

## ORIGINAL ARTICLE

# A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU

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## ABSTRACT

**BACKGROUND**

There is a need for close communication with relatives of patients dying in the intensive care unit (ICU). We evaluated a format that included a proactive end-of-life conference and a brochure to see whether it could lessen the effects of bereavement.

**METHODS**

Family members of 126 patients dying in 22 ICUs in France were randomly assigned to the intervention format or to the customary end-of-life conference. Participants were interviewed by telephone 90 days after the death with the use of the Impact of Event Scale (IES; scores range from 0, indicating no symptoms, to 75, indicating severe symptoms related to post-traumatic stress disorder [PTSD]) and the Hospital Anxiety and Depression Scale (HADS; subscale scores range from 0, indicating no distress, to 21, indicating maximum distress).

**RESULTS**

Participants in the intervention group had longer conferences than those in the control group (median, 30 minutes [interquartile range, 19 to 45] vs. 20 minutes [interquartile range, 15 to 30];  $P < 0.001$ ) and spent more of the time talking (median, 14 minutes [interquartile range, 8 to 20] vs. 5 minutes [interquartile range, 5 to 10]). On day 90, the 56 participants in the intervention group who responded to the telephone interview had a significantly lower median IES score than the 52 participants in the control group (27 vs. 39,  $P = 0.02$ ) and a lower prevalence of PTSD-related symptoms (45% vs. 69%,  $P = 0.01$ ). The median HADS score was also lower in the intervention group (11, vs. 17 in the control group;  $P = 0.004$ ), and symptoms of both anxiety and depression were less prevalent (anxiety, 45% vs. 67%;  $P = 0.02$ ; depression, 29% vs. 56%;  $P = 0.003$ ).

**CONCLUSIONS**

Providing relatives of patients who are dying in the ICU with a brochure on bereavement and using a proactive communication strategy that includes longer conferences and more time for family members to talk may lessen the burden of bereavement. (ClinicalTrials.gov number, NCT00331877.)

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HAVING A LOVED ONE DIE IN THE intensive care unit (ICU) is an extraordinarily stressful event.<sup>1</sup> The patient is usually unable to communicate with the family or with ICU staff. Qualitative and quantitative studies of families in this situation<sup>2</sup> have identified effective communication between caregivers and families and support from caregivers throughout the decision-making process as important to family members.<sup>3-9</sup>

In many ICUs, an end-of-life family conference, which is rooted in findings from epidemiologic and interventional studies on communicating with families of dying patients, is an important part of ICU practice.<sup>10</sup> In these conferences, family members and ICU staff discuss the patient's situation in a quiet room. Ideally, family members are given opportunities to ask questions, express concerns, and confront painful emotions with the help of caring, compassionate professionals.<sup>11,12</sup>

Although the conference is important, the effect of its structure on bereaved family members has not been evaluated in a randomized trial. We

conducted a multicenter, randomized, controlled study to evaluate the effect of a proactive communication strategy that consisted of an end-of-life family conference conducted according to specific guidelines and that concluded with the provision of a brochure on bereavement. We hypothesized that this intervention, as compared with the customary end-of-life conference, would decrease stress-related symptoms and symptoms of anxiety and depression in family members 90 days after the patient's death.

## METHODS

We conducted a prospective, randomized, controlled trial in 22 ICUs (Table 1) in France from May 2005 to October 2005. The study was approved by the institutional review board of the French Society for Critical Care, and oral informed consent was obtained from the participating families. At each ICU, one investigator was responsible for the study, which included six consecutive patients and their surrogates. On day 90, one mem-

