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Striving for quality or length at the end-of-life: attitudes of the Dutch general public

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Abstract

Questionnaires were mailed to 1777 members of the Dutch public (response: 78%), measuring to what extent respondents appreciate life-prolonging treatment, even if it would seriously impair their quality of life. The association between these attitudes and personal characteristics and initiatives to engage in advance care planning was analyzed. About one third of the respondents prefers quality of life at the expense of survival, another third prefers length of life regardless of impaired quality, whereas the remaining third did not express a clear attitude towards quality or length of life. People who were younger, male, having children, having religious beliefs, and without a history of serious illness were more likely to strive for length, whereas the reverse associations were found for striving for quality. The latter was related to undertaking initiatives to engage in advance care planning. Awareness of differences in attitudes towards life-prolonging treatment within the public may improve communication about appropriate end-of-life care.

Keywords: End-of-life; General public; Attitudes; Life-prolonging treatments; Communication

1. Introduction

End-of-life care is increasingly acknowledged to be patient centered, that is, the patients' preferences and wishes should play an important role in medical decision-making. Recognizing factors that determine patients' preferences and actual choices is necessary in guiding the patient through this decision-making process. Patients' actual treatment choices are found to be most strongly predicted by the treatment preferences they had before consultation with their physician, while these preferences are explained by patients' general attitudes towards treatment, such as striving for length or quality of life [1]. Therefore, being aware of the patients' attitudes and preferences is an important prerequisite for high quality end-of-life care. These preferences include wishes concerning the use of potentially life-prolonging treatments, such as anti-tumor therapy or mechanical ventilation, which may sometimes severely impair the quality of the last phase of life.

Most studies on attitudes and preferences towards medical treatments have focused on populations of patients. Preferences concerning life-prolonging treatments of patients with varying diseases in different stages have been studied extensively [2–9]. It has been shown that preferences vary according to the type of life-prolonging treatment, its expected outcome, and the probability of that outcome [6,9]. Furthermore, younger cancer patients and cancer patients with children were found to assign more importance to striving for prolonged survival, even when this would impair their quality of life [7].

It has been suggested that discussion about attitudes concerning end-of-life care before the patient becomes seriously ill facilitates medical decision-making at the

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end-of-life, because such discussions can provide a framework for all medical decision-making [10]. Although such advance care planning is generally assumed to be particularly relevant for older and sick people, a study of Emanuel et al. among patients and members of the general population showed that 89% of the general population desire some kind of advance care planning, such as filling out an advance directive or discussing their wishes concerning medical care at the end-of-life with their physician [11]. However, the number of people in the general public who have actually undertaken such initiatives to enhance personal control over their last phase of life is very small [11–13].

It has been proposed that advance care planning should occur within the community and specifically within the family, and not in hospitals when consulting a doctor [14,15]. However, little is known about whether healthy persons are willing and able to express attitudes towards the use of intensive medical treatments at the end-of-life, and how they weigh the benefits and disadvantages of it. The aim of our study was to gain insight in such attitudes within the Dutch general population. A second aim was to identify whether these attitudes are associated with personal characteristics and with initiatives that people undertake to enhance personal control over medical interventions during their last phase of life.

2. Methods

2.1. Study design and population

In September 2002, written questionnaires were sent to an established sample frame consisting of 1777 members of the Dutch general public (panel of the "Consumers' Association" Consumentenpanel Gezondheidszorg, NIVEL/Consumentenbond). Of the selected persons, 1388 returned the questionnaire (response: 78%). The sample included persons aged between 20 and 93 years. The distribution of age within the sample was representative for the whole population, but women were somewhat overrepresented. The sponsors of the study approved the study design, but were not involved in the data collection, data analysis, or data interpretation.

2.2. Questionnaire

The questionnaire addressed attitudes concerning various end-of-life decisions. Attitudes towards life-prolonging treatment at the end-of-life were assessed with the Quality Quantity Questionnaire [7]. This questionnaire contains eight statements about accepting or rejecting life-prolonging treatment at the end-of-life. The questionnaire was originally developed to assess attitudes towards life-prolonging treatment of patients with cancer, but by reformulating the statements, the questionnaire could be used within the general public. For example, the original statement "If a treatment could prolong my life, I would always accept it, whatever the side effects may be" was changed into "If I would become seriously ill, I would accept every treatment that can prolong my life, whatever the side effects may be". Respondents were asked to what extent they agreed with the statements on a five-point Likert scale (1 = totally disagree; 2 = more disagree than agree; 3 = neither agree, nor disagree; 4 = more agree than disagree; 5 = totally agree).

To identify whether attitudes towards life-prolonging treatment were associated with initiatives that persons can undertake to enhance personal control over their last phase of life, respondents were asked whether they had filled out an advance directive, whether they had designated a surrogate decision-maker, and whether they had ever discussed wishes concerning medical treatments at the end-of-life with a physician. Also, the respondents were asked to rate their general health status [16], and whether they had a history of serious illness. Lastly, sociodemographic characteristics were obtained (age, sex, educational level, having children, religious beliefs).

2.3. Statistical analyses and construction of attitude profiles

We calculated the mean and the median of responses per item. A principal-component analysis with the varimax method was carried out to reconfirm the structure underlying the relationships among the eight items of the Quality Quantity Questionnaire. The factor solution was based on the eigenvalues (>1.0). Two factors were found to underlie the questionnaire, which is consistent with the original findings within a group of patients with cancer [7]. Factor one, explaining 43% of the variance, contained items representing an inclinement to "strive for length of life regardless of impaired quality of life". Factor two explained an additional 16% of the variance and contained items representing an inclinement to "strive for quality of life at the possible expense of survival". Sum scores were calculated for the factor "striving for length of life" (L scale) and the factor "striving for quality of life" (Q scale). For both scales, internal consistency was assessed by means of Cronbach's α. By distinguishing high (above the median) and low (under the median) scores on each factor, we constructed three profiles of attitudes: (1) persons with a high score on the L scale and a low score on the Q scale were categorized as "striving for length"; (2) persons with a low score on the L scale and a high score on the Q scale were categorized as "striving for quality"; (3) persons with either a high score on both scales or a low score on both scales were categorized as "no clear attitude expressed". For the L and the Q scale, relationships with sociodemographic characteristics and initiatives concerning end-of-life care were calculated by Student's t-tests and Pearson's correlations. Two multivariate regression analyses were performed to