

## PAPER

# High prevalence of moral distress reported by oncologists and oncology nurses in end-of-life decision making

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**Abstract**

**Objective:** Decisions to limit life-prolonging treatment (DLT) are often accompanied by psychological and ethical difficulties. The aim of the study is to investigate prevalence and intensity of moral distress (MD) as well as potential causes experienced by oncology physicians and nurses in DLT situations.

**Methods:** This prospective study at a German university hospital included  $n = 100$  advanced cancer inpatients with DLT. We surveyed their respective physicians and nurses to assess MD in DLT using an adapted distress thermometer and an open-ended question to specify reasons of MD. We also collected data on the decision-making process from the perspective of the clinicians.

**Results:** Physicians report MD in 67% ( $n = 51$ ) and nurses in 74% ( $n = 67$ ) of the cases. The MD level in nurses (mean 2.3; SD 2.3) is significantly higher ( $P = .005$ ) than in physicians (mean 1.5; SD 1.4). Uncertainties concerning ethical aspects in DLT in a patient case are associated with MD in both physicians ( $P = .024$ ) and nurses ( $P = .004$ ). Involvement of nurses in DLT is the strongest predictor ( $P = .000$ ) for MD as indicated by physicians. Nurses experience MD especially, if the patient has a low quality of life ( $P = .001$ ).

**Conclusions:** Moral distress is experienced by both oncologists and nurses in DLT. Nurses report higher MD intensity compared with physicians although the ultimate responsibility for DLT lies with the physicians. Support for the challenging decisions may be provided through the implementation of an ethical guideline and enhanced interprofessional communication.

**KEYWORDS**

cancer, end-of-life, life sustaining treatment, moral distress, nurses, oncology, treatment limitation, withdrawal, withholding

## 1 | BACKGROUND

Towards the end of a cancer disease trajectory oncologists and their patients often have to decide when to shift therapy from disease-specific to standard palliative care.<sup>1</sup> In such situations, a decision against life-prolonging treatment and tumor-specific therapy is up for discussion. We define *decisions to limit treatment (DLT)*, as the

withholding or withdrawal of life-sustaining medical treatment such as intensive medical care, anti-infective treatment, blood products, parenteral nutrition, or tumor-specific therapies.

Although these decisions are important in order to avoid over-treatment near the end of life, oncologists perceive them as one of the biggest ethical challenges in clinical practice.<sup>2</sup> These decisions often generate controversies in the medical team or with patients

and their relatives<sup>3</sup> and can lead to moral distress (MD) in caregivers.<sup>4-7</sup>

Moral distress is a term that was firstly defined in nursing science by Jameton.<sup>8</sup> A redefinition of Varcoe et al shifts the focus from rather individual to more professional norms and describes MD as “The experience of being seriously compromised as a moral agent in practicing in accordance with accepted professional values and standards”.<sup>9</sup> Other existing variations of the initial definition and related concepts such as moral sensitivity,<sup>10</sup> ethics stress,<sup>11</sup> and stress of conscience<sup>12</sup> indicate a lack of theoretical consistency of MD.<sup>13</sup> Nevertheless, Wocial and Weaver argue that at its core it is a form of distress that occurs when one knows the morally right thing to do but is prevented from acting on that perceived obligation.<sup>14</sup> Based on this working definition, they developed the “Moral Distress Thermometer” to measure MD in the hospital setting.

With the growing interest on the phenomenon of MD empirical research in medical practice has increased intensely in the last years.<sup>15</sup> The majority of empirical studies on MD focus on the ICU setting and the nursing profession.<sup>16,17</sup> There is only a small number of studies investigating MD also in physicians,<sup>18,19</sup> although we know that deciding about limiting treatment is a complex and ethically contentious issue.<sup>20,21</sup> In addition, since most studies have been conducted in North America, the results are not necessarily applicable to other health and organizational systems.<sup>22</sup> A different historical development may have led to variances in social and professional values that determine, inter alia, the perception and ethical reflection of challenging treatment decisions like DLT.

Thus, the aim of this study is to examine MD related to end-of-life decision making in oncologists and oncology nurses of a German University Hospital by asking:

1. How frequently and to what extent do physicians and nurses experience MD surrounding DLT in oncology?
2. Which situations and challenges around DLT are associated with MD?
3. What are the reasons and circumstances that generate MD?

