Decisions Affecting Quality of Life or Survival for Severely Demented Persons

*A Survey on Doctors and Nurses of Nursing Homes and Districts*

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Those caring for severely demented people are often faced with difficult decisions that can affect the patient’s survival and quality of life. The objective of the study was to describe these “critical therapeutic decisions” concerning severely demented patients. A questionnaire was distributed to a convenience sample of doctors and nurses working in nursing homes and districts of two Italian provinces. A critical therapeutic decision involves starting, withdrawing, or withholding a treatment perceived as relevant for a patient’s survival or quality of life. Data collected included the frequency of critical therapeutic decisions and the description of two recent cases that the respondents had been involved with during the last year. Thirty-five doctors and 80 nurses answered the questionnaire; 48% of the doctors and 23% of the nurses reported being called often/very often to make a critical therapeutic decision mainly related to artificial nutrition/hydration, use of restraints, or pharmacological sedation. One hundred sixty-six cases were reported. The majority of decisions (38% for doctors and 63% for nurses) consisted of interventions, while in 38% of cases for doctors and 11% for nurses the decision was to withhold or withdraw a treatment. Decisions perceived as relevant for the survival or quality of life of demented patients are frequent. Studies to explore reasons behind decisions taken and outcomes are needed.

**KEY WORDS**
critical care decisions
dementia patients
decision making
end of life

Those caring for severely ill people are often faced with difficult decisions that can affect their survival and quality of life (QoL), such as starting or withdrawing artificial nutrition/hydration or giving antibiotics for pneumonia or infection. In fact, these decisions do determine the time of death (hastening or postponing it)
and/or the place of death (home, hospital, nursing home, etc) and/or the way that person will live his/her last days.7

These decisions can be initiating care such as prescribing a therapy; performing an intervention or a course of diagnostics, admitting or discharging the patient to/from the hospital or a nursing home, and so on, or interrupting a therapy or a treatment under way (withdrawing a drug or a tube feeding, stopping dialysis or an artificial respiration, etc). Decisions may involve determining not to perform interventions, such as withdrawing a drug, an intervention, a course of diagnostics, or a DNR order. These difficult decisions can often be made with the patient or may be based on his/her advanced directives.

In the case of advanced dementia, the problem is far more difficult, given the complete incapacity of the patient and, in Italy, the lack of any legal acknowledgement of living wills. Healthcare professionals (HCPs), and especially physicians, become the key decision makers. Advanced dementia is unquestionably a terminal disease, and the focus of medical decisions should shift from curative to palliative8 regardless of the longer expected survival.5 However, this is seldom acknowledged by doctors and health professionals5,9; therefore, patients are often exposed to aggressive treatments.10 Only a few studies, however, have been published on the subject, and most refer to situations affecting short-term survival.11,12 Most of these decisions impact patients’ QoL and/or survival. Examples could be whether to use restraints to limit a wandering patient’s mobility, to admit a demented patient to home care, to sedate an agitated patient, or to prescribe invasive diagnostic tests that may require hospital admission. Avoiding tests may delay the diagnosis of a cancer that may worsen the patient’s condition in the future. Changing his/her living environment with hospital admission may compromise a very delicate patient balance. It would be helpful to know which decisions are perceived as difficult by HCPs to offer support and study their implications for patients, families, and HCPs. Attempts to classify decisions as palliative or not palliative13 do not necessarily cover the whole range.

Interest in Alzheimer disease and demented patients has increased considerably in recent years but has mainly focused on treatments and the implications of care on nonprofessional caregivers.14 Only a few studies have focused on describing the range of critical or end-of-life decisions for these populations.7,14-16

The aim of this study was to describe the therapeutic decisions perceived as critical (critical therapeutic decisions [CTDs]) by health professionals, in the care of severely demented patients.

**METHODS**

A CTD is the decision to start, withdraw, or withhold a treatment perceived as relevant for the patient’s survival and/or QoL, according to the following:

- To start a treatment: a new treatment or a previously suspended treatment.
- To withhold a treatment: the decision to abstain from intervening in clinical situations that might have required action; examples are deciding not to do diagnostic tests when the patient reports symptoms (eg, to diagnose prostate cancer), not to start tube feeding in a dysphagic patient, and not to transfuse blood in a patient despite severe anemia (hemoglobin level, <7 mg/dl).
- To withdraw a treatment: to stop a therapy/treatment previously put in action.

A questionnaire was distributed to a convenience sample (snowball sampling technique) of doctors and nurses working in nursing homes and in home care district services of two areas in the province of Reggio Emilia and Cremona, Italy.

