The Terminally Ill Patient: Time to Turn a New Page

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The Terminally Ill Patient Law – 2005, which attempts to give patients autonomy to dictate clinical care at the end of their lives, took effect in December 2006 [1,2]. The law has been around for almost a decade; however, despite increasing numbers of Israeli physicians who support a patient’s right to refuse life-extending treatments [3,4], overall comprehension and implementation of the TIPL has not been assessed. The TIPL is a legal document, and although it was created together with medical, rabbinic, legal, and governmental oversight, we feel that it is lengthy (e.g., the printed English translation is 17 pages) [5], complex, under-utilized, inadequately disseminated, and does not propose a user-friendly and standardized process for implementation by physicians.

The need for a formal, user-friendly process to deliver compassionate, timely, and agreed-upon end-of-life care, is increasing. The acuity of patients in internal medicine departments is growing annually [6]. This is the result of an older in-patient population, coupled with a shortage of intensive care unit beds, strict entry criteria to the ICU (e.g., preference for patients without dementia), and the advent of “intubation rooms” on internal medicine wards caring for ICU level-of-care patients [7]. Our aim was to review a case-series of patients who underwent a user-friendly process to utilize the TIPL.

Internal Medicine Department D was created in December 2013, when the Shaare Zedek Medical Center took over the Bikur Cholim Hospital. Shaare Zedek is an 850-bed tertiary care medical center in Jerusalem with a long standing interest in end-of-life care [8-11]; additionally, the chairman of the committee that prepared the TIPL is senior faculty in the Division of Pediatrics [9].

We decided to implement a formal process to utilize the TIPL for our sickest patients. We designed a one-page form, to be completed by all stakeholders, and placed it in the patient’s chart [Appendix]. The form, capturing the essence of the TIPL, was created with input from rabbinic, medical and administrative leadership at Shaare Zedek. To promote innovation diffusion, multiple learning sessions were conducted to develop, present and teach the proposed process. In the hope of providing support for a formal and user-friendly means for delivering end-of-life care to our sickest patients, in compliance with the TIPL, we present here a case-series of 10 patients who underwent this process between June 2013 and December 2014.

METHODS

Patients were first identified as having either less than 2 weeks or 6 months to live. This discussion was conducted at morning report as well as on bedside rounds. The patient’s diagnosis was then documented and the patient was assessed for competence. If there was a question regarding competence, psychiatric consultation was obtained. If the patient was competent, we had a discussion regarding the patient’s wishes for clinical care. If the patient was not competent, the entire clinical team made an effort to determine if there existed a living will, advance directive, legal guardian or close person (i.e., a person who had a significant familial or personal relationship with the patient). If a guardian or close person was identified, this person was contacted and invited to come to the hospital or have an in-depth telephone conversation regarding the patient’s condition, prognosis, and potential end-of-life care. If no proxy could be identified, the State was formally assigned guardianship and the decision of care ultimately given to the treating clinical team.

End-of-life care options were geared to our specific patient population. These included: antibiotics, bi-level positive airway pressure, dialysis, intubation, resuscitation (i.e., CPR, vasopressors, electric shock), surgery, and blood transfusion. Once the list of care options was agreed upon, signatures were required by a senior physician, the patient’s proxy, the nurse, and the social worker. The form (available in different languages) was then placed in the patient’s chart along with a short note in the electronic medical record describing what transpired. Where applicable, a Do Not Resuscitate order was entered. End-of-life goals were then discussed again during evening bedside rounds (i.e., a “hard” sign-out), with the resident and attend-
ing covering the night shift. All deaths were discussed at the morning report.

## RESULTS

During the period June 2013 through December 2013, we identified 16 patients who met the TIPL definition of the terminally ill patient. Six patients, all incompetent, did not undergo the proposed process by request of their proxy. They all received traditional treatments to extend life. Of the 10 patients who underwent the process [Table 1], 60% were female, the mean age was 83.6 years (SD 10.1), and the mean length of stay 15.8 days (SD 16.9). Prior to hospitalization, the patients resided in a nursing home (n=1), skilled nursing facility (n=5), geriatric nursing home (n=1), and private home (n=3). The major diagnostic categories were infectious in 6 patients, infectious/renal in 2, infectious/cardiac in 1, and infectious/oncologic in 1. Most patients presented with dementia (n=9), general disability (n=9), and most patients died during the admission (n=6). The signatory was either a “close person” (n=6) or guardian (n=4). The mean signature day was hospital day 6.8 (SD 6.9). The average number of meetings prior to signing the form was 2, and the average time per meeting was 15 minutes. Signatory choice for end-of-life care included antibiotics in 9, BiPAP in 4, dialysis in 1, intubation in 1, resuscitation in 1, surgery in 1, and transfusion in 9 [Figure 1].

