Introduction

There is disagreement over the roles of the physician, the patient and the patient's family in making decisions to limit life-sustaining treatment [1]. For instance, British and Swedish guidelines acknowledge the right of a competent patient to refuse treatment, but both emphasize the physician's role as decision-maker, especially in the case of an unconscious or otherwise incompetent patient [2, 3, 4, 5]. In contrast, North American guidelines stipulate that the decision lies with the competent patient or with the family in the case of an incompetent patient [6, 7, 8].

It is important that both official policy and the existing practice of the health care system is in agreement with the values of the people in the community in ques-

Withdrawal of life support – who should decide?

Differences in attitudes among the general public, nurses and physicians

Abstract  
Objective: To examine the attitudes of the general public regarding who should decide about the withdrawal of life support and to compare these attitudes with those of intensive care personnel.

Design: Nationwide postal questionnaire survey.

Setting: Sweden.

Participants: One thousand one hundred ninety-six randomly selected persons from the Swedish population register, 339 nurses and 121 physicians from 29 randomly selected intensive care units (ICUs).

Measurements and results: Respondents' answers to questions related to two clinical scenarios: one with a conscious and competent patient and one with an unconscious patient. The response rates were 64% for the general public, 86% for the nurses and 88% for the physicians. Concerning the competent patient, 48% of the public, 31% of the nurses and 8% of the physicians were of the opinion that a decision about continued ventilator treatment should be made by the patient alone or together with the family, but without the physician. The vast majority of physicians (87%) wanted to make the decision themselves, either alone or together with the patient or family. Concerning the incompetent patient, 73% of the general public and 70% of the nurses advocated a joint decision made by the family and the physician together. The majority of the physicians (61%) regarded themselves as the sole decision-maker, a view supported by only 5% of the public and 20% of the nurses.

Conclusions: While existing Swedish guidelines recommend that the physician should be the sole decision-maker, the general public favour more patient and family influence on the decision to withdraw life support as compared with intensive care physicians.

Key words  Decision-making · Ethics medical · Intensive care · Life support · Questionnaire · Public opinion
tion. Part of the solution to the disagreements about end-of-life decisions would thus be to explore the views of the people in different societies. However, few surveys have been conducted concerning the attitudes of the general public regarding the decision to withdraw life support [9, 10, 11, 12, 13]. Public opinion in most countries remains unknown.

In this paper we examine the attitudes of the general public in Sweden regarding who should make the decision about withdrawal of life support and compare these attitudes with those of intensive care personnel and with existing guidelines.

**Material and methods**

**Questionnaire**

To survey the attitudes, we used a questionnaire with two scenarios, the first involving a conscious and competent patient and the second describing an unconscious patient (see Appendix). We focused on ventilator treatment, which is a form of life support well known among the general public.

The questionnaire was developed in co-operation with Statistics Sweden, the governmental agency that conducted the survey among the public. A preliminary version was pre-tested by the agency using a cognitive method [14]. In this pre-test, 15 randomly selected persons completed the questionnaire under the direct observation of the personnel administering the test. While completing the questionnaire, they voiced their associations and reactions. In addition, they were interviewed specifically about potential problems with the design of the questionnaire. The conclusion was that the technique with case scenarios was well accepted, but some elucidation of the questions was needed. All suggested modifications were implemented in the final version of the questionnaire.

The questionnaire was distributed during the autumn of 1997. The survey was approved by the Research Ethics Committee of the Örebro County Council.

Respondents

A sample of 1200 adults, aged 25–74, was randomly selected from the general population register in Sweden. The questionnaires were mailed and, when necessary, two reminders were sent by mail.

A random sample of 30 of 61 intensive care units (ICUs) in Sweden with the capacity to care simultaneously for at least three ventilator-dependent patients were included. These 61 ICUs represent the great majority of Swedish ICUs of this size. Twenty-nine of the 30 ICUs agreed to participate in the survey. One third of the nurses at these ICUs were selected at random from lists of employees.

In Sweden almost all ICUs are staffed by anaesthesiologists. However, a sample from the list of employees at a department of anaesthesia would include many anaesthesiologists who work only occasionally in the ICU. Instead of a random selection of anaesthesiologists, we thus surveyed specialists and residents who were on duty in the ICU during certain weeks which were determined beforehand. From each centre, the number of physicians included in the study was twice the number of physicians working day-time in the ICU. For example, in a centre with an ICU usually staffed by two physicians, four physicians were surveyed. The numbers of ICUs, nurses and physicians surveyed were selected to allow us to cover all areas in Sweden and to get appropriate sample sizes of both nurses and physicians.

The questionnaires were mailed to 339 nurses and 121 physicians by the authors. The respondents returned the questionnaires in coded envelopes to allow follow-up, but the questionnaires and the respondents’ answers remained anonymous to the investigators. One mail reminder was sent when necessary.

**Statistical methods**

According to standard practice at Statistics Sweden, a non-response study was conducted. In this non-response study [15] 212 of the 425 persons not responding after two mail reminders in the public survey were approached by phone. Eighty-four of the 212 persons approached in this follow-up completed the questionnaire by mail or phone. Their answers were used to calculate a weighted result for each question. In this calculation, a higher weight was given to the answers collected in the non-response study than to the answers from the regular survey. The rationale behind giving higher weight to those who responded after being reminded by telephone, is the assumption that the answers of non-responders are more in concordance with those responding after several reminders, than to those who answer immediately or following only a few reminders. These weighted results did not differ from the results in the regular survey by more than three percentage points for any question. Thus, if these assumptions are true, a higher response rate would not have significantly altered the results.

A chi-square test was used to test the null-hypothesis that the distribution of answers from the three groups were the same. When the null-hypothesis was rejected ($p < 0.005$), a subsequent analysis was made to determine which answers contributed to the differences among the groups.

**Results**

Of the 1200 persons in the general public sample, four had died or emigrated. Of the remaining 1196 eligible persons, 771 (64%) answered the questionnaire. The response rate for the nurses was 290/339 (86%) and for the physicians it was 107/121 (88%).

**Respondent characteristics**

Table 1 summarizes the demographic characteristics of the respondents. The data from those of the general public that responded were compared with the whole sample of the general public, regarding age, gender and community size. No significant differences were found, indicating that the respondents were representative of the general public of Sweden regarding these factors. Among the respondents from the public, 31% had up to 9 years of education, 42% had 10–12 years of education, and 27% had university education. According to the definitions used, all nurses and physicians had university education. The nurses and the physicians had a