TRUTH TELLING TO TERMINALLY ILL PATIENTS IN BULGARIAN HOSPICES

Silviya Aleksandrova-Yankulovska*

Abstract
For centuries there was an informal rule not to tell the truth to cancer patients. The paternalistic model of relationships still exists in many societies in relation to the issue of informing the patient.
The object of this paper is to study the issue of truth telling to terminally ill patients in Bulgarian hospices.
Materials and methods. The study employed a combination of sociological and statistical methods. Self-administered questionnaires were distributed among the personnel and patients’ relatives in 17 in-patient, 12 home care hospices and 5 palliative care units. Altogether, 190 health professionals and 216 patients’ relatives responded to the questionnaires. The response rates for the personnel and the relatives were 86% and 74.5% respectively.
Results. According to the personnel, there were 62.1% autonomous patients in palliative care units, and 23-24% in in-patient and home care hospices. The majority of the patients were familiar with the diagnosis (50.4% in in-patient hospices, 66.7% in home-care hospices, and 78.8% in palliative care units). There was a significant difference in the data obtained by the relatives. Most of the patients were informed by their physician before the hospice admission. 10.2%-18.5% of the patients were informed by the relatives.
Conclusion. Following the recent tendencies in favor of respect for autonomy, Bulgarian physicians inform patients and try to build partnerships in most of the therapeutic relations. The issue of truth telling in case of terminally ill patients is still one of the most complex and sensitive situations presenting moral dilemma in clinical practice.
Keywords: truth telling, terminally ill, hospices, Bulgaria

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Background

One of the oldest debates in bioethics is about telling the truth to terminally ill patients. For centuries there was an informal rule not to tell the truth to cancer patients. The debate on the issue of truth telling followed the introduction of the principle of respect for autonomy in contemporary bioethics.

Several arguments in favour of truth telling were pointed out in the literature:

- Patients can settle family and other problems.
- Patients get the opportunity to fulfil their last wishes and “prepare” for death.
- Increased sensitivity of terminally ill patients to the lie and their suspicion about bad diagnosis and prognosis (5).
- Patients want to be fully informed (9,14).
- Patients have the right to know. The responsibility of the physician to inform the competent patient has been underlined.
- More effective palliative treatment can be instituted (12).
- Communication in the family is facilitated.
- Decreased risk of psychological morbidity of relatives.
- Strengthens physician-patient relationship and fosters collaboration.
- Avoidance of uneasy situations among team members (11).
- Lack of candour or outright deception, even well intentioned, can undermine public’s confidence in medical profession.

Studies reveal other positive effects of truth telling as: reducing uncertainty and anxiety in cancer patients (11), decreased signing of do-not-resuscitate order (3), better quality of life, fewer symptoms, lower rate of emotional distress (17).

The corresponding most common arguments against truth telling are:

- Depriving patients from hope.
- Stress, caused by the communication process.
- Lack of time to attend patient’s emotional needs (7), lack of training in communication of bad news (4) and shortage of personnel (14).
- Risk of deterioration of patient’s health condition and suicidal attempts. The specific term in this relation is "therapeutic nondisclosure". It refers to a physician's decision not to inform a patient about the diagnostic or prognostic in order to protect him or her from the negative impact (8).
- Truth telling is difficult and stressful for the physician (8).
- Uncertainty about prognostication.
- Feeling of inadequacy or hopelessness regarding the unavailability of further
curative treatment (7).

Truth-telling, however, entails more than merely providing information related to the forthcoming death. Various uses of different coping strategies impact on the patient’s preferences concerning the communication with their doctors about the bad news (Table 1).

**Table 1 - Models of truth and correlating coping strategies**

<table>
<thead>
<tr>
<th>Modes of truth</th>
<th>Coping strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>The absolute objective truth that the patient is dying</td>
<td>Facing the truth in order to take action</td>
</tr>
<tr>
<td>The partial truth about patient’s condition including some facts but not all the details</td>
<td>Facing some parts of the truth in order to maintain hope</td>
</tr>
<tr>
<td>The desired truth, originating in the patient's own beliefs about a healthy or better life</td>
<td>Hovering about facing or avoiding the truth</td>
</tr>
</tbody>
</table>

Adapted from Friedrichsen et al., 2011

The Charter on Medical Professionalism, endorsed by more than 100 professional groups worldwide and the US Accreditation Council for Graduate Medical Education, requires openness and honesty in physicians' communication with patients (2). The standpoint of the World Medical Association on the issue is expressed in the Declaration on the rights of the patient: “Exceptionally, information may be withheld from the patient when there is good reason to believe that this information would create a serious hazard to his/her life or health” (16).

