between adult and pediatric ICUs. However, the Simplified Acute Physiology Score II and other data reflecting the seriousness of the patient's condition failed to correlate with symptoms of anxiety or depression in family members, indicating that symptoms of anxiety and depression may have been generated by idiosyncratic factors. It follows that the magnitude of the physical threat faced by the patient may not be a reliable indicator of the likelihood of anxiety or depression in family members.

We found that women were at higher risk of symptoms of anxiety and depression. Gender differences have been reported previously regarding satisfaction (18). Receiving help from the general practitioner may be an indicator of symptoms of anxiety, because anxious family members may be more likely to seek information from sources other than the ICU physicians. The higher prevalence of symptoms of depression in our family members who were not of French descent is consistent with the conclusion by Ip et al. (19) that family members from other cultures require special attention.

Two factors associated with symptoms of depression and two associated with symptoms of anxiety were caregiver-related and therefore amenable to modification. When defining the organization and policies of their ICU, caregivers should bear in mind the need to decrease the risk of anxiety and depression in family members. Based on our data, these steps should include holding regular nurse-physician meetings to discuss patient and family needs, having a room used only for meetings with families, having a waiting room, and ensuring that there are no contradictions in the information given to families. Some family members may feel that they received contradictory information because they did not understand the information given to them (2). If this is the case, our finding that perceived contradictions in information were associated with symptoms

Table 1. Prevalence of anxiety and/or depression in family members (n = 836)

n% [95% CI]	Spouses (n = 207)	Family Members Except Spouses (n = 629)	All Family Members (n = 836)
Anxiety	168 81.1 [28–96][a]	410 65.1 [33–77]	578 69.1 [44–88]
Depression	98 47.3 [29–89][a] 92	198 31.4 [17–49] 178	296 35.4 [17–55] 270
Both (anxiety and depression)	92 44.5 [31–50][a]	178 28.3 [15–41]	270 24.7 [11–56]
At least one (anxiety or depression)	174 84 [58–97][a]	433 68.8 [31–84]	608 27.7 [11–57]

CI, confidence interval.

[a] $p < .05$ between spouses and other family members by the exact Fisher test. Cutoff used for depression and anxiety: 10.

Table 2. Factors associated with symptoms of anxiety and/or depression in family members (n = 836): Results of two multivariate logistic regression models

	Odds Ratio (95% CI) for Anxiety	Odds Ratio (95% CI) for Depression
Patient related		
No chronic disease	1.52 (1.03–1.79); $p = .02$	NS
Age (/20 yrs)	NS	0.79 (0.67–0.97); $p = .02$
Family related		
Spouse	2.80 (1.67–4.69); $p = .0001$	2.1 (1.50–3.54); $p = .0001$
Female	2.42 (1.67–3.52); $p = .0001$	2 (1.40–2.84); $p = .0001$
Wanted help from psychologist	1.62 (1.11–2.36); $p = .01$	NS
Was receiving help from general practitioner	1.55 (1.07–2.25); $p = .02$	NS
Not of French descent	NS	1.90 (1.10–3.30); $p = .02$
Caregiver related		
No regular physician-nurse meetings	1.36 (1.04–1.79); $p = .02$	NS
No room dedicated for meetings with families	1.80 (1.10–2.96); $p = .01$	NS
No waiting room	NS	2.50 (1.25–5.02); $p = .009$
Perceived contradictions in information	NS	1.67 (1.01–2.75); $p = .04$

CI, confidence interval.

Hossmer Lemeshow χ^2 p value $>.05$.

More than two-thirds of family members visiting patients in the intensive care unit suffer from symptoms of anxiety or depression.

of depression suggests that depression should impair comprehension and/or that poor comprehension should be an indicator of depression. A local policy could be instituted to improve information and communication with family members.

Participation of family members in medical decisions concerning patients is standard practice in the United States. It has been estimated that <10% of ICU patients are competent (7, 9). In Europe, family members are informed of 50% of end-of-life decisions made about ICU patients (20), whereas in the United States family members participate in 70% to 80% of these decisions (7, 21). Physicians are probably at risk of overestimating the extent to which family members subjected to severe stress are capable of making choices, voicing their preferences, understanding and appreciating the significance of information relevant to treatment decisions, and finally making comparisons and weighing options based on that information. Moreover, depression has been shown to be associated with more rigid thinking and with seeing problems in black-and-white terms (22, 23). The emotional turmoil that family members visiting an ICU patient must deal with should make them particularly sensitive to suggestion and prone to acting out. When the outcome is uncertain, as is generally the case in ICU patients, family members may develop coping strategies aimed reducing their symptoms of anxiety and their ambivalence. The fastest way to obtain relief from ambivalence and uncertainty may be to make an end-of-life decision, which might be considered as an ethical risk. Thus, physicians should direct careful attention to the decision-making ability of family members (24, 25) in stressful situations: It has been reported that one third of U.S. ICU physicians are asked at least once a year by family members to stop treatment in the absence of a medical reason (26). Moreover, only very rarely (in 2% to 4% of cases) do family members oppose an end-of-life decision suggested by a physician (8, 27). For adults in the ICU, the spouse is often given priority in decision-making (11), although our data show that spouses are more likely than other family members to suffer symptoms of anxiety and depression. Despite recommendations about good communication (28) and protection of family members (29, 27), most authors consider that end-of-life decisions should be shared by the physician and family (30), and in practice family members usually are involved in these decisions (27, 31, 32).