**Table 1. Characteristics of the 22 ICUs in the Study.**

Characteristic	Value
Teaching hospital — no. (%)	15 (68)
Type of ICU — no. (%)	
Medical	10 (45)
Surgical	3 (14)
Medical and surgical	9 (41)
No. of attending physicians — median (interquartile range)	6 (5–6)
No. of residents — median (interquartile range)	3 (3–4)
No. of patients per nurse — median (interquartile range)	3 (3–3)
No. of beds — median (interquartile range)	16 (12–21)
Rooms with more than two beds — no. (%)	10 (45)
Regular (at least weekly) nurse–physician meetings — no. (%)	19 (86)
Availability of bereavement brochure before study began — no.	0
Research group on end-of-life family care — no. (%)*	8 (36)
End-of-life family conferences held before study began — no.	0
Routine involvement of family members in daily care — no. (%)	8 (36)
Routine involvement of family members in decisions — no. (%)	8 (36)
No. of family–staff conflicts in 2004 — median (interquartile range)	25 (12–41)
No. of visiting hours per day — median (interquartile range)	4 (2–8)
Unrestricted visiting hours — no. (%)	5 (23)
Psychologist present in ICU — no. (%)	5 (23)

\* The research groups consisted of nurses and doctors who met weekly to discuss how to improve the quality of care.

**Table 2. Characteristics of Patients and Enrolled Family Members at Time of ICU Admission.**

Characteristic	Control Group (N=63)	Intervention Group (N=63)	P Value
<b>Patients</b>			
Age — yr			0.10
Median	68	74	
Interquartile range	56–76	56–80	
Male sex — no. (%)	37 (59)	33 (52)	0.47
French descent — no. (%)	56 (89)	58 (92)	0.60
Unmarried — no. (%)	15 (24)	21 (33)	0.23
Direct admission to ICU — no. (%)	34 (54)	37 (59)	0.77
Coexisting conditions — no. (%)			
Chronic obstructive pulmonary disease	13 (21)	13 (21)	0.99
Chronic heart failure	10 (16)	14 (22)	0.36
Cancer	21 (33)	12 (19)	0.10
Cirrhosis	2 (3)	5 (8)	0.24
Poor performance status — no. (%)	28 (44)	27 (43)	0.61
Reason for ICU admission — no. (%)			
Acute respiratory failure	28 (44)	27 (43)	0.85
Coma	27 (43)	25 (40)	0.71
Shock	21 (33)	24 (38)	0.57
Acute renal failure	11 (18)	14 (22)	0.50
Cardiac arrest	14 (22)	16 (25)	0.67
Simplified Acute Physiology Score — median (interquartile range)†	64 (52–76)	59 (52–81)	0.85
Treatment needed at end of life — no. (%)			
Mechanical ventilation	56 (89)	58 (92)	0.54
Vasopressors	42 (67)	49 (78)	0.23
Dialysis	16 (25)	14 (22)	0.67
Sedation	47 (75)	49 (78)	0.83
<b>Family members‡</b>			
Male sex — no. (%)	12 (23)	17 (30)	0.39
Age — yr			0.48
Median	54	54	
Interquartile range	46–64	47–58	
French descent — no. (%)	46 (88)	48 (86)	0.35
Catholic — no. (%)	35 (67)	35 (63)	0.78
Married — no. (%)	24 (46)	22 (39)	0.57
Relationship to patient — no. (%)			
Spouse	22 (42)	20 (36)	
Child	22 (42)	30 (54)	
Parent	5 (10)	2 (4)	
Other	3 (6)	4 (7)	

\* Indicates that the participants and their parents were born in France.

† Scores range from 0 to 163, with higher scores indicating more severe illness.

‡ Data are for the 52 family members in the control group and the 56 family members in the intervention group who were interviewed at 90 days.

ber of each family — either the patient's designated surrogate or the person who ranked highest in the hierarchy for surrogate decision making — was interviewed.<sup>13</sup> Additional methodologic details are presented in the Supplementary Appendix, available with the full text of this article at [www.nejm.org](http://www.nejm.org).

