What degree of medical treatment do nursing home residents want in case of life-threatening disease?

CLAUS MOE, MARIANNE SCHROLL

Geriatric Department HL, The Copenhagen Municipal Hospital, Øster Farimagsgade 5, DK-1399 Copenhagen K, Denmark

Address correspondence to: C. Moe. Fax (+45) 33 95 0195.

Abstract

Aim: to examine the degree of medical treatment wanted by nursing home residents, their relatives and staff members should the resident develop a serious and life-threatening disease and to analyse the degree of agreement between the wishes of these parties.

Design: an epidemiological, descriptive cross-sectional study.

Material and methods: the study population consisted of 101 competent and 106 incompetent residents from 16 nursing homes; 142 relatives and 207 staff members were also interviewed. A hypothetical disease story was presented to residents, relatives and staff members and their choices classified into four groups according to degree of treatment.

Results: direct comparisons for the individual resident showed the greatest degree of disagreement whether to accept or refuse referral to hospital between relatives of incompetent residents and staff members, in that the preference for curative treatment was significantly more frequent among the relatives.

Conclusions: nursing home staff should try to discuss with relatives of incompetent residents their preferences for treatment in case the resident develops a serious disease before an acute situation arises.

Keywords: degree of treatment, elderly residents, life-threatening illness, nursing home, patients' wishes

Introduction

In Denmark, the number of circulars and laws governing informed consent and right of autonomy has increased considerably during the last 15 years. In 1992 informed consent was enacted in Denmark as laid down in the Practice of Medicine Act and living wills [1] became legally binding on the attending physician, if the patient was inevitably dying. Autonomy to accept or refuse treatment is secured by informed consent [2]. Communication can be hampered if patients have difficulty understanding the information given because of the impairment that accounts for their residence in a nursing home. In the case of acute life-threatening disease, the doctor is duty-bound to act. So, if the resident or the relatives refuse treatment, the doctor has an ethical dilemma.

As pointed out by Wooldridge et al. [3], however, a rigid distinction between resuscitation and non-resuscitation does not necessarily solve the problem of giving treatment or no treatment. A 'sliding scale' is more likely to be the answer. Such a scale would range from attempting maximum curative treatment to providing purely palliative care. In between these extremes one or several categories (or degrees) of treatment could be defined with different weighting between curative and palliative. Such 'degree of intervention guidelines' with four degrees have been worked out by The Continuing Advisory and Subcommittee on Health Care of the Elderly and Long Term Care of the professional advisory committee to the Ministry of Health, British Columbia, Canada [3]. Others have defined similar degrees of treatment for nursing home residents [4, 5].

Before we started this study, we assumed that few residents in Danish nursing homes had documented in writing their decision on refusal of treatment in case of life-threatening disease. Our aims were: (i) to examine the degree of medical treatment wanted by nursing home residents, their relatives and staff members should a resident develop a serious and life-threatening disease and (ii) to analyse the degree of agreement between the wishes of these parties.
Methods

The study is an epidemiological descriptive interview study. It provides a snapshot of attitudes to choice of treatment.

Material

Data were collected as part of a study on health and functional capacity of 3451 nursing home residents in the Municipality of Copenhagen, Denmark [6]. A Danish version of the Resident Assessment Instrument (RAI)—a US standardized questionnaire used in several countries to assess health, functional capacity, and psycho-social status—was employed. The validity and reliability of the RAI has been extensively tested [7]. We also conducted a questionnaire study on a representative sample from the same population selected on the basis of the RAI scores on memory and decision-making skills. The resulting sample consisted of the most competent and the most incompetent residents. Using a structured form, 450 interviews were performed with residents, their relatives and staff members. The study population consisted of 101 competent and 106 incompetent residents from 16 nursing homes, together with 142 relatives and 207 staff members. One of the authors (CM.) conducted all interviews during the period 1 April–30 September 1993. All residents, staff members and relatives were interviewed separately to avoid interaction.

Hypothetical disease story

A hypothetical disease story was presented to residents (with the exception of incompetent residents), relatives and staff members. First, all of them were asked to consider whether or not they would want referral to hospital if the resident contracted acute life-threatening pneumonia. If referral was chosen, the interviewee was asked to consider whether or not they would be in favour of a few days’ treatment with respirator if this was necessary for survival. If referral was not chosen, the interviewee was asked to consider antibiotic treatment according to the routine of the nursing home. In this way all interviewee responses were divided into four defined degree-of-treatment groups (Table 1).

