

# Quality of life of Do-Not-Resuscitate (DNR) patients: how good are physicians in assessing DNR patients' quality of life?

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## Summary

**Questions under study:** To assess 1) the impact of quality of life evaluation on the implementation of Do-Not-Resuscitate (DNR) orders by physicians, 2) the accuracy of physicians' estimation of DNR patients' quality of life

**Methods:** A 10-month prospective clinical study in a community hospital including 255 DNR patients and 9 physicians in postgraduate training. Outcomes of interest were the influence of quality of life on the DNR decision and the assessment from patients and physicians of five different components related directly or indirectly to quality of life: mental (the Mini Mental State Examination), physical (the Activities of Daily Living) and social (Framingham Disability), degree of pain (visual analogical scale of pain) and of depression (Geriatric Depression Scale).

**Results:** Quality of life intervened in more than 70% of the DNR decisions. However, physicians underestimated quality of life components of DNR patients (Kappa <0.4 for each functionality). Severe depression, social isolation and physical dependence influenced negatively patients' perception of their quality of life ( $p < 0.01$ ).

**Conclusion:** Physicians often (71%) rely on the assumed quality of life of their patients in their DNR decision but unfortunately tend to underestimate it. Greater involvement of patients in the DNR decision could improve quality of care.

**Key words:** quality of life; DNR; patient/physician agreement

## Introduction

In many fields of medicine quality of life is becoming a common item in the assessment of outcome and health status [1, 2]. Furthermore, it is often used as a criterion for the appropriateness of intervention or treatment in clinical situations [3, 4]. Thus, it is of considerable importance to know to what extent physicians are able to estimate their patients' quality of life.

Previous studies have shown that health care providers tend to underestimate patients' quality of life [5]. Furthermore, they consider quality of life more often to withhold therapy than to support decisions for aggressive treatment [3, 6-7].

In this study we have focused our attention on the quality of life of a group of patients given a Do-Not-Resuscitate (DNR) order in a Swiss community hospital. We evaluated, first, how often phy-

sicians relied on the notion of quality of life when implementing a DNR order and, second, how accurate was the physicians' assessment of their patients' quality of life. Five components of quality of life (mental state, physical and social condition, degree of pain and depression) were analysed. We further tried to determine which component best correlated with the patient's own assessment of quality of life.

Data come from a prospective clinical study assessing the use and understanding of DNR orders in a Swiss community hospital [8]. Contrary to the United States and the United Kingdom, recommendations for the use and application of DNR orders have not been issued on a national level, and physicians' attitude towards DNR orders have been rarely assessed in our country [8, 9].

## Methods

We conducted a 10-month prospective clinical study on DNR patients in the Department of Internal Medicine (70 beds) at La Chaux-de-Fonds Hospital, between October 1996 and September 1997. All patients who stayed more than 24 hours in the medical ward and were provided with a DNR order have been included. If previously DNR patients had to be rehospitalised during the time of the study, they were considered as new patients, as they were often under the care of another physician in a different ward.

New DNR patients were included by examining three times a week the nurses' files where new DNR orders were documented. All data were collected within 5 days following DNR order implementation. We were unaware of patients' wishes regarding DNR status. Patients were asked to grade their quality of life. Five quality of life components were assessed with the Mini Mental State Examination (MMSE) (mental score), the Activities of Daily Living (ADL) (physical evaluation), a questionnaire taken out of the Framingham Disability Study (FDS) (social assessment), the Geriatric Depression Score (GDS) (depression score), and the visual analogical scale of pain [10-13]. Oral consent was requested. If patients were uncooperative or unable to answer, questionnaires were submitted to the closest family member, the mental and depression assessment being withdrawn. In case of death before the interview or refusal, patients were not included. One of us (NJP) collected all these data during the time of the study.

Nine physicians, 3 women and 6 men in their first to fifth year of postgraduate medical training, were asked to anonymously answer a questionnaire about their percep-

tion of quality of life components (mental, physical, social, degree of depression and pain) of their DNR patients and indicate whether quality of life, life expectancy or both influenced their decision to implement a DNR order. The study protocol was approved by our local Hospital Directory Committee.