#### PARTICIPANT SELECTION AND STUDY PROCEDURES

The only criterion for inclusion in the study was the belief by the physician in charge that the patient would die within a few days. Patients young-

er than 18 years of age were excluded from the study, as were family members who had insufficient knowledge of French for a telephone interview. Table 2 lists characteristics of the patients and family members. Surrogates were assigned at random to the intervention or control group. In the control group, interactions between the family and the ICU staff, including the end-of-life conference, occurred according to the usual practice at each center. In the intervention group, the end-of-life family conference was held in accordance with detailed guidelines developed by

**Table 3. Implementation of the Intervention and End-of-Life Care, Including Decisions to Forgo Life-Sustaining Treatments.\***

Variable	Control Group (N=63)	Intervention Group (N=63)	P Value
<b>Implementation of intervention</b>			
Family informed of decision to forgo life-sustaining treatment — no. (%)	61 (97)	63 (100)	0.99
More than one family member informed of decision — no. (%)	55 (87)	58 (92)	0.55
Involvement of family in decision — no. (%)			
No involvement	2 (3)	0	0.15
Family members expressed patient's wishes	34 (54)	44 (70)	0.04
Family members expressed their own wishes	53 (84)	44 (70)	0.05
<b>End-of-life conference</b>			
No. of family members present			0.07
Median	2	3	
Interquartile range	2–3	2–3	
Nurse present — no. (%)	38 (60)	51 (81)	0.03
No. of ICU physicians present			0.05
Median	1	2	
Interquartile range	1–2	1–2	
Duration of conference — min			<0.001
Median	20	30	
Interquartile range	15–30	19–45	
Total time that family members spoke — min			<0.001
Median	5	13.5	
Interquartile range	5–10	8–20	
Total time that nurse spoke — min			0.006
Median	1	3	
Interquartile range	0–3	0.5–5	
Clinicians' observations — no. (%)			
Family expressed guilt	13 (21)	7 (11)	0.01
Family reported successful expression of emotions	47 (75)	60 (95)	0.03
Family believed that patient's symptoms were controlled	61 (97)	61 (97)	0.99
Family reported conflicts with ICU staff	1 (2)	1 (2)	0.95

one of the authors at the University of Washington.<sup>10,14,15</sup> Families were given a brochure on bereavement (see the Supplementary Appendix for the original French version and a version translated into English by the authors). The end-of-life conference used in the intervention group had five objectives for the caregivers, summarized by the mnemonic VALUE<sup>10,14,15</sup>: to value and appreciate what the family members said, to acknowledge the family members' emotions, to listen, to ask questions that would allow the caregiver to understand who the patient was as a person, and to elicit questions from the family members. Each

investigator received a detailed description of the conference procedure.<sup>10</sup> Randomization was performed centrally in blocks of six, stratified according to the ICU, with group assignments sent in sealed envelopes to the study centers (for details see the Supplementary Appendix).

#### OUTCOME MEASURES

One family member per patient was interviewed over the telephone 90 days after the patient's death; the interviews took place between August 2005 and January 2006. The primary outcome measure was the score on the Impact of Event Scale

**Table 3. (Continued.)**

Variable	Control Group (N=63)	Intervention Group (N=63)	P Value
<b>End-of-life care</b>			
Decision to forgo life-sustaining treatments — no. (%)	63 (100)	63 (100)	1.00
No. of days from ICU admission to decision			0.38
Median	5	2	
Interquartile range	2–10	2–14	
Nonbeneficial interventions after end-of-life conference — no. (%)			
Mechanical ventilation	47 (75)	41 (65)	0.30
Vasopressors	23 (37)	17 (27)	0.33
Dialysis	1 (2)	0	0.99
Other†	35 (56)	28 (44)	0.16
No. of nonbeneficial interventions provided after decision to forgo life-sustaining treatments			0.04
Median	3	2	
Interquartile range	2–3	2–3	
Life-sustaining treatments withdrawn — no. (%)			
Mechanical ventilation	9 (14)	17 (27)	0.03
Vasopressors	19 (30)	32 (51)	0.01
Dialysis	15 (24)	14 (22)	0.78
<b>Other data</b>			
No. of days from decision to forgo life-sustaining treatments to death			0.16
Median	2	1	
Interquartile range	1–3	1–2	
No. of days in ICU			0.54
Median	9	7	
Interquartile range	5–20	4–14	
Conflicts with family members reported by ICU staff — no. (%)	4 (6)	8 (13)	0.36
Patients who survived and were discharged — no. (%)	2 (3)	1 (2)	0.30

\* The intervention began on the day that the end-of-life family conference was held.