Analysis of reproducibility

Choice of degree of treatment was analysed for intra-observer variation. This analysis comprised staff members only, since it was considered unethical to expose residents and relatives to repeated interviews. Altogether 50 staff members, nursing 29 competent and 21 incompetent residents, were interviewed. About 1 month (median 41 days, range 14–93) after the first interview the staff members were re-interviewed. If some episode had occurred that might have changed the score for the sample selection between the two interviews, or if the resident had fallen ill or died, the corresponding staff member was withdrawn from the analysis of reproducibility. In 43 cases there was complete agreement \((k = 0.82)\) as to choice of treatment. In all the remaining seven disconcordant cases the trend was for a lesser degree of treatment.

Analysis of drop-out

An analysis of age and sex was performed on the 13 competent and four incompetent residents who did not want to participate. There was no significant difference in the mean age of participants and non-participants for either competent \((P = 0.82)\) or incompetent \((P = 0.20)\) residents. There was no difference between the sex distribution for competent \((P = 1.00)\) or incompetent \((P = 0.60)\) residents.

Ethical aspects

The scientific ethical committee of the Municipalities of Copenhagen and Frederiksborg approved the project. Written and oral informed consent was a prerequisite for participation in the study. When the resident was incompetent in the legal sense or physically or mentally unable to give informed consent, permission from, respectively, the legal guardian or the

Table 1. Nominal and operational definitions on choice of degree of treatment

<table>
<thead>
<tr>
<th>Operational definition</th>
<th>Nominal definition</th>
<th>Degree of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refusal of referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refusal of treatment</td>
<td>Purely palliative treatment in the nursing home</td>
<td>1</td>
</tr>
<tr>
<td>with penicillin</td>
<td>Curative plus palliative treatment in the nursing home</td>
<td>2</td>
</tr>
<tr>
<td>Acceptance of treatment with penicillin</td>
<td>Curative plus palliative treatment in hospital (minus intensive care)</td>
<td>3</td>
</tr>
<tr>
<td>Acceptance of referral</td>
<td>Curative plus palliative treatment in hospital (plus intensive care)</td>
<td>4</td>
</tr>
</tbody>
</table>

134
Treating nursing home residents with life-threatening diseases

Table 2. Frequencies and percentage distributions of choice of degree of treatment for competent residents

<table>
<thead>
<tr>
<th>Interviewed person</th>
<th>Degree of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Competent resident (n = 101)</td>
<td>10 (9.9%)</td>
</tr>
<tr>
<td>Relative of competent resident</td>
<td>2 (3.0%)</td>
</tr>
<tr>
<td>Staff member (n = 101)</td>
<td>4 (4.0%)</td>
</tr>
</tbody>
</table>

Table 3. Frequencies and percentage distributions of choice of degree of treatment for incompetent residents

<table>
<thead>
<tr>
<th>Interviewed person</th>
<th>Degree of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Relative of incompetent resident</td>
<td>11 (14.7%)</td>
</tr>
<tr>
<td>Staff member (n = 106)</td>
<td>15 (14.2%)</td>
</tr>
</tbody>
</table>

nearest responsible relative replaced the resident's informed consent. The interviewees' right to protect their integrity was always respected.

Statistical analyses

Acceptance/refusal of referral was chosen as a well-defined point of intersection. The mean age of the four treatment groups was compared using a one-sided analysis of variance (F-test). The sex distribution in the treatment groups was compared by calculating the exact probabilities using the \( \chi^2 \) test with three degrees of freedom. The degree of agreement between the groups on choice of treatment was analysed using a binomial test for comparison of the frequencies of two alternative events \( A > B \) and \( A < B \), where \( A \) and \( B \) are the choice of degree of treatment in the groups. The exact 95% confidence limits for true frequencies were calculated using the \( F \)-distribution. For the analysis of reproducibility, data were evaluated by calculating the \( \kappa \) value.

Results

Of the 3451 residents in the study on health and functional capacity, 2630 (76.2%) were women and 821 (23.8%) men. The median age was 86.1 years (range 36.9-106.4) for women and 80.6 years (range 33.2-99.8) for men. There were 3442 valid answers. The distribution of written documentation of the residents' decisions on refusal of treatment was as follows: 2.8% had a living will, 1.5% had do-not-resuscitate orders, 1.2% wanted no referral to hospital in case of acute illness and 0.8% wanted no intravenous infusion or feeding tube. In 3238 residents (94.1%) there was no documentation of their decision.

Of the 101 competent residents in the sample, 81 (80.2%) were women and 20 (19.8%) men. The median age was 84.0 years (range 52-97) for women and 75.0 years (range 44-90) for men. Of the 106 incompetent residents, 86 (81.1%) were women and 20 (18.9%) men. The median age was 87.0 years (range 49-102) for women and 77.0 years (range 46-99) for men.