## 2 | METHODS

### 2.1 | Participants and procedures

We recruited  $n = 100$  cancer inpatients at the Department of Hematology/Oncology of the University Hospital in Munich, Germany from five hospital units ( $n = 5$  normal wards). The inclusion criteria were hospitalized cancer patients over 18 years old; diagnosed with advanced cancer; with DLT being either discussed or determined. We excluded patients with cognitive impairment and/or with a general state of health that did not allow assessment. The patients were recruited through a researcher of our study group who identified patients with DLT by the notes in their medical record as well as checking with the physicians on the units. All patients matching the inclusion criteria were informed about the study. The respective physicians and nurses of patients who consented were asked to complete

a survey about the decisional process with a return of  $n = 76$  physician and  $n = 90$  nurses questionnaires. The respective physicians were concerned with the patient case and normally initiated the discussion about DLT. The final decision was made in consultation with the responsible senior physician. This study protocol was approved by the Ethics Committee of the Medical Faculty of the University of Munich (number 140-10).

### 2.2 | Measures

For studying the complex phenomenon of MD, qualitative as well as quantitative empirical research methods were used.

#### 2.2.1 | Moral distress

Moral distress intensity was assessed by Wocial's MD thermometer (MDT).<sup>14</sup> The MDT is a single-item tool with an 11-point scale from 0 to 10. We used the validated German version<sup>23</sup> where a definition of MD was provided and physicians and nurses were asked to rate their current level of MD referring to a patient case (number 1-100).

To capture the dimensions of the concept more comprehensively, we included an open-ended question (“What burdens you the most in connection with the discussion about treatment limitation in this patient?”). The aim of this approach is to describe participants' experiences of MD and to identify possible factors causing MD. In this respect, participants were also asked to rate the influence of different factors with respect to DLT from 1 (not influencing at all) to 4 (very influencing).

#### 2.2.2 | Nurses' involvement into decision-making

Since there is some evidence that disagreement between physicians and nurses can cause MD, we included one item for oncologists to report the involvement of nurses: “The nurses were asked for their personal assessment in this treatment limitation” from 1 (strongly disagree) to 5 (strongly agree).

#### 2.2.3 | Satisfaction with the DLT

We measured the satisfaction with the DLT by asking the physicians and nurses “How satisfied are you with the decision making *process* of the treatment limitation in this patient?” and “How satisfied are you with the *result* of the decision making for treatment limitation in this patient?” from 1 (very satisfied) to 4 (very dissatisfied).

#### 2.2.4 | Patients' quality of life, socio-demographic data

The quality of life of the patients as perceived by their oncologist and nurses was measured by a 7-point Likert scale from 1 (very bad) to 7 (excellent). The survey also included socio-demographic data of the participants: age, gender, and professional experience.

### 2.3 | Data analysis

All data from the questionnaires were entered into a database using IBM SPSS software. Descriptive statistics including means, standard deviations, and frequencies were calculated to summarize the demographic characteristics of the sample participants, MD intensity, and

satisfaction with the DLT. The statistical significance of the differences between the two groups of physicians and nurses was analyzed by the *t*-test. Bivariate associations between variables were calculated using Spearman's correlation coefficient. Those characteristics found to have a statistically significant relationship with MD were included in a multiple linear regression model. All significance tests were two-sided using a significance level of  $\alpha < .05/\alpha < .01$ .

Qualitative content analysis according to Mayring<sup>24</sup> was performed through the process of coding the responses of the open-ended question to create meaningful patterns for interpretation by developing categories.

### 3 | RESULTS

#### 3.1 | Quantitative findings

Overall, 39 physicians and 50 nurses participated in the survey. As some of the participants were in charge for more than one patient, we received a total of 166 answered questionnaires basing on a survey's response rate of 76% for physicians and 90% for nurses in relation to the 100 patient cases (see Table 1). In most of the patient cases, the DLT "no resuscitation" (96%) and "no transferal to ICU" (92%) were made.

The following results refer to the patient cases and base on the 166 questionnaires answered by physicians and nurses. Regarding the incidence of MD, physicians report a burden by MD in 67%

( $n = 51/76$ ) and nurses in 74% ( $n = 67/90$ ) of the patient cases (see Table 2). The median reported intensity score was 2 for both groups. Overall, physicians show a mean score of 1.5, while nurses' stress is significantly higher ( $P = .005$ ) with mean 2.3 (ranging from 0 [=none] to 6 [=distressing] for physicians and 0 to 9 [=very distressing] for nurses).

Physicians are more satisfied with both the process and content of decisions to limit treatment than nurses. While nurses' dissatisfaction with the DLT process is significantly higher ( $P = .000$ ) with a mean score of 2.7 than physicians' (mean 1.8), they do not differ substantially in terms of their assessment of the final decision (nurses mean 1.8; physicians mean 1.5).