Data were collected with an ad hoc questionnaire. Sociodemographic information included sex, age, professional qualification, place of work (nursing home or district), the

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number of severely demented patients cared for in the last month, the frequency of CTDs for those patients, and the content of the decision. No strict indications were provided to define a patient with severe dementia. The respondents were offered a list of 12 possible CTDs, identified by a panel of three physicians and one nurse, which included nutrition and hydration, treatment of infection, blood transfusions, diagnostic exams, use of restraints, sedation, surgery, and admission to hospital or nursing home. Decisions that did not fit in the list could be added.

To have a clearer picture of the type and aim of the decisions, each respondent was also asked to describe two cases that had occurred within the last year, reporting a brief description of the problem, main information on the patient (sex, age), and the content and nature of the decision. When the description was insufficient to understand the problem or the decision taken, the situation was considered not classifiable.

The transcripts were read by two researchers independently, and key categories of decisions were identified and classified according to the list of CTDs provided in the questionnaire. Disagreements during this process were discussed until a consensus was achieved. The aim of the decision for each case described was independently classified by two nurses. Any doubt or discrepancy was discussed with a clinician to agree on the aim of the decision.

**RESULTS**

Thirty-five doctors and 80 nurses (all those who volunteered for the survey) answered the questionnaire. Table 1 presents the doctors’ and nurses’ responses. Table 2 reports the frequency of CTDs.

<table>
<thead>
<tr>
<th>Place of Work</th>
<th>Doctors (n = 35)</th>
<th>Nurses (n = 80)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Nursing home</td>
<td>17</td>
<td>48.5</td>
</tr>
<tr>
<td>District</td>
<td>7</td>
<td>20.0</td>
</tr>
<tr>
<td>Clinic</td>
<td>6</td>
<td>17.1</td>
</tr>
<tr>
<td>Not reported</td>
<td>5</td>
<td>14.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years of experience, mean (range)</th>
<th>Doctors (n = 35)</th>
<th>Nurses (n = 80)</th>
</tr>
</thead>
<tbody>
<tr>
<td>17+ (3-28)</td>
<td>16+ (1-25)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>No. of demented patients in care in the last month</th>
<th>Doctors (n = 35)</th>
<th>Nurses (n = 80)</th>
</tr>
</thead>
<tbody>
<tr>
<td>21.3</td>
<td>14.7</td>
<td></td>
</tr>
<tr>
<td>21.0</td>
<td>5.1</td>
<td></td>
</tr>
<tr>
<td>27.7</td>
<td>21.2</td>
<td></td>
</tr>
</tbody>
</table>

Doctors and nurses caring for demented patients are often required (alone or as a team) to make CTDs: 17 of 35 doctors (48%) and 23 of 80 nurses (28.7%) reported that they were called often or very often to make a CTD, more often in nursing homes (47%) than in the districts (17%).

Table 3 shows the areas of CTDs in the last month, for doctors and nurses and clinical site (nursing home and district or clinics). One doctor and four nurses reported no critical decisions. Overall, doctors reported 152 decisions (mean, 4.6 decisions; range, 2-10 decisions), and nurses, 241 decisions (mean, 3.2 decisions; range, 1-8 decisions). The most frequent involved artificial nutrition/hydration. All the nursing home doctors reported they had to decide at least once in the last month whether to continue to feed a patient. As expected, doctors (particularly in nursing homes) are more frequently involved in decisions related to hospital admission or diagnostic tests. Nursing home nurses were more often faced with decisions related to the use of restraints or pharmacological sedation.

Two hundred five cases (65 from doctors and 140 from nurses) occurred in the previous year where a CTD had been made were described. Sixteen cases by doctors (24.6%) and 23 by nurses (16.4%) could not be analyzed because the patient situation or the decision made was not clearly described, or it did not refer to a specific patient (eg, “nurses are very often involved in helping relatives make a choice”). Therefore the results refer to 49 cases from 28 doctors and 117 cases from 75 nurses. The patients for whom decisions had to be made were advanced in age (mean age, 84 years; range, 69-102 years). More than 95% had a relative or significant caregiver, all were already known to the team, and more than half (55% for doctors and 64% for nurses) were residents in nursing homes.
Most decisions were made by the team (43% reported for doctors and 54% for nurses) or only by one member (30.6% for doctors and 20.6% for nurses); 11.4% of the decisions were made by the family alone, and 10% by family and team. In 78% of cases, the decision was entered on the clinical record.

The majority of CTDs were made by the team, after discussion with the family. Discussion with the healthcare team was reported in 42.8% of cases; 26% of doctors and 19.6% of nurses involved relatives in the decision. Examples of decisions not involving the family included the start of antibiotic therapy or tracheal suctioning. Families were always involved in the initiation or discontinuation of artificial nutrition or hydration.

