

## The End-of-Life Family Conference Communication Empowers

The last two decades have witnessed the development of family-centered care provided by intensive care unit (ICU) workers. The results of epidemiologic studies identifying family needs (1) and barriers to compassionate care for family members (2, 3) have been used to improve the effectiveness of information given to families (4, 5) and to benefit communication between families and physicians in the ICU. Indeed, the cornerstone of family-centered care is early, effective, and intensive communication with the patient's relatives (4, 5). Information empowers family members by answering their needs (1), enabling them to understand the patient's situation (4), and reducing anxiety and depression (6). Effective communication puts family members in a position to act as surrogates (7) and to work with the intensivists on making decisions about the patient (8), should they so wish (9).

Honing our communication skills so that family members of patients dying in the ICU can be partners in discussions and decisions deserves our best efforts. Studies of long-term outcomes (10, 11) found that the relatives of patients who died in the ICU were left with a heavy burden of emotional distress, indicating a pressing need for improving caregivers' response to specific informational family needs at the end of life (12). The ideal level of family involvement is the shared decision-making model (8), which allows intensivists to uphold the principle of autonomy while making full use of their technical skills. However, differences may exist between a patient's relatives regarding the desired level of involvement, and end-of-life care should therefore be tailored to the clinical setting and to the family's wishes (7, 9). Clearly, intensivists need to improve their knowledge of patients and surrogates and to refine their communication skills (12).

End-of-life family conferences are the fruit of 20 years of research aimed at improving communication with relatives of dying patients and at easing the burden that weighs on the family (13). Family conferences are held when a shift is needed from curative to palliative care, from cure to comfort (13). Several studies have used family satisfaction and the perceived quality of dying in the ICU as the outcome variable (13).

In this issue of the *Journal*, Curtis and his colleagues (pp. 844–849) have made valuable contributions toward providing guidance for conducting end-of-life family conferences. In a previous study, they demonstrated that intensivists needed not only to deliver information but also to learn how to listen: the proportion of time the family spent talking was a major determinant of their satisfaction (14). This is in agreement with evidence that families need to ventilate their emotions (12) and reflects respect for autonomy in the family–physician relationship in the ICU. The new study by Curtis and coworkers (15) provides us with a method for improving our communication with family members. Using qualitative analysis of audiotaped family conferences, Curtis and coworkers (15) identified opportunities for better answering family needs during end-of-life family conferences. Their descriptions of concrete situations taken from real life can keep

us from missing opportunities to improve family satisfaction. Attention to the risk of missing opportunities to improve communication with the family results in greater family empowerment and autonomy, as it places the family, not the doctors, at the center of the end-of-life conference.

Intensivists need to listen carefully, respond adequately, acknowledge emotions, and alleviate family guilt, while remaining mindful that a need for palliative rather than curative care exists. In this way, intensivists can explore family statements regarding patient preferences, empower family members to engage in surrogate decision making should they so wish, and assure the family that patients in palliative care receive the same high-quality medical attention as do patients in curative care. Moreover, in Curtis and coworkers' (15) study, the conferences with missed opportunities were conducted by either junior or senior physicians, indicating that all ICU physicians need to improve their communication skills, even those with considerable ICU experience (16).

In their new study, Curtis and colleagues (15) transcribed 100 hours of conference audiotapes verbatim. The transcripts were subjected to qualitative analyses aimed at finding areas for improvement in communication with families about withholding and withdrawing life-sustaining treatments. Missed opportunities were first identified by two analysts. A consensus among analysts was then built, and the missed opportunities were reviewed by the main investigator. This original, careful, and time-consuming (1,600 hours of analysis time) study shows that sound scientific methods can benefit end-of-life care as much as other areas of medicine.

When providing care to dying patients and their families, exercising compassion is not enough: critical-care physicians and nurses must sharpen their communication skills, continuously evaluate their practices, identify inadequacies and mistakes, and work toward correcting them. The impact of end-of-life family conferences on the long-term well-being of family members deserves further investigations. Studies of family members 3 to 12 months after the death of a relative in the ICU indicate a pressing need for continuing family-centered care after the death (10, 11), either by using interventions that have long-term effects or by enlisting the help of non-ICU physicians. In addition, investigations must be done in larger numbers of family members and in various cultures or countries. Data should also be obtained about families who refuse to participate in studies of family-centered care, those who cannot participate because of language barriers, those who refuse to participate in decisions about patients, and those who, on the contrary, want to make decisions without input from physicians.

By teaching ourselves how to take full advantage of all opportunities to provide effective information and emotional support, we will make the family end-of-life conference a powerful, sensitive, and enriching tool for addressing the specific needs of each patient dying in the ICU and of his or her family members. The study by Curtis and coworkers (15) serves as another important reminder of the importance of family–physician communication in the ICU (12).

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## From Quantitative Trait Locus to Gene A Work in Progress

Genetic background is an important determinant of many pulmonary diseases. Although single-gene (mendelian) disorders have been identified (1), most diseases are quantitative or complex, the result of an interaction between multiple genes. Because the contribution of each gene in a complex trait is relatively minor, identification of each of the genes that ultimately determine a complex trait is a major challenge. Furthermore, susceptibility genes interact with multiple environmental exposures or stimuli important in the etiology of a disease, and these interactions may vary from one population to another. Despite the enormous complexity of pulmonary diseases, results from studies, such as that presented by Reinhard and colleagues (pp. 880–888), have substantially enhanced our understanding of genetic contributions to physiologic and pathophysiologic changes in the lung (2).

Traditionally, two broad research strategies have been used to identify loci or genes that determine disease susceptibility. The first incorporates meiotic mapping and positional cloning. Meiotic, or linkage, mapping exploits within-family associations between marker alleles and putative trait-influencing alleles that arise within families and may be followed by methods of cosegregation analyses (3). This approach is designed to identify association of a quantitative trait locus (QTL) within the entire genome that may contain one or more genes that are polymorphic and may account for the differential response phenotype under study. That is, meiotic mapping or positional cloning assumes no *a priori* hypothesis about the role of a specific gene

or genes. The second main approach for gene discovery is to focus on a candidate gene or genes using a case-control design (association study). In this approach, genes are chosen *a priori* as likely biological candidates involved in the mechanisms that are believed to determine the phenotype of interest, and as such, become potential targets for genetic susceptibility. With the advent of high-density polymorphic maps that reveal gene sequence variation across the genome, interrogating the sequence variants between two different phenotypic strains for a number of gene candidates is realistic. Moreover, as the genotyping capabilities expand, it will be feasible to identify the genetic variation across thousands of genes in one single assay.

Although the strength of linkage analysis is that it covers the entire genome, its weakness is that relatively large chromosomal intervals may associate with particular phenotypes. For instance, initial linkage analyses identify significant QTLs that may be as large as 10 to 20 cM and include hundreds or thousands of genes. Therefore, investigators must reduce the QTL to a more “manageable” size that will ultimately lead to identification of a gene that determines the phenotype of interest. In contrast, although the strength of the candidate gene approach is that it is focused on a specific gene that is pathogenically related to a phenotype, the results of this approach may be influenced by unique (genetic, behavioral, or environmental) characteristics of the study population/strain. Moreover, employing association studies alone could implicate certain genes in the expressed pheno-