† Other treatments were blood transfusions, antibiotics, and vitamins.

(IES), which assesses symptoms related to post-traumatic stress disorder (PTSD); scores range from 0 (no PTSD-related symptoms) to 75 (severe PTSD-related symptoms).<sup>5,16-18</sup> We classified patients as having low or high IES scores, using 30 as the cutoff, in agreement with previous reports.<sup>5,18</sup> Secondary outcome measures were symptoms of anxiety and depression, which we assessed using the Hospital Anxiety and Depression Scale (HADS); subscale scores range from 0 (no distress) to 21 (severe distress).<sup>19,20</sup> HADS subscale scores above 8 were considered to indicate clinically significant symptoms of anxiety or depression.<sup>19</sup>

#### DATA COLLECTION

Investigators recorded ICU and patient characteristics on standardized forms. The data elements included in Table 3 were gathered in a prospective fashion. In addition, a specific form was used to collect data describing the end-of-life family conference, and investigators were asked to clock family conference times. Primary-outcome data were collected by the interviewer 90 days after the patient's death.

#### STATISTICAL ANALYSIS

On the basis of data from our previous study,<sup>5</sup> we hypothesized that the intervention would decrease the risk of PTSD-related symptoms by 30%. To detect a significant difference between the two groups with a type I error of 0.05 and a power of 0.90, 100 families had to be recruited, 50 in each group. We decided to include 132 family members (66 in each group) to allow for families lost to follow-up on day 90 (up to 25%).<sup>5</sup> Continuous variables were reported as medians and interquartile ranges, and categorical variables as proportions. Comparisons of continuous variables between the two randomized groups were performed with the Wilcoxon rank-sum test, whereas comparisons of categorical variables were performed with the Pearson chi-square test or Fisher's exact test, as appropriate. All tests were two-sided, and P values of less than 0.05 were considered to indicate statistical significance. Statistical tests were performed with the SAS software package, version 9.1 (SAS Institute).

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## RESULTS

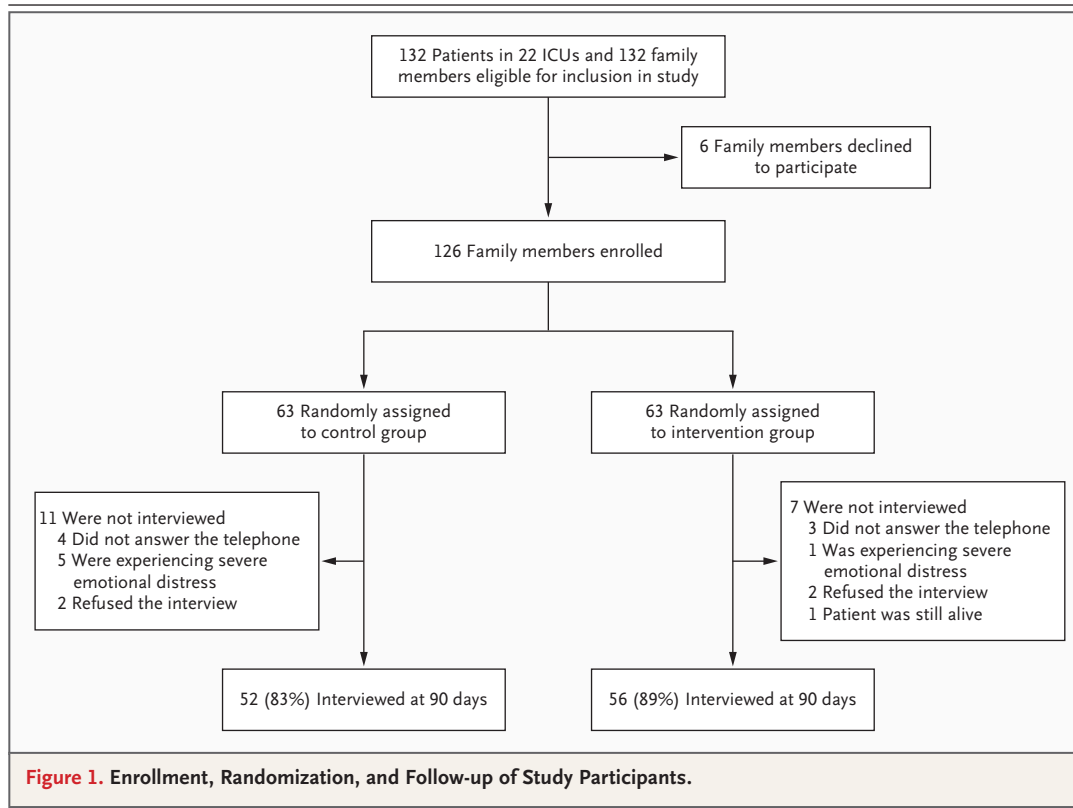
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Of the 132 eligible family members, 126 were randomly assigned to a study group, and 108 (86%)

