"It Was the Only Thing I Could Hold Onto, But…": Receiving a Letter of Condolence After Loss of a Loved One in the ICU

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"It Was the Only Thing I Could Hold Onto, But…": Receiving a Letter of Condolence After Loss of a Loved One in the ICU: A Qualitative Study of Bereaved Relatives' Experience

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Objectives: Family members of patients who die in the ICU often remain with unanswered questions and suffer from lack of closure. A letter of condolence may help bereaved relatives, but little is known about their experience of receiving such a letter. The objective of the study was to understand bereaved family members' experience of receiving a letter of condolence.

Design: Qualitative study using interviews with bereaved family members who received a letter of condolence and letters written by these family members to the ICU team. This study was designed to provide insight into the results of a larger randomized, controlled, multicenter study.

Setting: Twenty-two ICUs in France.

Subjects: Family members who lost a loved one in the ICU and who received a letter of condolence.

Measurements and Main Results: Thematic analysis was used and was based on 52 interviews and 26 letters. Six themes emerged: 1) a feeling of support, 2) humanization of the medical system, 3) an opportunity for reflection, 4) an opportunity to describe their loved one, 5) continuity and closure, and 6) doubts and ambivalence. Possible difficulties emerged, notably the re-experience of the trauma, highlighting the absence of further support.

Conclusions: This study describes the benefits of receiving a letter of condolence; mainly, it humanizes the medical institution (feeling of support, confirmation of the role played by the relative, supplemental information). However, this study also shows a common ambivalence about the letter of condolence's benefit. Healthcare workers must strive to adapt bereavement follow-up to each individual situation.

Key Words: bereavement research; end-of-life; intensive care; qualitative study; letter of condolence

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During the last days of life, the physician not only cares for the patient but also for the relatives. Interaction during this period is important for relatives; however, quality of communication is not always optimum (1). Many relatives often have unanswered questions regarding the patient's ICU stay that can hinder the grieving process. Furthermore, relatives develop relationships with the caregivers and need an opportunity to say good-bye to them: closure may help grieving. After the patient has died, "all the doctors just suddenly go" (2), although the relatives continue to need contact from the physician.

Follow-up of bereaved relatives by physicians has essentially been described in oncology and palliative care (3–5). These studies show diverse practices, less than 50% of physicians send letters of condolence. It is still difficult to achieve consensus regarding what is the best support for bereaved persons (6). According to Bedell et al (7), a letter of condolence can contribute to the healing of the bereaved family by acknowledging the loss, expressing sympathy, and offering an opportunity to clarify questions about the patient's terminal care. A recent study shows that a letter of condolence is perceived as satisfactory by grieving relatives (8). However, to the best of our knowledge, no study had yet focused on the impact of a letter of condolence on bereaved relatives' experience. This question is particularly important in the ICU context where death is frequent and bereaved relatives' burden is high: finding ways to alleviate post-ICU burden is necessary.

Surprisingly, in our randomized controlled trial (9), we showed that receiving a letter of condolence was significantly associated with increased risk of developing symptoms of depression and posttraumatic stress disorder 6 months after the loss. However, if these results provide evidence of the impacts of a letter of condolence on the grieving process, they do not help understand how relatives perceive and interpret the letter: giving voice to the relatives will permit a better understanding of their feelings by obtaining an in-depth description of their experiences. This study was designed to provide insight into the results of our larger randomized, controlled, multicenter study.

METHODS

This study is part of a larger randomized, controlled, multicenter study (10) whose objective was to measure the impact of the letter of condolence on bereaved relatives' grieving process after a death in the ICU. Two groups of bereaved relatives were compared: those who did not receive a letter of condolence (control) and those who received a letter of condolence 15 days after the death (intervention). Participating relatives were followed up by phone with a call at 1 month and one at 6 months to complete questionnaires permitting evaluation of post-ICU burden (10). These calls were made by a psychologist, a sociologist, and a research nurse, all experienced in bereavement research. The study protocol was approved by the French ethics committee CPP Ile de France IV, Saint-Louis (April 15, 2014, #2014/14SC), and French health authorities (CNIL MMS/VCS/AR149697 and CTTIRS #14284).

