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Needs of the Families of Dying Patients

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Professor Wilmer and his colleagues report a study showing that honesty, assurance that patients are not suffering and liberal visiting hours are the most important needs of relatives of patients who are dying in intensive care.

Introduction

Caring for families is an integral part of intensive care medicine. In previous studies we assessed the degree of anxiety and the needs of relatives of patients hospitalised in the Intensive Care Unit (ICU) (Bijttebier et al. 2001; Delva et al. 2002). These and other studies showed that the state of anxiety of relatives of patients hospitalised in ICU is extraordinarily high, mainly because most perceive admission to ICU as a very frightening and stressful event (Azoulay et al. 2001; Lee & Lau 2003; Leske 1986; Molter 1979; Ward 2001; Zazpe et al. 1997). These studies also revealed that relatives experienced recognisable and specific needs. The most important needs were for information, assurance and proximity. Identifying these specific needs led to a new integrative approach within our team of caregivers emphasizing improvement and more skilful communication with relatives.

In our Medical Intensive Care Unit (MICU), the annual mortality rate is approximately 25%. In more than 98% of cases the death of the patient is predictable, and in almost all cases the death of the patient is preceded by extensive communication with the relatives. We felt that the needs of relatives in these very specific, critical, end-of-life care situations deserved further investigation. We therefore assessed the needs of patients' relatives, after they had been told that their loved one was going to die. Additionally we studied characteristics of the relatives and patients, which may influence the needs of the relatives.

Methods

This study was completed between May 2002 and April 2003 in the MICU of the University Hospital Gasthuisberg, at the Catholic University of Leuven. The MICU is one of several intensive care units in our 1700-bed hospital. The unit has 17 beds and admits approximately 650 patients per year.

Once relatives had been informed by the treating physician that the situation had become untenable and that the patient was going to die, they were contacted by the social worker or head nurse of the MICU and informed about the purpose of the study. Inclusion criteria for the study were that relatives 1) had been informed of the imminent death of the patient, 2) were older than 18 years, 3) could read and write in Dutch, and 4) gave informed consent. If eligible, the needs of the relatives were assessed with the Critical Care Family Needs Inventory (CCFNI), a self-reporting questionnaire with 45 items, scoring on a 4-point Likert scale ("not important" to "very important") (Bijttebier et al. 2000; Molter 1979). The questionnaire assessed 5 categories of information: needs for information, comfort, support, assurance, and accessibility/proximity to patients. Additionally, relatives were asked questions on their possible needs (n=14) and on social and demographic characteristics. The data were analysed statistically using averages, correlation coefficients (CC) and variance analysis.

Results

Characteristics of Patients and Their Relatives

Data were collected prospectively from 101 relatives of 45 patients (average = 2.2 contacts per patient). The mean age of the patients was 65.5 yrs (20 women), and the mean age of the relatives was 49 yrs (range 20-77, 40 women). The highest qualifications attained were high school diplomas for 73% of the respondents and university degrees for 27%. This was the first admission to an ICU for 18 of the 45 patients and for 4 patients it was the first admission to a hospital. All patients died within 1 to 360 hours (average 30 hours) following the first contact between the social worker or head nurse and the relative.

Relatives' Needs

The individual items (from the original 45) with the ten highest and the ten lowest scores are summarized in table 1. Scores for the five categories focused in the CCFNI were derived from the item scores in each category. The need for information scored highest (3.68), followed by assurance (3.33), proximity (3.16), and support (2.71). The need for comfort scored lowest (2.54).

Influence of Socio-Demographic Variables of Relatives or Patients on Relatives' Needs

Need for information or for proximity: Need for information or proximity was independent of variables such as age of the patient, age or gender of the relative, or the number of the patient's previous ICU admissions. Need for assurance: older relatives needed more assurance about the comfort of the dying patient than younger relatives (CC 0.22, $p=0.03$). Need for support: the relatives of younger dying patients needed support more than those of older patients (CC=-0.21, $p=0.04$). Need for comfort: relatives of patients who had been admitted to ICU repeatedly needed comfort more than those of patients who had been admitted to ICU for the first time (t-test, $p=0.02$). Similarly, women relatives needed comfort more than men (t-test, $p=0.04$).

Summary

This study explores the needs of relatives of patients who are hospitalised in intensive care after being told that their loved one is going to die. The data show that the most important needs are honest and understandable information about the patient and his or her prognosis, assurance that the patient does not suffer and is being given the best medical care, to be able to communicate with caregivers about death itself, and to see their loved one frequently. These needs are comparable to the needs of relatives of patients who are hospitalised in the ICU, but not necessarily predicted to die (Delva et al. 2002). The only need which scores as more important in this study is the need for proximity, that is, for the relative to be able to see the patient more frequently.

Not unexpectedly, relatives of younger dying patients needed support more than relatives of older dying patients. On the other hand, older relatives needed assurance about the comfort of their dying relative more than younger relatives. Similarly, women experienced the need for comfort more than men. These observations can be used to differentiate the care for specific groups of relatives, focussing on their specific needs.

The need for family conferences as a focus to improve communication about end-of-life care in ICU has been emphasized earlier (Curtis et al. 2001). Previous research has also shown that adequate communication, good decision making, respect and compassion are key determinants to family satisfaction with critical care patients (Clarke et al. 2003; Heyland et al. 2003;

Kirchhoff et al. 2004). Based on the present data, we propose the following guidelines for good clinical practice to care for relatives in end-of-life situations:

1. The treating physician should communicate clearly, honestly and with empathy about the impending death of the patient.
2. The nurse should participate actively in the process of communication, evaluate the quality of the communicative process and respond to ongoing needs of the families.
3. Visiting hours should be liberal in end-of-life situations.
4. There should be daily contact between the relatives, social worker, nurse and physician. The team of caregivers should coordinate information delivery on the status of the patient, in advance.
5. Continuous attention should be paid to how individual relatives cope and apparent needs should be addressed and attended to wherever possible.

We believe that this approach will not only alleviate relatives' acute anxieties and needs, but may also foster the healing process at the close of life. Good ICU management includes good protocols for caring for patients' relatives. Regular training within the team to improve and harmonise communication skills should be part of the routine organisational program.

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