## Statistics

Agreement between physicians' and DNR patients' perception of quality of life components was evaluated by the kappa coefficient which measured, in this study, the degree of concordance between the physicians' and the patients' quality of life scores that occurred beyond that expected by chance alone. Kappa values ranged between +1 (complete concordance) and -1 (complete discordance). Twelve variables were compared. The MMSE score was divided in 2 categories: normal (24-30), abnormal (0-23) [11]; ADL score in 3 categories: independent (0-1), moderately dependent (2-4) and severely dependent (5-7); FDS in 2 categories: socially integrated (7-12) and isolated (13-21); GDS (abridged version) in 3 categories: no depression (0-5), moderately depressive (6-10) and severely depressive (11-15); pain in 2 categories: no or little pain (0-4), moderate to severe (5-10); and quality of life in 3 categories: good, moderate, poor. A kappa coefficient <0.4 was considered to be poor agreement, between 0.4 and 0.6 moderate and beyond 0.6 good. Relationship between the patient assessment of quality of life and its five different components (mental, physical, social, degree of pain and depression measured by standardised scales) was analysed with the  $\chi^2$  test,  $p < 0.05$ .

## Results

255 DNR patients were assessed during the 10-month study. Twenty of them were readmitted. Sociodemographic data and medical diagnosis are shown in table 1. Global quality of life, physical and social condition and degree of pain were assessed in 85.5%, 89.2%, 86.3% and 86.7% of DNR patients. Mental and depression scores were obtained in 70.6% and 71.0% of the cases. A majority of DNR patients had a normal MMSE

(63.3%), were socially integrated (82.1%) and reported little or no pain (73.7%) (table 2). The percentage of patients physically independent (40.4%) or totally dependent (39.0%) was the same. 91.2% of the DNR patients reported that they were not or moderately depressed (47.5% and 43.7%). Half of the patients considered their quality of life to be good and 20% to be bad.

When implementing DNR orders, physicians relied on their perception of patients' quality of life (associated or not with life expectancy) in 71.1% of the cases. In the other 29.9%, physicians were only influenced by their assessment of patients' life expectancy.

Most patients were seen by physicians as socially well integrated (78.9%) and with little or no pain (77.4%). They considered half of their patients to be mentally well (48.3%), 17% to be physically independent and 37.6% to be not depressed. Patients with good quality of life were identified in only 8.7% of the cases.

Agreement between DNR patients' and physicians' assessment of quality of life components was extremely poor regarding global quality of life ( $K = 0.046$ ), very low for depression ( $K = 0.150$ ), social environment ( $K = 0.198$ ) and physical condition ( $K = 0.251$ ), and low for mental state ( $K =$

**Table 1**

Demography and medical diagnosis of Do-Not-Resuscitate (DNR) patients. La Chaux-de-Fonds, Switzerland, 1996-1997.

Variables	categories	n	%
Age (years)	≤65	60	23.5
	66 to 80	107	42.0
	>80	88	34.5
Sex	male	129	50.6
	female	126	49.4
Marital status	single	18	7.1
	married	130	51.2
	widowed	78	30.7
	divorced/separated	28	11.0
Medical diagnosis	cancer	39	15.3
	metastatic cancer	76	29.8
	cardiac disease	42	16.5
	others	98	38.4

**Table 2**

Quality of life components and global quality of life values as assessed by Do-Not-Resuscitate (DNR) patients and their physicians as well as patient/physician agreement about different functionalities and quality of life. La Chaux-de-Fonds, Switzerland, 1996–1997.

Quality of life components	categories	assessment by patients		assessment by physicians		agreement patient/physician Kappa
		n	%	n	%	
Mental <sup>a</sup>	abnormal	66	36.7	93	51.7	0.350
	normal	114	63.3	87	48.3	
Physical <sup>b</sup>	independent	90	40.4	38	17.0	0.251
	moderately dependent	46	20.6	84	37.7	
	totally dependent	87	39.0	101	45.3	
Social <sup>c</sup>	integrated	179	82.1	172	78.9	0.198
	isolated	39	17.9	46	21.1	
Depression <sup>d</sup>	not depressed	86	47.5	68	37.6	0.150
	moderately depressed	79	43.7	102	56.4	
	severely depressed	16	8.8	11	6.0	
Pain <sup>e</sup>	no or little pain	160	73.7	168	77.4	0.377
	moderate to severe pain	57	26.3	49	22.6	
Quality of life <sup>f</sup>	good	106	48.6	19	8.7	0.046
	moderate	68	31.2	112	51.4	
	bad	44	20.2	87	39.9	

<sup>a</sup> Mini-Mental State Examination (MMSE)

<sup>b</sup> Activities of Daily Living (ADL)

<sup>c</sup> Social assessment through the Framingham Disability Study (FDS)

<sup>d</sup> Geriatric Depression Score (GDS)

<sup>e</sup> Visual analogical scale of pain

<sup>f</sup> Closed-ended question about quality of life

0.350) and pain ( $K = 0.377$ ) (table 2). Physicians systematically underestimated their DNR patients' mental state and physical condition: 23.9% of patients with a normal MMSE were considered by their physicians to be mentally abnormal, 28.7% with a normal ADL score were seen as physically moderately or totally dependent. For quality of life, they misclassified 44.1% of the patients reporting a good quality of life. Physicians were however slightly better in detecting patients with no or little pain and socially well-integrated (underestimation in 9.7% and 14.2% of the cases respectively) and tended to overestimate the pres-

ence of depression among DNR patients (28.2%) (results not otherwise shown in a table).