Correlations between MD and other variables are demonstrated in Table 3: Physicians' MD is significantly correlated with a diverging assessment of treatment options by colleagues (Spearman's rho .268,  $P = .019$ ) and uncertainty regarding ethical aspects (Spearman's rho .258,  $P = .024$ ). Also, a high level of involvement of nurses in DLT is strongly associated with MD of physicians (Spearman's rho .436,  $P = .000$ ).

With regard to the nurses, we found a significant relation between MD and low quality of life of the patient (Spearman's rho  $-.345$ ,  $P = .001$ ). Highly influencing difficulties in the DLT like uncertainty regarding ethical aspects (Spearman's rho .303,  $P = .004$ ), communication barriers with the patient due to language barriers or compromised consciousness (Spearman's rho .250,  $P = .018$ ), or communication difficulties in the medical team (Spearman's rho .237,  $P = .025$ ) correlate with nurses' MD as well. Socio-demographic

**TABLE 1** Demographic information on the participating physicians and nurses ( $n = 89$ ) and on the overall returned questionnaires ( $n = 166$ )

	Participating Physicians and Nurses ( $n = 89$ )		Returned Questionnaires ( $n = 166$ )	
	Physicians	Nurses	Physicians	Nurses
Number	$n = 39$	$n = 50$	$n = 76$	$n = 90$
Gender				
Female	33%	60%	26%	50%
Male	67%	40%	74%	50%
Age [years]				
Mean (SD)	31.1 (3.8)	34.2 (8.8)	31.7 (3.9)	34.1 (7.7)
Professional experience [years]				
Mean (SD)	In medicine: 3.5 (2.8) In oncology: 2.8 (2.6)	In patient care: 12.7 (8.9) In oncology: 9.8 (7.8)	In medicine: 4.3 (3.3) In oncology: 3.5 (3.0)	In patient care: 13.3 (7.9) In oncology: 10.4 (7.0)

**TABLE 2** Descriptive statistics for moral distress and satisfaction with DLT and significance of differences between physicians and nurses

	Physicians	Nurses	P
Moral distress incidence in patient cases (MD > 0)	67%	74%	
Moral distress intensity (0 = none to 10 = worst possible)			
Median	2	2	
Range	0-6	0-9	
Mean (SD)	1.5 (1.4)	2.3** (2.3)	.005
Satisfaction with the decision to limit treatment (1 = very satisfied to 4 = very dissatisfied)			
Process: Mean (SD)	1.8 (0.6)	2.7** (0.8)	.000
Decision: Mean (SD)	1.5 (0.6)	1.8 (0.6)	n.s.

Significance (*t*-test for independent samples):

\*\*( $P < .01$ ); n.s. = not significant.

**TABLE 3** Correlation between moral distress and quality of life of the patients, influence of difficulties, and involvement of nurses

	Moral Distress of Physicians Spearman's Rho (p)	Moral Distress of Nurses Spearman's Rho (p)
Quality of life of the patients	n.s.	-.345** (.001)
Difficulties in the DLT		
• Different assessment of treatment options by colleagues	.268* (.019)	n.s.
• Uncertainty regarding ethical aspects	.258* (.024)	.303** (.004)
• Communication barriers with the patient	n.s.	.250* (.018)
• Communication difficulties in the medical team	n.s.	.237* (.025)
Involvement of the nurses in DLT	.436** (.000)	Not asked

Significance

\*P &lt; .05.

\*\*P &lt; .01; n.s. = not significant.

characteristics like age or professional experience do not show significant relations to MD.

In order to detect determinants for MD, we did a multiple linear regression analysis. All variables correlating significantly with MD in physicians are predictive in the model with "involvement of nurses in DLT" as strongest predictor ( $P = .000$ ), followed by "different assessment of treatment options by colleagues" ( $P = .001$ ) and "uncertainty regarding ethical aspects" ( $P = .021$ ) (see Table 4). A significant contribution for explanation of variance regarding MD in nurses is only made by the quality of life rating with respect to the patient ( $P = .001$ ). The models explain 35% ( $R^2 = .35$ ) of the variance of MD in physicians and 21% ( $R^2 = .21$ ) MD variance in nurses.

### 3.2 | Qualitative findings

Physicians provided responses to the open-ended question on stressing aspects of DLT in 21 of the 100 patient cases, nurses in 36 patient cases. Three themes were identified in the answers of physicians: *timing*, *identification with the patient*, and *dissenting positions*.