## DISCUSSION

Prior to the above cases, no formal process existed for approaching care at the end of life for our sickest patients. Additionally, there was poor (or absent) literacy of the TIPL among both patients and clinical staff. While this process is still in development in our department, documentation has improved and the feedback from patients and staff has been positive. For example, the covering nighttime medical team now has a clear and well-documented directive for care for those patients who underwent this process. There is also more comprehension of delivery of end-of-life care. As a team, our devised process forced us to become intimately familiar with the numerous terms used for delivery of care for this sickest of populations; for example, advance directives, allow natural death (AND), comfort measures only (CMO), do not intubate (DNI), DNR, close person, durable power of attorney, guardian, hospice, living will, palliative care, code note, code order, code status, full code, and proxy. It also became abundantly clear that a multi-disciplinary team (including a palliative care consultant) was necessary to deliver the best end-of-life care.

The average age was higher and length of stay longer in our cases compared to our department as a whole; 83.6 vs. 67 years,

### Table 1. Patient characteristics

<table>
<thead>
<tr>
<th>Patient</th>
<th>Gender</th>
<th>Age (yr)</th>
<th>LOS</th>
<th>Residence</th>
<th>Diagnosis category</th>
<th>Dementia</th>
<th>Disabled</th>
<th>Deceased</th>
<th>Signature Day</th>
<th>Signatory</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>86</td>
<td>9</td>
<td>NH</td>
<td>Infectious</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>3</td>
<td>Close person</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>85</td>
<td>14</td>
<td>SNF</td>
<td>Infectious</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>5</td>
<td>Guardian</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>67</td>
<td>8</td>
<td>SNF</td>
<td>Infectious/Renal</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>3</td>
<td>Guardian</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>91</td>
<td>16</td>
<td>GH</td>
<td>Infectious/Cardiac</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>10</td>
<td>Guardian</td>
</tr>
<tr>
<td>5</td>
<td>F</td>
<td>74</td>
<td>23</td>
<td>HM</td>
<td>Infectious</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>18</td>
<td>Close person</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>79</td>
<td>3</td>
<td>HM</td>
<td>Infectious/Oncologic</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>2</td>
<td>Close person</td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>93</td>
<td>11</td>
<td>SNF</td>
<td>Infectious</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>1</td>
<td>Close person</td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>97</td>
<td>4</td>
<td>HM</td>
<td>Infectious</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>4</td>
<td>Close person</td>
</tr>
<tr>
<td>9</td>
<td>F</td>
<td>92</td>
<td>9</td>
<td>SNF</td>
<td>Infectious</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>2</td>
<td>Guardian</td>
</tr>
<tr>
<td>10</td>
<td>F</td>
<td>72</td>
<td>61</td>
<td>SNF</td>
<td>Infectious/Renal</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>20</td>
<td>Close person</td>
</tr>
</tbody>
</table>

Average (SD) 83.6 (10.1) 15.8 (16.9) 6.8 (6.9)

NH = nursing home, SNF = skilled nursing facility, GH = geriatric nursing home, HM = private home

**Table 1. Patient characteristics**

**BiPAP** = bi-level positive airway pressure

**DNR** = Do Not Resuscitate

**Figure 1. Signature treatment choice**
and 15.8 vs. 6.6 days respectively. The increased LOS might reflect the influence of the process we developed. Additionally, the average time it took to obtain signatures from patients or proxies was 6.8 days. These data possibly reflect a delay in initiating our process by the staff, or time needed by the proxy (e.g., to absorb presented information, and/or speak with family, friends, or a spiritual advisor). These values may also reflect overall increased acuity of patients at the end of their lives. In time, as we become more adept at this process, and more research is conducted, we may see LOS decrease for these patients. However, longer LOS may positively correlate with a perceived "positive" experience by family members, proxies, and staff. Signatory treatment choices were as expected, with the exception of BiPAP, a non-invasive, possible palliative treatment option. This may reflect the patient's underlying condition, or a poor understanding of the uses and benefits of this modality.

Most patients had a diagnosis of dementia, were disabled, and had chronic medical problems; that is, there was a steady decline in their general condition. This is not a great deviation for the baseline patient in our department, at times representing 70% of our admissions. However, the fact that none of these patients arrived at our department with any advance directives speaks poorly for the present system in Israel. The absolute worst time to address these issues is during an admission for an acute illness: patients usually cannot represent themselves in any meaningful way, many times they arrive alone (due to the acute nature of the illness), and the added stress causes a tense dynamic in their support system, possibly clouding good judgment. One systems-approach method to address this issue would be to initiate the process of advance directives in the community at the level of the health insurance fund. We propose (as a start) that all patients over the age of 70 and/or with a diagnosis of dementia be required to have an advance directive on file. This would be required by the health fund and would be included in the routine health care maintenance provided by the local family physician, similar to preventive vaccines, cholesterol checks, and colonoscopy.