The paternalistic model of relationships still exists in many societies in relation to the issue of informing the patient and involving him in the decision-making. In the collectivist Asian and Muslim cultures, for example, illness is a shared family matter. Consequently, decision making is family centered and beneficence and non-maleficence play a dominant role in their ethical model, in contrast to the patient’s autonomy in Western cultures (13). Even in Western societies, however, significant numbers of physicians do not reveal terminal diagnosis to patients. According to a study run by Schildmann et al. (14) 96.2% of physicians preferred to inform the relatives instead of the patient. Daugherty and Hlubocky’s (4) results showed that although 98% of oncologists informed the patients about the terminal illness, 48% explained the prognoses only when specific preferences for such information were expressed. Greek physicians informed 1/10 of their new cancer patients, mainly due to the perceived limited competency, patient's low cognitive state, fear of harming the patient and relatives' objection (15). Bulgarian authors found that only 23% of physicians never attempted to hide the truth from the patient and 14% lied and even falsified documents accordingly (1).

In Bulgaria the last legal amendments have closed the door for
the possibility of not telling the truth. Such exception existed for last time in the National health contract in 2000 (article 22, paragraph 4) and it was considered in situations of existing risk of deteriorating the patient’s physical or mental status.

The wide variety of the debated issues of truth telling as well as the existing differences in the interpretation of the term “truth telling” itself lead to the conclusion that we need to apply individual approach in the communication with terminally ill patients.

The object of this report is to study the issue of truth telling to terminally ill patients in Bulgarian hospices.

Methods
The study employed a combination of sociological and statistical methods. The present study is a part of a bigger survey on hospice care in Bulgaria. First phase focused on the identification of registered hospices in the country using the official databases of regional health authorities. Second phase determined the functional status of hospices. The third phase involved contacting the hospices’ managers and obtaining their consent for participation in the survey. Self-administered questionnaires were distributed among the personnel and patients’ relatives in 17 in-patient, 12 home care hospices and 5 palliative care units. All in all, 190 health professionals and 216 patients’ relatives responded to the questionnaire. The achieved response rates for the personnel and the relatives were 86% and 74.5% respectively.

Hospice managers and staff were asked how many patients were autonomous. Three answers were provided: “most patients are autonomous”, “few patients are autonomous” and “we do not have autonomous patients”. In regard to patients’ informing about the diagnosis, they were asked two questions: “Do the ward patients know their diagnosis?” and “If yes, when were they informed?” Three answers were provided to the first question: “most yes”, “small part yes” and “no”. Three answers were also provided to the second question: “before admission, by other colleagues”, “after admission, by the treating physician” and “some of the relatives had informed the patient”.

Relatives were asked two questions regarding the patients’ awareness of the diagnosis. The first question was whether the patient knew the diagnosis. The second question asked about the source of information to the patient. Three answers were provided: “the treating physician, before the admission to the hospice”, “the treating physician, after the admission to the hospice” and “some of the relatives”. The survey was organized in accordance with the ethical standards, and the protocol was approved by the institutional ethics committee.

The statistical analysis was done by Microsoft Office Excel 2003 and SPSS v.13.

Results and discussion

Respondents’ characteristics
In total, 190 staff members
participated in the study. The majority of them (102) worked in in-patient hospice units; 27 - in home care hospice settings and 61 - in palliative care units. 141 (74.2%) of the participants were nurses, physicians and other team members (therapists, social workers, psychologists) represented 8.4% and 17.4% of the respondents respectively.

The group of relatives consisted of 216 people - 108 relatives of patients from in-patient hospice units; 64 relatives of patients in home hospice settings; 44 relatives of patients in palliative care units. The majority of relatives were patients’ children (115 people – 53.2%) and patients’ spouses (50 people – 23.1%).

**Patients’ autonomy**

Truth telling is interrelated with many factors, the most important of them being the patient’s autonomy.

The majority of respondents (55.4%) considered only a small part of patients as autonomous. About one third (35.3%) of hospice managers and personnel assessed patients as autonomous. 62.1% of patients in palliative care units were assessed autonomous (Figure 1).

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**Figure 1** - Patients’ autonomy (based on data from hospices’ managers and staff)
The last result was rather unexpected because 89.4% of the patients in these units were cancer patients in acute condition. In comparison, the personnel from in-patient hospices and home care settings assessed 23-24% of patients as autonomous. The most common diagnoses in in-patient hospices and home care settings were post-stroke conditions (63.9% and 48.7% respectively), and vascular dementia (22.7% and 17.9% respectively). Both conditions are known to be often related with incompetency of patients.

**Patients’ awareness of the diagnosis**

Data on patients’ awareness of the diagnosis are presented in Table 2 (based on hospices’ managers and personnel opinion) and Figure 2 (based on relatives’ opinion).