#### 3.2.1 | "Timing" in the physician answers

Responses in the theme *timing* include comments about the right point in time to forgo tumor specific therapy. Five out of 21 physician answers referred to this theme.

"A treatment limitation/high palliative situation was not discussed with the patient early enough. Instead chemotherapy was offered [...]" (Physician comment on Patient No 006).

"The decision was taken too early; chemotherapy could have improved the patient's life in terms of time and quality." (Physician comment on Patient No 044).

#### 3.2.2 | "Identification" in the physician answers

*Identification* reflects the emotional response to the young age of some patients and was mentioned 6 times.

"The reason why the situation was not discussed with the patient was probably his age of 29 years and the fact that we found it difficult to talk to him about death." (Physician comment on Patient No 006)

"Young patient with great desire for therapy but only little therapeutic options" (Physician comment on Patient No 024).

#### 3.2.3 | "Dissenting positions" in the physician answers

The theme *dissenting positions* includes comments regarding discrepancy between patients or relatives' preferences and the clinicians' position in DLT; it occurred 5 times.

**TABLE 4** Standardized regression coefficients and significances for multiple linear regressions (dependent variable: Moral distress intensity)

	Physicians Beta (p)	Nurses Beta (p)
Quality of life of the patients	-	-.422** (.001)
Difficulties in the DLT		
• Different assessment of treatment options by colleagues	.323** (.001)	-
• Uncertainty regarding ethical aspects	.229* (.021)	n.s.
• Communication barriers with the patient	-	n.s.
• Communication difficulties in the medical team	-	n.s.
Involvement of the nurses in DLT	.414** (.000)	-
$R^2$	.35	.21

Significance

\*P &lt; .05.

\*\*P &lt; .01.

\*\*\*P &lt; .001; n.s. = not significant.

“Conflict between wish of the patient and assessment of the clinicians; promised chemotherapy by another senior physician” (Physician comment on Patient No 009)

“Opposing desires within the family of the patient and influence of members on the patient as well as attempts to exert influence on the doctors” (Physician comment on Patient No 035).

Looking at the answers given by the nurses three themes were identified: *respect for patient autonomy*, *compassion*, and *communication structures*.

### 3.2.4 | “Respect for patient autonomy” in the nurse answers

Responses in the theme of *respect for patient autonomy* include comments about the lack of patient involvement in DLT and were mentioned 8 times out of 36 answers by nurses.

“Although in a very poor general condition the patient was still dialyzed and got Antibiotics until death, he has received no information about the decisions.” (Nurse comment on Patient No 016)

“The patient was not ‘seen’ by the persons who make the decisions [...]” (Nurse comment on Patient No 072).

### 3.2.5 | “Compassion” in the nurse answers

*Compassion* of nurses refers to the suffering of the patients, which they can hardly influence (11 times mentioned).

“The patient had severe pain; he seemed very distressed, crying a lot.” (Nurse comment on Patient No 007)

“The patient wanted to live only for her child.” (Nurse comment on Patient No 009)

### 3.2.6 | “Communication structures” in the nurse answers

Fifteen answers by nurses with reference to *communication structures* show the insufficient involvement of nurses in DLT and a poor communication in the medical team.

“Because of the lack of communication between physicians and nurses [...]” (Nurse comment on Patient No 012).

“We as caregivers are neither involved in decisions nor sufficiently informed about the result.” (Nurse comment on Patient No 030).

## 4 | DISCUSSION

This is the first study that investigates MD of oncology physicians and nurses in Germany. Knowing that MD and its consequences might undermine the sustainability of the medical staff, the quality of clinical decision making, and care for seriously ill patients,<sup>25</sup> it is necessary to understand factors that initiate the development of MD in end-of-life decision making.

Key findings of our study based on quantitative as well as qualitative data are:

1. The majority of physicians and nurses caring for advanced cancer patients experience moral distress in situations of treatment limitation, albeit in low intensity.