One of the secondary purposes of this study was to investigate relatives' experience and reactions in receiving a letter of condolence. For this purpose, the persons calling relatives for response to the quantitative questionnaires transcribed verbatim every spontaneous saying regarding the letter. As relatives were not informed that the letter of condolence was the object of the study and as interviewers were blinded to group allocation, the researchers could not explicitly question them about the letter: only spontaneous declarations were possible, then followed by deeper interviews. Also, in both groups, the clinicians recorded all reactions or feedback (telephone calls, letters, or visits) from the relatives within 4 months following death. Any letters written to the teams by the relatives during this period were photocopied and sent to the Famiréa group.

Analysis comprised examination of both the relatives' spontaneous declarations during telephone follow-up interviews and their letters spontaneously written to the ICU teams (textual analysis). Our approach respected the guidelines for qualitative research (relevance, appropriateness, transparency, soundness) (11).

Subjects

As described elsewhere (9), 242 relatives from 22 ICUs in France participated in the original study between December 2014 and April 2015. One member per family was invited to participate in this study (the designated surrogate or the person who ranked highest in hierarchy for surrogate decision-making). Inclusion criteria included the following: adult patients, ICU length stay before death greater than 48 hours, and at least one visit from the relative in the ICU. The only exclusion criterion was the relative's lack of sufficient knowledge of French.

At the time of the patient's death, an information letter was given to the relative, and consent to participate was obtained. Once consent was obtained, relatives were randomized to the intervention or the control group. In the intervention group, a letter of condolence was written according to a guide developed by study investigators (10). Letters were handwritten by the patient's physician and nurse and sent by standard mail 15 days after the patient's death.

Analysis

Relatives' spontaneous declarations regarding the condolence letter were transcribed verbatim. These declarations and all letters received by the participating ICUs from bereaved relatives having received a letter of condolence were analyzed. The data were analyzed by two sociologists (N.K.B., Z.C.S.), both researchers with extensive experience in bereavement research and a research nurse (V.S.). A psychologist (M.G.) also read the transcripts and the letters and further clarified the results. We used a thematic approach, and our processes were similar to those described for previous studies (12–15). Each team member independently read all of the transcripts and letters. The team then met and offered what they considered to be meaningful descriptions of relatives' experiences with reception of a letter of condolence. The descriptions were then sorted into themes, that is, patterns across the data that are important to the description and understanding of a phenomenon. Differences of opinion about the themes were reviewed by the team members during several analysis meetings. Final themes and examples of relatives' experiences and reactions to the letter of condolence were agreed upon by all members of the team. Findings from this process are reported as descriptive information, and a sample of quotes were selected to represent the themes. We created a table of quotes that reinforce each theme (**Supplemental Table 1**, Supplemental Digital Content 1, http://links.lww.com/CCM/C841).

RESULTS

A total of 242 relatives of patients who died in the 22 participating ICUs were enrolled in the original study, including 123 who received a letter of condolence. There were no significant differences in characteristics of relatives who received versus those who did not receive a condolence letter (**Table 1**). During follow-up, 208 (85.9%) completed the telephone interview at 1 month after the patient's death and 188 (77.6%) at 6 months (**Fig. 1**). Among the relatives who completed the questionnaires at 1 month, 107 had received a letter of condolence.

At 1 month, 30 of 107 relatives (27.5%) expressed themselves spontaneously about receiving a letter of condolence and another 22 (including 16 who had not already expressed themselves at 1 month) at 6 months. Just over 40% of relatives (51/123; 41.4%) who received a letter of condolence contacted the ICU teams either by letter, visit, or phone call versus only 6.6% of relatives who had not received a letter. Among the 40%, 26 wrote a letter, 15 called, 10 visited the ICU. An example of a letter of condolence and of a letter written in response to the physician is available in **supplemental document 1** (Supplemental Digital Content 2, http://links.lww.com/CCM/C842).