The differences between doctors and nurses relate mainly to the type of decision: artificial hydration and tube feeding were the most frequently reported area of decision. The third area was hospitalization for doctors and the use of restraints for nurses. To decide whether to start artificial nutrition/hydration or to prescribe diagnostic

<table>
<thead>
<tr>
<th>Areas of CTDs by Working Sitea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors (n = 35)</td>
</tr>
<tr>
<td>NH</td>
</tr>
<tr>
<td>n</td>
</tr>
<tr>
<td>Tube feeding</td>
</tr>
<tr>
<td>Artificial hydration</td>
</tr>
<tr>
<td>Restraints</td>
</tr>
<tr>
<td>Pharmacological sedation</td>
</tr>
<tr>
<td>Antibiotics</td>
</tr>
<tr>
<td>Diagnostic tests</td>
</tr>
<tr>
<td>Tracheal suctioning</td>
</tr>
<tr>
<td>Hospitalization</td>
</tr>
<tr>
<td>Surgery</td>
</tr>
<tr>
<td>Admission to NH</td>
</tr>
<tr>
<td>Blood transfusion/hemodialysis</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

Abbreviations: Dist, district; NH, nursing home; NS, not specified.
aThe number of decisions exceeds the number of respondents as the content of more decisions was reported.

Table 2
Frequency of CTDs in the last month

<table>
<thead>
<tr>
<th>Doctors (n = 35)</th>
<th>Nurses (n = 80)</th>
<th>Total (N = 115)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n %</td>
<td>n %</td>
<td>n %</td>
</tr>
<tr>
<td>Never</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Rarely</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Seldom</td>
<td>13</td>
<td>37.2</td>
</tr>
<tr>
<td>Often</td>
<td>15</td>
<td>42.9</td>
</tr>
<tr>
<td>Very often</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Not specified</td>
<td>1</td>
<td>2.8</td>
</tr>
</tbody>
</table>

Table 3
Areas of CTDs by Working Sitea
tests was much more frequent in nursing homes. For the
nurses, the decision to use restraints or to sedate the pa-
tient was more frequent in nursing homes.

The content of the decisions (to initiate, to discontinue,
or to abstain from intervening) is reported in Table 4,
according to the type of problem (eg, blood transfusions,
antibiotic therapy, restraints, etc). Situations where an
intervention was implemented were prevalent for both
doctors and nurses. Less frequent was the decision to
discontinue or withhold a treatment. The main decision
topics were artificial nutrition/hydration and treatments
(eg, blood transfusions).

Examples of withholding treatments included the fol-
lowing:
- A diabetic patient living alone developed dangerous
  behavior such as eating ointments. He resisted at-
ttempts at admission to a nursing home and refused a
  full-time caregiver (24 hours). The family, backed by
  the physician, decided to keep the patient at home,
  with a caregiver only a few hours a day.
- A decision for a bedridden, anorexic, severely mal-
nourished patient not to start artificial nutrition or
  hydration to avoid unnecessary treatments.
- A decision not to start dialysis for a patient with
  severe heart failure and acute kidney failure to avoid
  an excessive treatment.

Examples where treatment was suspended included the
following:
- Antibiotics were stopped in a patient with recurrent
  fever because the treatment would have prolonged
  suffering.
- Intravenous hydration was stopped in a terminally
  ill, dysphagic patient with severe pressure sores and
  no venous access.
- Treatment for bladder cancer (intravesical chemother-
yapy) was stopped to avoid hospital admissions,
  which were disrupting for the patient.

Whether to insert a nasogastric or percutaneous endo-
scopic gastrostomy tube for artificial feeding was the most
frequent type of decision that doctors and nurses had to
face. The use of restraint was an intervention reported
more by nurses, as was the administration of antibiotics
and treatments in general.

**DISCUSSION**

The majority of articles on decisions for patients with
severe cognitive impairment involve end-of-life deci-
sions. Choices regarding the well-being and
QoL of severely demented patients are regularly made in