Taking into consideration that MD has been reportedly associated with end-of-life situations,<sup>6,13,26</sup> the stress level among the nurses and physicians in our investigation was lower than we expected, and lower than reported elsewhere.<sup>14</sup> Nevertheless, we observed inter-individual variations, and some physicians and nurses showed a considerable level (max. 6/9 on 11-point scale) of MD. Although the median and mean score indicated a mild degree of MD intensity as measured by the MDT, it is a frequent phenomenon experienced by the majority of physicians and nurses. Mean MD in the present study reported by nurses was significantly higher than that reported by physicians, in line with other studies.<sup>6,25,26</sup> Reasons for the higher intensity on the part of nurses might be their closer contact to the patient: nurses report distress due to their witnessing the suffering of patients. Also, they are not involved and responsible for DLT, although they have to put the decision into practice. Another reason could be differences in professionals' “socialization” and medical education of physicians regarding their dealing with uncertainty.<sup>27</sup> With regard to the specific circumstances and challenges around DLT that might lead to MD, we found that:

2. Uncertainty regarding ethical aspects is associated with MD in both oncologists and oncology nurses.

Correlation analysis showed that physicians were particularly burdened by MD in patient cases where colleagues held divergent opinions and where great involvement of nurses strongly influenced the DLT. Nurses experienced MD especially when patients' quality of life was low or the DLT was preceded by communication barriers with the patient or communication problems in the medical team. For both, physicians and nurses, MD was associated with uncertainty regarding ethical aspects around DLT.

Our findings resonate with the result of other qualitative studies since the answers of nurses to the open-ended question indicate that they experience MD, if they perceive that patient wishes are not sufficiently respected by physicians.<sup>28</sup> Furthermore, a lack in interdisciplinary and collaborative structures led to insufficient involvement in decisions and inadequate communication in the medical team from the point of view of the nurses.<sup>18</sup> As the responses of the physicians to the open-ended question are related to aspects of uncertainty and dissenting positions and therefore stronger to the DLT itself, our study supports the assumption that physicians question themselves while nurses are questioning physicians.<sup>18</sup> This leads to the third finding with reference to determinants of MD:

3. Physicians experience MD due to a challenging decision-making, nurses experience MD due to the suffering of patients.

An interesting result of the regression analysis was that the involvement of nurses in DLT is the strongest predictor for MD in



physicians. It might be explained by the mentioned hypothesis that oncologists and their decisions are challenged by nurses and underlines the importance of improving team-communication to increase the awareness for the demanding task oncologists have to undertake when deciding over treatment limitation.

On the part of the nurses, patients' low quality of life was predictive for MD. In accordance with the open-ended question, compassion might be a factor that enhances uncertainty about the treatment limitation. The perception of patients' suffering, which nurses have little power to influence, may contribute to the experience of MD, in line with other studies.<sup>16</sup> However, it can be questioned if empathy with the patient can lead to MD in the sense the MDT defines it (being prevented from acting ethically correctly). Maybe, in this respect, the instrument cannot distinguish clearly between moral and general emotional distress.

## 5 | CONCLUSION

This study found that MD is experienced by oncologists and oncology nurses in most situations of treatment limitation. Nurses report higher MD intensity compared with physicians although the ultimate responsibility for the end-of-life decision lies with the physicians. This corresponds with our finding that MD in physicians can be explained by other factors than MD in nurses, according to the division of labor and areas of responsibility: While physicians are burdened due to a challenging decision-making, nurses experience MD due to compassion with the patients and an unmet need for participation in end-of-life decisions. It is therefore necessary to involve nurses in DLT to ensure that a therapeutic concept is shared by all. This and further aspects could be determined in a guideline on treatment limitation assuring a structured decision-making process and providing guidance in ethical questions and interprofessional cooperation.

## CLINICAL IMPLICATIONS

Sensitization and support for the challenging decisions on treatment limitation in advanced cancer patients may be provided through the implementation of an ethical guideline. With respect to decidedly ethical conflicts in a particular patient, ethical case consultation has proven helpful to develop a sound decision dedicated to the wellbeing of the patient. Apart from that, platforms are needed where feelings of overload, injustice, and lack of respect within the professional team could be discussed and structural changes regarding work distribution may be initiated.

## STUDY LIMITATIONS

Our study has several limitations. The case numbers are comparatively low as physicians answered in  $n = 76$  and nurses in  $n = 90$  of the 100 patient cases in total. Possible self-selection bias limits generalizability to similar groups of professionals. Answers on personal experiences of burdens and stress are commonly biased by social desirability. Although a validated scale, the adequacy of the MDT can be discussed. We argue that the instrument is useful for detection of MD, but interpretation of intensity is difficult in our view: As there

are no relevant cut-points to identify elevated risks we do not know what the measured median score of 2 actually indicates. An 11-point scale from 0 to 10 tends to consider values around 2 as low, but under the given definition (to have to act against one's own convictions) all values above 0 could be seen as remarkable. Taking this and the answers to the open-ended question into account, the MDT may also capture the general emotional burden nurses and physicians experience in situations of DLT. For further development, we propose the supplement of an additional open-ended question on consequences of MD for one's own behavior.

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## CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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