TABLE 1. Characteristics of the Family Members

Quantitative Study (Randomized Controlled Trial)		
Relatives at the 1-Mo Interview	**Condolence Letter, *n* = 109**	**Control Group, *n* = 99**
Age, median (25–75th percentiles)	57 (46–65.5)	56 (44–64.5)
Female gender, *n* (%)	74 (67.9)	71 (71.7)
Relationship to the patient, *n* (%)		
Spouse	42 (38.5)	32 (32.3)
Adult child	43 (39.4)	40 (40.4)
Other	24 (22.0)	26 (26.2)
Living alone after the patient's death, *n* (%)	45 (41.3)	43 (43.4)

Qualitative Study		
Relatives' Characteristics, n = 52	**n (%)**	**Description of Relatives' Gender and Relationship to Deceased**
Female gender, *n* (%)	41 (79)	
Relationship to the patient, *n* (%)		
Spouse	15 (28.8)	11 wives, four husbands
Adult child	20 (38.5)	15 daughters, five sons
Other	17 (32.7)	Five mothers, five sisters, two aunts, two female cousins, one niece/one male cousin, one nephew
Living alone after the patient's death, *n* (%)	18 (34.6)	

Our analyses are based on these 52 spontaneous declarations made during telephone interviews and 26 letters.

We derived six themes that helped answer our two research questions: how do relatives experience receiving a letter of condolence (emotions)? What are their reactions and responses to the letter? Below are the descriptions of the six themes and quotes from relatives that help support our themes (**Table 2**; and Supplemental Table 1, Supplemental Digital Content 1, http://links.lww.com/CCM/C841).

Theme 1. A Feeling of Support

This theme was endorsed by nearly 80% of relatives (interviews and letters). First, relatives perceive three benefits:

1) To feel support and help during bereavement: "My family and I would like to express our profound gratitude. Your letter helped us tremendously in surpassing our huge pain" (sister, letter)

2) To release emotions: "Thank you for your kind letter: I was filled with emotion as I read it. It was a great comfort although each time I read it, I weep but it is important to evacuate one's pain" (sister, letter)
3) To feel reassured that the patient was in good hands: "I received a kind letter with explanations… I now see that he was cared for like a human being, alive and worthy. It really helped me to read that letter." (daughter, during follow-up interview)

Second, relatives highlight the importance of receiving both personal consideration and extra medical information.

1) Confirmation that they played a role during the patient's ICU stay: "I received a handwritten letter from the two physicians who looked after him. They said how important it was that I was there, that I didn't try to escape in the most difficult moments as others might have done. It came as an great comfort" (wife, during follow-up interview)
2) Obtaining important information about the dying process: "He died alone but recently we received a very kind letter from the physician who said we could call him if we needed to, so I did. In his letter he gave the name of the nurse who was with my dad when he died, that was very important to us." (daughter, during follow-up interview)
3) Remembering the experience: "Your letter sincerely and deeply touched me and moved me. As I read it, I saw myself by Mummy, the way we looked at each other, the way we smiled to each other for the last time, the last words we exchanged and… her last moments" (daughter, letter)

Theme 2. Humanization of the Medical Institution

Receiving a letter of condolence increases the relatives' trust in the medical institution: just over half express this theme (interviews and letters). First, it is interesting to note that during the difficult period of grieving, the letter of condolence is not only seen as an attention but also as a gift: "I found a gift, a very very beautiful gift, I found a letter. A handwritten letter. It was a very personal letter about me and my husband. It was a beautiful gift. When I read it, I felt a rush of happiness" (wife, during follow-up interview)

Second, receiving such a gift leads to satisfaction and increases trust in the medical institution, as expressed by many relatives: "It is the first time that our family has been the object of such sensitivity from the members of a medical team and, even if I hope you are not an exception, you will remain one for us. For that also I am grateful as, thanks to your letter, I rediscover the hope that medicine can be humanized, and that's a lot" (niece, letter)

Theme 3. Reflection: Thoughts About the Patient's Care

Receiving a letter encourages the relatives to write to the ICU team:

1) To thank the team for the quality of care (expressed in 40% of letters written to the team): "Thanks to your professionalism, your kindness and your capacity to listen, you helped and supported us so that J. could have a dignified and painless end-of-life" (sister, letter)