were interviewed 3 months after the patient's death (range, 90 to 104 days) (Fig. 1). Of the 22 ICUs in the study, 15 were in teaching hospitals, and 7 in general hospitals. In all the ICUs, nurses and physicians held regular meetings about end-of-life issues; however, only three ICUs had written procedures for delivering information to families of dying patients, and only five ICUs had unrestricted visiting hours. Before the study, none of the ICUs provided family members with written information about bereavement, and none were aware of the VALUE-based guidelines for end-of-life conferences. The characteristics of the patients at enrollment did not differ significantly between the two study groups. A decision to forgo life-sustaining treatment was made for all the study patients; at the time that the decision was implemented, 114 patients (90%) were receiving mechanical ventilation and 96 (76%) were deeply sedated, precluding meaningful communication between the patient and family.

A comparison of the characteristics of the end-of-life conferences in the two study groups provides a measure of the implementation of the intervention. The significant differences in the conduct of the conferences, shown in Table 3, suggest that the guidelines for the intervention conferences were followed.<sup>2,21</sup>

Regarding the prespecified process-of-care measures listed in Table 3, although the length of stay in the ICU and in the hospital did not differ significantly between the intervention and control groups, there were fewer nonbeneficial interventions (continued life support after a decision to withhold or withdraw life-sustaining treatments) in the intervention group (see Fig. 1 of the Supplementary Appendix), and withdrawal of mechanical ventilation and vasopressors was more common in this group than in the control group. Among the relatives who initially disagreed with the ICU clinicians regarding decisions to forgo life-sustaining treatments, those in the intervention group were more likely to agree with the decisions eventually (six relatives in the intervention group vs. none in the control group,  $P=0.02$ ). Among the family members in both groups, 96 (89%) reported that the amount of time spent providing information was sufficient, and 97 (90%) felt that the information was clear; 41 (38%) reported a desire for additional information that was not provided (Table 4). The proportions of family members who reported a desire



for additional information, who received newly prescribed psychotropic drugs, and who expressed feelings of guilt were lower in the intervention group than in the control group. In addition, 95% of family members in the intervention group said they were able to express their emotions to the ICU team, as compared with only 75% of family members in the control group.

Regarding the prespecified main outcome variables recorded 90 days after the death of the patient (Table 4), the IES scores in the intervention group were lower than those in the control group (median score, 27 [interquartile range, 18 to 42] vs. 39 [interquartile range, 25 to 48];  $P=0.02$ ), indicating that 25 family members in the intervention group (45%) were at risk for PTSD as compared with 36 (69%) in the control group. Similarly, family members in the intervention group had significantly lower HADS scores than those in the control group (median score, 11 [interquartile range, 8 to 18] vs. 17 [interquartile range, 11 to 25];  $P=0.004$ ), with 25 family members (45%) reporting clinically significant symptoms of anxiety and 16 (29%) reporting clinically significant symptoms of depression, as compared with 35

(67%) and 29 (56%) in the control group, respectively ( $P=0.02$  and  $P=0.003$ , respectively) (Fig. 2).