Table 4

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Intervention</th>
<th>No intervention</th>
<th>Stop treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nasogastric tube, artificial feeding</td>
<td>MD</td>
<td>Nurse</td>
<td>MD</td>
</tr>
<tr>
<td>Artificial hydration</td>
<td>6</td>
<td>32</td>
<td>7</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>4</td>
<td>15</td>
<td>—</td>
</tr>
<tr>
<td>Restraints</td>
<td>4</td>
<td>7</td>
<td>—</td>
</tr>
<tr>
<td>Sedation</td>
<td>1</td>
<td>13</td>
<td>—</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>3</td>
<td>4</td>
<td>—</td>
</tr>
<tr>
<td>Blood transfusion/hemodialysis</td>
<td>2</td>
<td>8</td>
<td>—</td>
</tr>
<tr>
<td>Admission to NH</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Therapies</td>
<td>3</td>
<td>3</td>
<td>—</td>
</tr>
<tr>
<td>Diagnostic tests</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Surgery</td>
<td>—</td>
<td>3</td>
<td>—</td>
</tr>
<tr>
<td>Others</td>
<td>3</td>
<td>14</td>
<td>—</td>
</tr>
<tr>
<td>Total no.</td>
<td>30</td>
<td>103</td>
<td>14</td>
</tr>
<tr>
<td>%</td>
<td>61</td>
<td>88</td>
<td>29</td>
</tr>
</tbody>
</table>
routine care. In the majority of cases, the choice is to actively tackle the problem identified. It is often easier to act on a problem (eg, to start subcutaneous or intravenous hydration for a dysphagic patient) than to decide to withdraw or withdraw a treatment. At present in Italy, there is no law on advanced directives, and the courts’ decisions are few and contradictory. The government is claiming to promulgate a bill, but the political debate is difficult, and the Roman Catholic Church is carrying out intense lobbying aimed at limiting the patients’ right to refuse all interventions whose withdrawal or withholding may precipitate death. If a patient does not express personally and promptly his/her wishes, the decisions are left to the HCPs (eventually to the physician in charge) who may or may not take into account the wishes of the patient’s family. Very seldom, especially in case of dementia, living wills are implemented. In a recent survey in seven nursing homes of northern Italy, none of the 141 patients who died with advanced dementia had an advanced directive.19

During the course of the illness, it is difficult to foresee the start and duration of the terminal phase (unless shortly before death)15,20; however, critical situations often arise that call for decisions that may affect the patient’s QoL or survival. Decisions perceived as critical are frequent for doctors and nurses. Nurses reported fewer such decisions because although they may be involved in the decisional process, the final responsibility for decisions such as whether to transfuse blood or to propose surgery order, diagnostic tests, or the admission to a hospital is made by the physician. More frequent are decisions involving feeding and hydration of dysphagic patients and specifically whether to insert a percutaneous endoscopic gastrostomy or nasogastric tube or to start intravenous hydration.5 Nurses feel that their role in feeding decisions is minor,24 and they are also reluctant to play a role in such decisions.25 In half the cases, the decision was made by the team, and in two-thirds, it was discussed with the family and reported in clinical or nursing records. The involvement of caregivers is important also for providing support.5 In a recent survey in nursing homes19 only three of 141 clinical records documented the involvement of the family. Because the habit of documenting care, especially in Italian districts and nursing homes needs improvement, the low figures are more likely to reflect a failure to record than any lack of involvement.

The limited number of cases and the nature of the sample do not allow any comment on the content of choice per type of problem or on differences between nursing homes and districts. Any critical situation raises ethical questions: in 38% of cases for doctors and 11% for nurses, the decision not to start treatment or to stop ongoing treatments. Withdrawing is possibly more awkward than withholding, even for futile treatments. Although most Western bioethicists consider withdrawing and withholding morally equivalent, withdrawing is often perceived as more closely linked to an intentional termination of the patient’s life and thus psychologically more troublesome.23-25

The vast majority of problems reported involved decisions affecting patients’ survival (nutrition and hydration, hospitalizations, administration of antibiotics) or physical aspects of care. Although QoL is affected by most decisions, no decisions related to the psychological care of patients and family members were reported. This may be due to the fact that decisions involved only patients with severe dementia, and this focused the attention on physical aspects of care. The psychological aspect deserves attention in future research. There were limitations to this study. This was a convenience sample, and general practitioners are not represented, even though they are often involved in these choices. A clear definition of the “severe patient” was lacking. More stringent criteria (for instance, according to the FAST scale [Functional Assessment Staging System])26 would have permitted a better understanding of the cases reported. The request to select two cases may have created some bias as more difficult situations are more likely to be remembered and therefore to be reported.

❯ CONCLUSION

Despite its limits, this survey produced data not otherwise available in the literature. Decisions perceived as critical for the survival or QoL of demented patients are often made in everyday care, not only in terminal care and not only related to critical choices such as to hydrate or not or to stop or start treatments. The decision to start diagnostic examinations that require frequent changes of environment (from home to hospital or clinic, etc) that may compromise the patient’s balance is perceived as critical, as is the decision to use restraints or to limit ambulation or prevent falls, thus restricting the patient’s freedom.

Prospective studies are needed to explore if critical choices are as frequent as perceived, or are they so emotionally burdened to be perceived more frequent than in reality. Research is also needed to determine when critical decisions are taken along the trajectory of the illness, the reasons behind the choice, and the outcomes.

A more detailed understanding of the decisions considered critical for survival or QoL may cast a light on some of
the problems and help mark out areas for research, in addition to giving a picture of the difficulties healthcare workers encounter in caring for these patients.

Acknowledgments

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