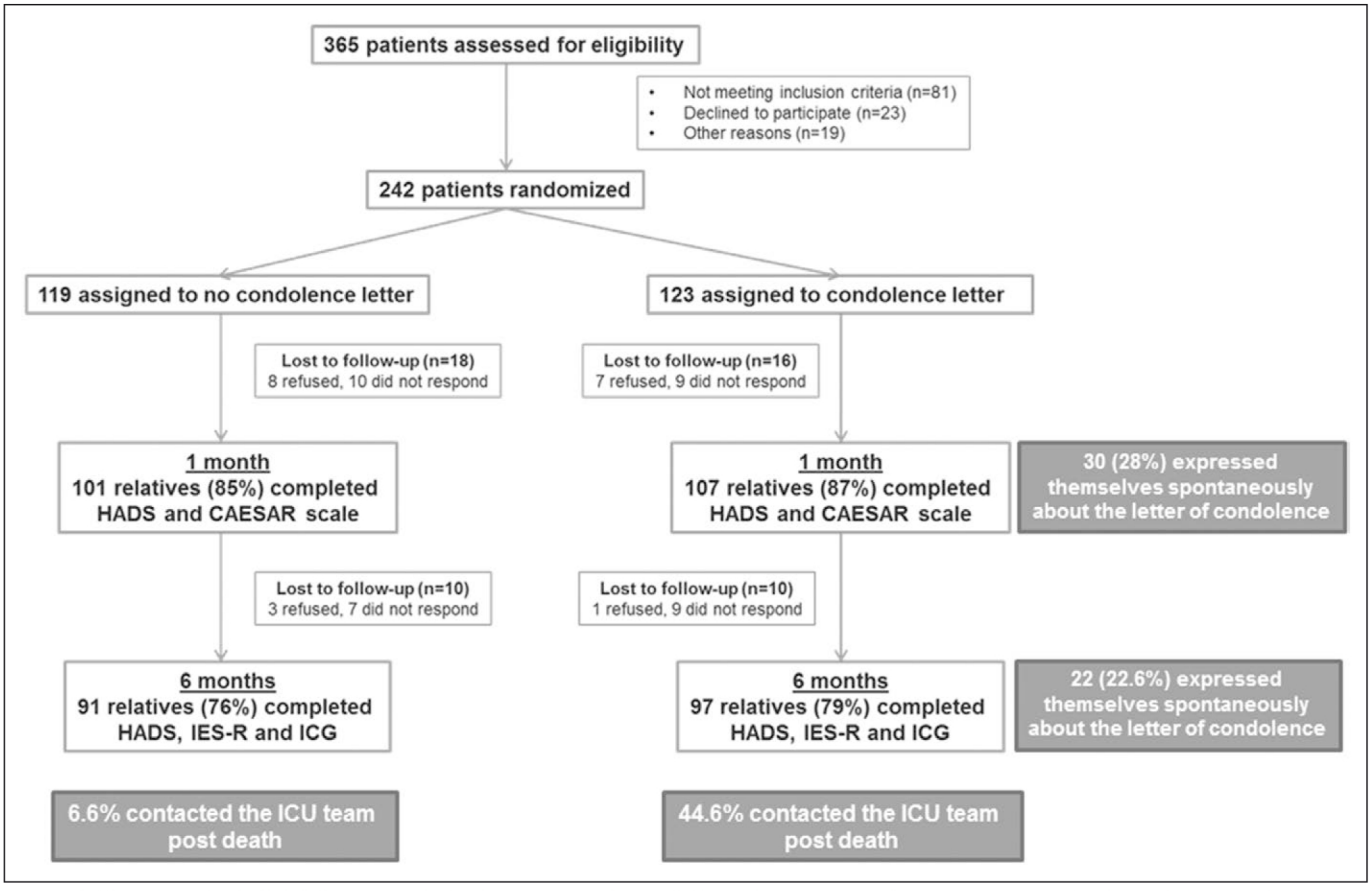

Figure 1. Study flow chart. CAESAR scale = relatives' experience of end-of-life, HADS = Hospital Anxiety and Depression Scale, CG = Inventory of Complicated Grief, IES-R = Impact of Event Scale-Revised (posttraumatic stress disorder).