## DISCUSSION

Over the past decade, epidemiologic studies have identified the specific needs of family members of dying patients,<sup>3-7</sup> thereby allowing the development of proactive interventions that have improved communication with family members.<sup>22,23</sup> End-of-life family conferences are rooted in the evidence provided by this literature, their main goals being to improve communication between ICU staff and family members and to assist families when difficult decisions need to be made.<sup>10,11,14</sup> In our multicenter, randomized study, we compared two end-of-life conference formats, one reflecting a proactive approach to communication and ending with the provision of a brochure on bereavement, and the other reflecting the typical approach used by each center. The proactive communication strategy decreased PTSD-related symptoms and symptoms of anxiety and depression among family members.

In the intervention group, ICU clinicians were

**Table 4. Outcomes Assessed on Day 90.**

Variable	Control Group (N=52)	Intervention Group (N=56)	P Value
IES score			0.02
Median	39	27	
Interquartile range	25–48	18–42	
Presence of PTSD-related symptoms (IES score >30) — no. (%)	36 (69)	25 (45)	0.01
HADS score			0.004
Median	17	11	
Interquartile range	11–25	8–18	
Symptoms of anxiety — no. (%)	35 (67)	25 (45)	0.02
Symptoms of depression — no. (%)	29 (56)	16 (29)	0.003
Saw a psychologist after death of patient — no. (%)	6 (12)	4 (7)	0.41
Received newly prescribed psychotropic drugs after death of patient — no. (%)	12 (23)	6 (11)	0.05
Effectiveness of overall information provided — no. (%)			
Time allotted to provide information was sufficient	45 (87)	51 (91)	0.45
Information was clear	45 (87)	52 (93)	0.34
Additional information requested	24 (46)	17 (30)	0.05

asked to follow detailed published guidelines<sup>14,15</sup> to ensure a uniform and effective change in their approach to communication. As compared with the control conferences, the intervention conferences were attended by a larger number of relatives and were associated with longer times spent delivering information and listening to relatives. The intervention conferences also provided family members with more opportunities to discuss the patient's wishes, to express emotions, to alleviate feelings of guilt, and to understand the goals of care. Our finding that patients in the intervention group received fewer nonbeneficial treatments concurs with evidence of the efficacy of proactive strategies such as ethics consultation<sup>24</sup> and early palliative-care consultation for dying patients in the ICU.<sup>25</sup>

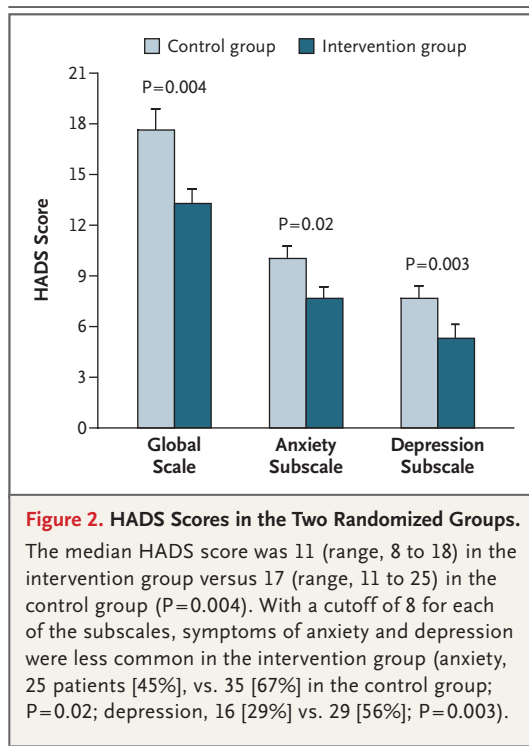
A bereavement brochure was given to the family at the end of the intervention conference. Previous studies by our research group showed that comprehension was markedly improved by simply delivering standardized written information for families.<sup>23</sup> This experience prompted us to include a brochure in our proactive communication strategy. Furthermore, prior research suggests that multifaceted interventions are necessary to effect changes in clinicians' behavior.<sup>26</sup>