While we appreciate the conscientious work done by the formulators of the TIPL, it is our impression that its actual implementation lags behind similar processes in the United States and Europe. The reasons are most likely multi-factorial. We suggest that the "Israeli ethos... granting overriding consideration to the sanctity of life" [12] coupled with cultural and religious norms may make it difficult to approach end-of-life discussions with patients and their families. There are those who take issue with the TIPL and feel that its interpretation of the patient's autonomy doctrine is narrow and limited [13]. However, this does not explain why the TIPL has not been fully embraced. Education may be a key factor. Very little time is spent educating medical students and physicians on proper care for the patient at the end of his or her life. A new curriculum needs to be integrated into medical education to teach new physicians about end-of-life care. The Israeli view of hospice is also narrow. Hospice in Israel is primarily focused on the oncologic patient, and palliative care is a relatively new specialty that has yet to find its place in the care of the medical patient. These fields need to continue to evolve to include other medical conditions (e.g., end-stage congestive heart failure, chronic obstructive pulmonary disease). Lastly, many may feel they do not have the time and resources to address these issues in any meaningful way. We found that this can be done, but requires a top-down, formal, multi-disciplinary approach. We feel that without a formal process (e.g., proper documentation and communication), vital decisions (whether to intubate) will be made within seconds during change of shifts from the daytime to nighttime coverage.

CONCLUSIONS

No process is perfect, and the TIPL needs to continue to improve and evolve. For example, there should be a medium for feedback, improvement, and integration of the TIPL into our health care system. Advance directive forms can be found on the Ministry of Health website [14], and the Ministry is attempting to link hospitals with a central database/receptacle of advance directives for access by a select few physicians at each institution. This is a start, but not a solution to the core of the problem. This receptacle will remain relatively empty if the health funds do not initiate/mandate the discussion of advance directives when the patient is healthy and capable of thinking for him or herself. If this can be accomplished, we envision greater quality communication between health fund physicians, the patient or proxy, and the hospitalist, as they work together to deliver a high level of individualized patient-focused care.

Now is the "teachable moment." The TIPL exists to allay any medico-legal fears. We presented a small case-series, but formal research needs to be conducted to better understand and perfect the process of delivering the highest level of end-of-life care to our patients. Future studies may address the integration of the electronic medical record with the TIPL, end-of-life course curricula, patient's perception of quality of life, cultural differences in approaches to end-of-life care within Israel, and the ability of physicians to predict the lifespan of critically ill patients. We have demonstrated in a few patients that we can, formally and efficiently (e.g., with a one-page document), deliver care in accordance to the TIPL, but this will need to be validated on a much larger scale.

Acknowledgments

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LOS = length of stay
## References


## Appendix. Advance Directives during Admission

Department of Internal Medicine D, Shaare Zedek Medical Center (In Compliance with the Terminally III Patient Law, 2005)

<table>
<thead>
<tr>
<th>Section 1:</th>
<th>Section 4:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does the patient have less than 2 weeks to live?</td>
<td>1. Is the patient interested in resuscitation?</td>
</tr>
<tr>
<td>Does the patient have less than 6 months to live?</td>
<td>[ ] Yes [ ] No</td>
</tr>
<tr>
<td>If the answer to one of the questions in Section 1 is “yes,” continue.</td>
<td>2. Is the patient interested in mechanical ventilation?</td>
</tr>
<tr>
<td>Diagnosis: _________________________</td>
<td>[ ] Yes [ ] No</td>
</tr>
<tr>
<td>2. Is the patient competent?</td>
<td>3. Is the patient interested in BiPAP?</td>
</tr>
<tr>
<td>(If in doubt, obtain Psychiatric consultation and add consult to medical record)</td>
<td>[ ] Yes [ ] No</td>
</tr>
<tr>
<td>If the answer to Question #2 is “yes,” proceed with Section 2.</td>
<td>4. Is the patient interested in dialysis?</td>
</tr>
<tr>
<td>If the answer to Question #2 is “no,” skip to Section 3.</td>
<td>[ ] Yes [ ] No</td>
</tr>
<tr>
<td><strong>Section 2 (Patient Competent):</strong></td>
<td><strong>Section 4:</strong></td>
</tr>
<tr>
<td>If the patient is competent, discuss wishes regarding future treatment. Continue with Section 4.</td>
<td><strong>Note:</strong> Incompetent patients must receive palliative care, fluids, and nutrition (at physician’s discretion). Patients unable to represent themselves/or without representation, will receive traditional treatments to extend life, until State guardianship is established. Physicians convinced that continuing treatment is not beneficial to the patient should contact the local Institutional Ethics Committee.</td>
</tr>
</tbody>
</table>

Date: ______________

Signature & stamp(s) of Senior Physician: ______________,

________________________

Nurse: ______________

Social Worker: ______________

Signature of “close person” or “guardian”: ______________

Signature confirms discussion of patient’s condition, prognosis, and end of life care. Further details can be found in the medical file.