There often may be a gap between the patient's wishes and the opinions of family members about those wishes, because relationships within families are often complex and conflictive. This gap is probably widened by symptoms of anxiety and/or depression in the family members. Moreover, the risk of posttraumatic stress disorder in family members who participated in end-of-life decisions for a relative must be borne in mind.

There may be no single answer to the question of how much decision-making ability is enough. Providing more information, allowing longer visiting hours, broadening visiting policies (2, 18), and encouraging family members to discuss and agree among themselves should decrease symptoms of anxiety and depression and increase decision-making ability. Informed debate about end-of-life decisions should recognize the importance of psychological factors in family members (33, 34). Neither a paternalistic nor an autonomous patient-physician relationship approach is appropriate for addressing the problems raised by family information and participation. The ethical principles of circularity (the consequences of a decision must be optimally protective for all persons concerned) (35), authority (the decision is primarily medical and the responsibility for it rests on the physicians, not the family), and contextuality (the psychological factors and relationship patterns in each family are recognized as unique and complex) should be followed at all times (36). It is very likely that many family members have transient symptoms related to the acute stresses of the illness event. Studies establishing the clinical impact of these are needed. Physicians should be committed to caring for both patients and family members.

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Appendix 1. Hospital anxiety and depression scale and percentage of answers (n = 836)

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings, he will be able to help you more. This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply that comes closest to how you have been feeling in the past week. Do not take too long over your replies: your immediate reaction to each item will probably be more accurate than a long, thought-out response. Tick only one choice in each section.

A1. I feel tense or wound up:
3. Most of the time (24%); 2. A lot of the time (29.5%); 1. Time to time (39.5%); 0. Not at all (7%)

D1. I still enjoy the things I used to enjoy:
0. Definitely as much (22%); 1. Not quite so much (36%); 2. Only a little (22%); 3. Hardly at all (20%)

A2. I get a sort of frightened feeling as if something awful is about to happen:
3. Very definitely and quite badly (42.5%); 2. Yes but not too badly (27%); 1. A little, but it does not worry me (18.5%); 0. Not at all (12%)

D2. I can laugh and see the funny side of things:
0. As much as I always could (16.5%); 1. Not quite as much now (33%); 2. Definitely not so much now (32.5%); 3. Not at all (18%)

A3. Worrying thoughts go through my mind:
3. A great deal of the time (47.5%); 2. A lot of the time (29%); 1. From time to time but not too often (20.5%); 0. Only occasionally (3%)

D3. I feel cheerful:
3. Not at all (3%); 2. Not often (22.5%); 1. Sometimes (44.5%); 0. Most of the time (30%)

A4. I can sit at ease and feel relaxed:
0. Definitely (5%); 1. Usually (35%); 2. Not often (40%); 3. Not at all (20%)

D4. I feel as if I am slowed down:
3. Nearly all the time (10.5%); 2. Very often (20.5%); 1. Sometimes (45%); 0. Not at all (24%)

A5. I get a sort of frightened feeling like butterflies in the stomach:
0. Not at all (13%); 1. Occasionally (45%); 2. Quite often (22%); 3. Very often (20%)

D5. I have lost interest in my appearance:
3. Definitely (7.5%); 2. I do not take as much care as I should (22%); 1. I may not take quite as much care (32%). 0. I take just as much care as ever (38.5%)

A6. I feel restless, as if I have to be on the move:
3. Very much indeed (27%); 2. Quite a lot (31%); 1. Not very much (24.5%); 0. Not at all (17.5%)

D6. I look forward with enjoyment to things:
0. As much as ever I did (33%); 1. Rather less than I used to (34.5%); 2. Definitely less than I used to (22%); 3. Hardly at all (10.5%)

A7. I get sudden feelings of panic:
3. Very often indeed (10.5%); 2. Quite often (22.5%); 1. Not very often (40.5%); 0. Not at all (26.5%)

D7. I can enjoy a good book or radio or TV program:
0. Often (40%); 1. Sometimes (29%); 2. Not often (15.5%); 3. Very seldom (15.5%)