For the competent residents, the percentage distribution of choice of degree of treatment among the residents themselves, their relatives and staff members is given in Table 2. There is no significant difference between the mean age \( (P = 0.49) \) or sex distribution \( (P = 0.80) \) of the subjects in the residents' four treatment groups. Similarly, there are no significant differences between the mean age \( (P = 0.14 \) and \( P = 0.11) \) or sex distribution \( (P = 0.72 \) and \( P = 0.33) \) of the residents in the corresponding treatment groups of relatives and staff members, respectively.

For the incompetent residents, the percentage distribution of choice of degree of treatment among the relatives and staff members is given in Table 3. There is no significant difference between the mean age \( (P = 0.44 \) and \( P = 0.72) \) or sex distribution \( (P = 0.27 \) and \( P = 0.64) \) of the residents in the four treatment groups of relatives and staff members, respectively.

Figures 1-4 show the percentage distribution of agreement/disagreement with 95% confidence limits as to acceptance/refusal of referral between competent residents and relatives and staff members, respectively and between relatives of incompetent residents and staff members. The degree of agreement/disagreement was computed by counting the number of cases where e.g. degree of treatment\(_{\text{resident}}\) = degree of treatment\(_{\text{relative}}\), number of cases where degree of treatment\(_{\text{resident}}>\)degree of treatment\(_{\text{relative}}\) and number of cases where degree of treatment\(_{\text{resident}}<\)degree of treatment\(_{\text{relative}}\). The highest degree of disagreement was found between relatives of incompetent residents and staff members \( (P = 0.017) \), where
in 33.8% of the cases the relatives preferred a higher degree of treatment than did staff members.

Written guidelines for refusal of treatment had been given by only four of the 101 competent residents interviewed and among the 106 incompetent residents by only five residents or their relatives.

**Discussion**

With this study design it is not possible to evaluate in what direction and to what extent the choices in the hypothetical disease story differ from those which would be made in a real life-threatening situation. This would require interviewing during critical illness, which would be unethical. Moreover, if information about the attitude of a resident and their relatives were required (e.g. in connection with admission to a nursing home), it would always be based on a hypothetical situation.

There was no significant difference between the mean age of the residents in the sample and in the remaining background population and consequently no selection bias. Neither was there any difference in the distribution of the ability to make independent decisions as assessed by RAI. To minimize interviewer bias all interviews were performed by one of the authors (C.M.) so there is no inter-observer variation. The reliability was high, as seen from the results of the analysis of reproducibility. With regard to acceptance/refusal of degree 4, the staff members (in contrast to the residents and the relatives) knew the risks of complications associated with respirator treatment and this may explain why more of them rejected this treatment. This does not influence the frequencies of acceptance/refusal of referral, which was chosen as the point of intersection in the analyses.

With regard to choice of degree of treatment in the hypothetical disease story we found a better agreement between the residents themselves, their relatives and the staff members among the competent than among the incompetent residents. In the incompetent residents, the preference for curative treatment among the relatives and staff members was less pronounced than that found for the competent residents, but the relatives wanted curative treatment more often than did staff members. This is consistent with the report by Cogen et al. [8] who were surprised to find that relatives of even very demented nursing home residents preferred referral to hospital and intensive care for acutely ill residents, and that only 11.8%
Treating nursing home residents with life-threatening diseases

wanted purely palliative care. Thus, 63.4% of the relatives wanted the resident referred to hospital in case of acute pneumonia and 43.6% wanted respirator treatment for respiratory insufficiency. The authors did not include staff members in their study.

It would be helpful if the staff of nursing homes were to make an effort to discuss with the relatives of incompetent residents their preferences for treatment should the resident develop a serious disease — and to do so before an acute situation arises. Gunasekera et al. [9] found that in connection with admission to a geriatric ward, 80.5% of elderly patients wanted to discuss and express their wish concerning resuscitation in case of cardiac arrest. Lo et al. [10] report that 68% of subjects over 65 years living at home or subjects with cancer or a chronic disease living at home wanted to discuss life-sustaining treatment with their general practitioner, although only 6% had actually done so. Kellogg et al. [11] found that most elderly people welcomed a discussion about life-sustaining treatment such as resuscitation, intubation and tube-feeding.

**Key points**

- In elderly nursing home residents incapable of making decisions on whether to have curative treatment for life-threatening illness, relatives would choose more intensive treatment than staff members would choose.
- In competent residents there is general agreement between patients, relatives and staff on the degree of treatment that is appropriate.
- Nursing home staff should discuss treatment preferences with residents and relatives before an acute illness develops.

**Acknowledgements**

The study was financially supported by 'Alice og Joergen Rasmussens Mindelegat'. The Danish Hospital Foundation for Medical Research, Region of Copenhagen, The Faroe Islands and Greenland, The Danish Medical Research Council and The DaneAge Foundation.

**References**


Received 25 September 1996
Photograph: Sam Tanner.