TABLE 2. Family Members' Experience and Reactions

Themes	Subthemes
Support	Support and reassurance
	Recognition
Humanization	A gift
	Increased trust in the medical institution
Reflection	Thank the team
	Recognize the physician as a person
Narration	Narrate the patient
	Narrate the relationship
	Narrate the funeral
Continuity	Closure and other expectations
	Hesitations
Doubts	Negative interpretation
	Commitment

2) To recognize the physician as a Person: "My family and I would like to thank you for your welcome in the ICU and more particularly you, Doctor, you managed to find the words and to show us compassion. You are a good doctor, but mostly you are a generous woman." (wife, letter)

Theme 4. Narration: An Opportunity to Describe…

The letter of condolence comes as a confirmation of the link between themselves and the caregivers, encouraging just under one third of relatives to go further in their bond by telling the team more about the patient, their relationship and also the funeral (letters written to the team). These last revelations also come as a way to close the relationship with the team.

1) To describe the patient: "Yes, you are so right, she was an elegant, courageous woman, who deeply loved life, her family and mankind" (niece, letter)
2) To describe the relationship: "I cannot express all that my mother meant to me and for those who surrounded her. I hope, and I believe, that I managed to always be and to do all that I should have been and done for my mother, just as my mother always was and did for me" (daughter, letter)
3) To describe the funeral: "You may find my approach curious but attached to this letter is the text I wrote to my mother and that I read on the day of her funeral (…)" (son, letter)

Theme 5. Continuity: Hesitations About Contacting the Team…

As mentioned above, 40% of relatives who received a letter of condolence contacted the team in the weeks that followed. Most did so to express thanks and gratitude, whereas others used the opportunity mentioned in the letter to ask for a meeting so as to go over the hospitalization and/or the dying process with the physician.

However, although all letters ended with an invitation to contact the team, some relatives still did not dare to call for fear of bothering the physician. A small number of relatives (2) felt socially obliged to answer the letter as is expected by prescribed social etiquette. Another small number of relatives (2) contacted the physicians with very different motives, such as asking for advice on a different subject and even proposing a date (Supplemental Table 1, Supplemental Digital Content 1, http://links.lww.com/CCM/C841a).

Theme 6. Doubts: Some Negative Reactions

Approximately 30% of relatives (interviews and letters) were surprised to receive a letter and wondered why they should benefit from such a personalized attention: "(…) I was also very surprised. I did not expect such follow-up care as it is, one has to admit, very rare in the medical milieu" (wife, letter)

Some relatives were so surprised to receive a letter of condolence that they felt the physician was either hiding something or worried that the family may be dissatisfied with the quality of care. "I was mostly surprised really (…). I don't think it's a frequent practice (…). I wondered if the physician wasn't feeling guilty about something" (father, during follow-up interview)

Last, the study puts forward the importance of commitment. All letters of condolence ended with an invitation to contact the team if wanted. Most relatives received a positive answer to their request, but when this did not happen, the letter and the sincerity of the physician were questioned, leaving the relative feeling extremely upset and angry: "The letter was extraordinary. They proposed help, time to listen to the family… but then nothing happened. If it's just mere politeness, there is no point in sending out a letter like that. It was the only thing I could hold onto but in the end it didn't work, it came to nothing. I was very upset. As it came to nothing, it actually made things worse" (daughter, during follow-up interview).

DISCUSSION

This study explored bereaved relatives' experience and reactions after receiving a letter of condolence. Many caregivers wonder what kind of follow-up they should provide, and in the ICU context, bereavement follow-up is extremely rare (16). However, ICU culture is changing, and attention is drawn to family-centered care in order to alleviate the burden experienced by relatives after the loss of a loved one in the ICU (17).

It is common and intuitive to recommend writing letters of condolence, but one knows little about bereaved relatives' experience of receiving such letters from the team that cared for the patient. A recent study (8) set in the palliative care context shows family satisfaction regarding reception of such a letter. Our larger follow-up study puts forward a higher risk of developing symptoms of depression and posttraumatic stress in relatives who received a letter of condolence (9). Our two approaches are complementary: the quantitative study was based on measuring a risk, whereas our qualitative study aimed to better understand an experience. Indeed, this study adds to the literature by providing insights into relatives' experience of receiving a letter of condolence after loss in the ICU. We

found that relatives describe several benefits from receiving a letter of condolence but also express some doubts and negative reactions.