*Table 2 - Patients’ awareness of the diagnosis (based on data from hospices’ managers and personnel)*

<table>
<thead>
<tr>
<th>Do patients know their diagnosis?</th>
<th>In-patient hospice</th>
<th>Home care settings</th>
<th>Palliative care units</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>5.9</td>
<td>1</td>
</tr>
<tr>
<td>The majority Yes</td>
<td>60</td>
<td>50.8</td>
<td>26</td>
</tr>
<tr>
<td>Small part Yes</td>
<td>49</td>
<td>41.5</td>
<td>11</td>
</tr>
<tr>
<td>Not specified</td>
<td>2</td>
<td>1.7</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>118</td>
<td>39</td>
<td>66</td>
</tr>
</tbody>
</table>

The majority of patients were informed about the diagnosis (50.8% in in-patient hospices, 66.7% in home care settings and 78.8% in palliative care units). The percentage of informed patients was highest in palliative care units. These patients were hospitalized and cared in accordance with the clinical guidance for care of terminally ill patients. Part of the clinical guidance is the requirement for informed consent. As for the high proportion of informed patients in the hospices, it can be attributed to the fact that the majority of them were not terminally ill cancer patients and the communication of their diagnoses was not so complicated.

Some differences were observed in the opinion of personnel and relatives about non-informed patients. The percentage of relatives who believed that the patient was not informed was higher in all types of institutions studied. The difference can
be explained by the fact that the staff’s opinion was aggregated and general for the group of patients as a whole. On the contrary, the relatives answered for each patient. On the other hand, there is a chance that some patients avoided discussing their condition with the relatives in order to prevent them from stress and anxiety (10).

Despite of the differences, most of the patients seemed to be informed. This fact was in accordance with the recent tendencies against paternalism in bioethics.

Figure 2 - Patients’ awareness of the diagnosis (based on data from relatives)

**Time and source of information**

No difference was observed in the data provided by the personnel and relatives in regard to the time and source of information (Table 3). Most of the patients were informed by the physician before their admission to the hospice/palliative care unit. It has been estimated that 5.1% of patients in home care settings and 25.8% of patients in palliative care units were informed after their hospice admission. About 10.2% to 18.5% of the patients were informed by the relatives.
When and who informed the patient about the diagnosis?

<table>
<thead>
<tr>
<th></th>
<th>In-patient hospices</th>
<th>Home care settings</th>
<th>Palliative care units</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Managers and personnel</td>
<td>Relatives</td>
<td>Managers and personnel</td>
</tr>
<tr>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>7</td>
<td>5.9</td>
<td>38</td>
</tr>
<tr>
<td>Physician before hospice admission</td>
<td>60</td>
<td>50.4</td>
<td>47</td>
</tr>
<tr>
<td>Physician after hospice admission</td>
<td>16</td>
<td>13.4</td>
<td>7</td>
</tr>
<tr>
<td>Relatives</td>
<td>22</td>
<td>18.5</td>
<td>16</td>
</tr>
<tr>
<td>Combined</td>
<td>2</td>
<td>1.7</td>
<td>-</td>
</tr>
<tr>
<td>Not specified</td>
<td>12</td>
<td>10.1</td>
<td>-</td>
</tr>
<tr>
<td>TOTAL</td>
<td>119</td>
<td>100.0</td>
<td>108</td>
</tr>
</tbody>
</table>

Table 3 - Time and source of information (based on data from hospices’ managers, staff and patients’ relatives)

Involvement of patients and patients’ relatives in decision-making

Data in Table 4 confirms the tendencies towards the partnership model in Bulgarian hospices. In majority of cases, patients and their relatives were involved in decision-making: 88.3% in in-patient hospices, 92.3% in home care settings, and 95.5% in palliative care units.

Table 4 - Involvement of patients and relatives in decision-making (based on data from hospices’ managers and staff)

<table>
<thead>
<tr>
<th>Do you involve patients and their relatives in decision-making?</th>
<th>In-patient hospice</th>
<th>Home care settings</th>
<th>Palliative care units</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Yes</td>
<td>42</td>
<td>35.4</td>
<td>20</td>
</tr>
<tr>
<td>Yes, when it is possible</td>
<td>63</td>
<td>52.9</td>
<td>16</td>
</tr>
<tr>
<td>Only relatives</td>
<td>13</td>
<td>10.9</td>
<td>3</td>
</tr>
<tr>
<td>Not specified</td>
<td>1</td>
<td>0.8</td>
<td>-</td>
</tr>
<tr>
<td>Total number of respondents</td>
<td>119</td>
<td>100.0</td>
<td>39</td>
</tr>
</tbody>
</table>

Conclusion

Following the recent tendencies in bioethics in favor of respect for autonomy, the Bulgarian physicians inform the patients and try to develop partnerships in most of the therapeutic
relations. The issue of truth telling in case of terminally ill patients, however, is still one of the most complex and sensitive situations presenting moral dilemma in clinical practice. The last amendments in health law closed the door for the possibility of not telling the truth. However, it is questionable whether this strict rule makes things easier in practice.

References
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