We also analysed which quality of life component correlated best with the patient's global assessment of quality of life. We found no statistically significant correlation with mental state ( $p = 0.22$ ) and degree of pain ( $p = 0.45$ ). Quality of life correlated negatively with physical impairment ( $p = 0.004$ ), social isolation ( $p = 0.001$ ) and degree of depression ( $p < 0.01$ ). Patients' quality of life and physicians' assessment of it were not associated with any of the following patients' characteristics: age, gender, medical diagnosis.

## Discussion

Studies on physicians' evaluation of patients' quality of life have already been performed in elderly, chronically diseased or cancer patients [6], but rarely in DNR patients [14].

Our two main results were, first, that quality of life intervenes in more than 70% of the DNR decisions taken by the medical staff. Thus, when implementing a DNR order, physicians are very often influenced by their perception of patients' quality of life. Second, physicians systematically underrate their DNR patients' quality of life components (including mental state, physical and social condition, degree of pain and depression).

These findings confirm that physicians' and patients' perception of the patients' quality of life are often discordant [6, 7, 15]. These discrepancies may be attributable to working in an acute care setting, where the physician-patient relationship is superficial and centered on diagnosis and treatment. However, Pearlman showed that differences

in perception regarding patients' quality of life also existed in chronically diseased, community residing elderly with established physician-patient relationships [6]. The age of the physicians may play a role since young physicians in training do not have a large experience with elderly patients and therefore may not be good at assessing the adjustment processes to age, reduced health status and functional limitations of their patients when implementing DNR orders. Bio-medical aspects of care are often emphasised by physicians in an acute care setting while others factors such as interpersonal relationships, psychological aspects of well being, housing or economic situation are neglected [6].

Physicians' estimations of patients' quality of life have been found to be strongly related to their attitudes towards life-sustaining treatment for patients [14, 15]. In contrast, quality of life perceived by patients does not appear to be associated with

their preferences for life-sustaining treatment [15].

In our study, DNR patients with poor quality of life were more likely to be depressed, physically impaired or socially isolated. It is of great importance for physicians to detect and assess the severity of depression since this treatable condition may influence negatively physicians and patients in the DNR decision.

Our study has several limitations. Questionnaires about physical and social condition, degree of pain and quality of life were submitted to the closest family member if the patient was uncooperative or unable to answer. This is a source of potentially serious bias since family members are generally inaccurate in assessing patients' quality of life [16]. This occurred in 16% of the cases. However, degree of concordance between DNR patients' and physicians' assessment of patients' quality of life components was still poor after exclusion of the questionnaires answered by proxies (Kappa = 0.199 for physical state, 0.095 for social state, 0.334 for pain and 0.08 for quality of life).

Another limitation is that data about quality of life components were collected only once during the time of the hospital stay. Patients' perception of their quality of life and degree of pain may change over time. MMSE score can vary as a function of the dose of sedation/analgesics or of the degree of consciousness. Furthermore, the complexity of the notion of quality of life could be inappropriately expressed by a grossly qualitative answer [17]. In addition, physicians' perception of

patients' quality of life in acute care setting may be biased because the quality of life of sick patients is truly impaired [15]. Finally, the comparison between standardised multi-item questionnaires completed by patients and 3-item questionnaires submitted to the physicians for each component of quality of life may tend to increase the discordance between patients' and physicians' assessments.

Despite these limitations on the interpretation of the results, the poor correlation between physicians and DNR patients about quality of life shown in this study strongly suggests that physicians in training are not good in assessing their patients' quality of life. They should therefore be taught to explore their patients' perception of quality of life since it influences most of their DNR decisions [18-21]. However, patients' preferences for or against life-sustaining measures should be first known by physicians when implementing a DNR order, since patients' preferences about DNR may not be linked to their perception of quality of life.

In practice, physicians should not base decisions on their perception of patients' quality of life, especially in those involving life-and-death issues.

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