One important finding is that receiving such a letter increases trust in the medical institution and the medical profession—the physician does not simply disappear after the patient's death (2). The letter is perceived as a form of support and permits to release emotions which can be very helpful to some relatives (18, 19). However, this reaction may also set off symptoms of depression by forcing relatives to grasp the reality of the loss during the denial stage of the grieving process (20). As said by the son of a patient, "it hurt."

During the patient's ICU stay, relatives can experience close relationships with the ICU caregivers. After the patient's death, relatives do not always have the opportunity to close the relationship (12). The letter of condolence permits acknowledgement of the connection between the team and the family and also shows that this connection had meaning (7). Interestingly, relatives themselves use the words "humanity" and "humanization," thus showing that the letter leads to a shift of perception, from an institution seen as cold and anonymous to one that is warmer and more personalized. In this perspective, relatives perceive the letter as a gift, something special that they will keep and share with other members of the family. Social scientists have found that giving/receiving gifts is an important part of human interaction that helps to define relationships and strengthen bonds between people. The letter strengthens the feeling of nonabandonment. However, it also creates a feeling of duty, a social obligation to acknowledge and answer the letter. In this, it may prolong the relationship, possibly increasing the relative's burden, as some believe that the most appropriate time to cease contact with the team is time of the patient's death (21). Following the give/giving pattern (22, 23), relatives seek to reciprocate. In writing these letters, both have given a part of themselves, and the balance is restored.

A second important finding is that the letter permits continuity between the experience in the ICU and the outside world. In the ICU, "everything is done for the patient," and it is difficult for the relative to find a place, leaving them feeling helpless and sometimes guilty. Helping relatives understand that they did play a role and that their presence was in itself a way of caring for the patient (14) helps relatives give meaning to the time they spent with the patient. Furthermore, during the patient's stay, relatives suffer from anxiety, depression (24), and find medical information difficult to understand (25): the letter either answers their questions or gives an opportunity to contact the team to obtain answers. However, it can be said that the letter offers only a vague proposition of help and not real help, leaving the ultimate search for support to the relatives and a possible feeling of solitude.

A third important finding is that the letter is an opportunity for relatives both to reflect on the care received by the patient and to thank the team for the quality of care. As said earlier, only 6.6% of relatives who did not receive a condolence letter contacted the team versus 41.4% of those who did. Very often relatives value the team's efforts and want to express their appreciation (12), most often putting forward the importance of quality communication (26, 27).

Last, it is important to note that sending a letter of condolence cannot be taken lightly. The letter is a sign of commitment, it has meaning and is powerful, "the only thing I could hold onto" says the daughter of a patient. The letter of condolence ends with a formal invitation to contact the team. Such an invitation must be offered seriously: if the physician does not make him/herself available, the relative feels angry and abandoned, thus aggravating his/her burden rather than alleviating it, making the letter counterproductive.

Although our quantitative study shows that the condolence letter does not lessen psychologic distress (and may even worsen some symptoms), this qualitative study shows that the letter can help some relatives feel supported and recognized. The two are not contradictory but make clear to clinicians that these letters must not be sent in the intention to reduce grief symptoms, but rather to manifest support, and cannot be systematized: clinicians and relatives must feel that it is appropriate and has meaning.

Our study presents several limitations. First, all participating ICUs were in France, and whether our findings can apply to other cultural settings is uncertain. Second, as interviewers were blinded to study arm, they could not openly question all relatives about the condolence letter: our analysis is based on spontaneous interviews and letters written by bereaved relatives but does not explore the experience of those who did not express explicit reactions to the letter. Our study may suffer from a selection bias as we more likely captured relatives who were the most satisfied. Of course, once the relative had mentioned the letter, the interviewer was no longer blinded to study arm. Third, member checking, in order to decrease the frequency of incorrect interpretation of data, was not performed. Last, this study is focused on bereavement after loss in the very specific environment of the ICU: the same study conducted in other settings may find different results.

CONCLUSION

This study puts forward the benefits of receiving a letter of condolence but also shows that relatives sometimes experience doubts and ambivalent feelings about the letter, such as pain, suspicion, and a social obligation to answer the letter. Although the study shows global satisfaction, it also shows that the letter is not systematically beneficial, and healthcare workers must strive to adapt bereavement follow-up to each individual situation.

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