Our study has several limitations. First, it was performed in France, where the patient-physician

relationship is perceived as more paternalistic than elsewhere,<sup>27</sup> with physicians having final authority in decisions to forgo life-sustaining treatments.<sup>5</sup> Nonetheless, the intervention used in our study was rooted in the international literature and is relevant to other countries.<sup>2</sup> It might be argued that the gap between the intervention and the control groups was larger as a result of paternalistic attitudes in the control group, since this group replicated usual practice; if this view is correct, the magnitude of the beneficial effect of the intervention in France would be greater than could be expected in countries where shared decision making with family members is more firmly established. A strong argument against this view, however, is the fact that interactions with family members in the control group were similar to those reported in other European countries and in North America.<sup>14,15</sup> Furthermore, the results of our intervention were consistent with those in earlier studies of proactive interventions.<sup>22,24,25</sup> In addition, 22 centers participated in our study, further enhancing the generalizability of our findings.

Second, our only criterion for inclusion in the study was the belief on the part of the physician in charge that death was inevitable and that a decision to forgo life-sustaining treatment was in order. In some cases, however, patients in such





circumstances survive.<sup>28,29</sup> Conceivably, our intervention might have a negative effect on the family members of patients who survive, a situation that transpired only once in this study. Nevertheless, the possible negative effects of such an event must be compared with the negative effects of suboptimal communication on the much larger number of families whose relatives die.

Third, we did not determine how many families read the bereavement brochure or how those who did reacted to it. The multicenter design of the study and the fact that each ICU physician held only three intervention conferences did not allow us to evaluate the physicians' learning curve. Previous work has shown that even a brief course of training may improve communication skills.<sup>30</sup> A study over time would be useful to determine whether benefits to the families increase as ICU physicians improve their communication skills. There is a need to develop a process for evaluating and improving end-of-life conferences in ICUs. Also, to make sure that the interviewer was unaware of the group assignments, we did not ask questions about the intervention itself during the telephone interview.

Fourth, because we did not assess the HADS score before the critical illness or at the time of

the patient's death, we cannot be sure that the two groups of family members were not different at baseline. However, in a recent noninterventional study, we recorded the HADS score for family members 90 days after the patient's discharge or death.<sup>5</sup> The median score was 17 (interquartile range, 10 to 22), suggesting not only that symptoms of anxiety and depression were common and lasting but also that the proactive communication strategy we tested in the current study had positive effects.

Fifth, although the interviewer and the analyst were unaware of the group assignments, blinding of family members and ICU clinicians was not feasible. Consequently, we cannot exclude the possibility that the investigators believed strongly in the effectiveness of the intervention and that this may have influenced other interactions with family members.

Finally, the positive results of the current study might in theory indicate that in the control group, communication was less personalized and interactive than the norm. However, we believe that the characteristics of the control conferences (reported in Table 3) — notably, their longer duration, as compared with that in earlier work by our group (20 minutes vs. 10 minutes) — show that communication with families was as good as, or better than, the norm. In addition, the proportion of relatives who were satisfied with the information they received and the proportion who requested additional information indicate that the standard of care for providing information was met.<sup>5,23,31</sup> The fact that the IES and HADS scores in the control group were similar to those in our previous studies argues against the possibility that the control conferences were substandard, as does the extensive experience acquired over the years by the ICU physicians in our study group.<sup>5,19,23,31-34</sup>

In summary, a proactive strategy for routine end-of-life family conferences that included provision of a brochure on bereavement, as compared with customary practice, resulted in longer meetings in which families had more opportunities to speak and to express emotions, felt more supported in making difficult decisions, experienced more relief from guilt, and were more likely to accept realistic goals of care. The result of this strategy was a decrease in PTSD-related symptoms and symptoms of anxiety and depression 3 months after the patient's death.

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