Promoting Communication and Documentation of Advance Care Planning in Long Term Care Facilities

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Abstract: This paper describes the findings of Phase I of an advance care planning (ACP) demonstration project, undertaken collaboratively between the Texas Partnership on End-of-Life Care and the North Texas Alliance of Nursing Homes. The goal of the project, designed as a continuous quality improvement program for the nine volunteer nursing facilities (NFs), was to increase the systematic implementation of ACP. Phase I consisted of baseline data collection of ACP documentation from the nine NFs. This was followed by a pre-intervention train-the-trainer educational program for facility coordinators and other interested staff, who subsequently would implement the procedures in their NFs, to increase the use of advance directives (ADs). Following the Phase II implementation, a model will be developed for replication in other Texas facilities. Reported here are the pre-intervention baseline chart review findings documenting ACP and various AD documents. Based on the experience of this chart review, recommendations are outlined for improving the quality of ACP communication and documentation.

Introduction/Background

In recent years, a focus on quality of care at the end of life and the availability of life-extending technology has raised questions about its aggressive use for frail and terminally ill elders. Quality of life and comfort care are important issues when determining treatment options. The ability of families, physicians, and nurses to make appropriate elder-centered decisions for those who have lost decisional capacity is dependent on knowledge of the elders’ values and desires. Advance care planning (ACP) is the process by which persons and their families/surrogates discuss and document these wishes through advance directives (ADs) as a basis for future decision making.

Numerous studies identify the need to promote ACP in nursing facilities (NFs) (Bradley, Blechner, Walker, & Wetele, 1997; Forbes, Bern-Klug, & Gessert, 2000; Molloy et al., 2000; Teno, 2000; Tilden et al., 2000; Volicer et al., 2002). Forbes et al. (2000) state, “Advance care planning... is a communication process prompted by changes in physical condition, occurring at more than one time, and is not limited to the advance directive document” (p. 252). This dynamic process is of particular importance in a long-term care (LTC) setting, where many residents enter the NF with chronic and/or progressive multi-system diseases. In addition, 50% of NF residents have some degree of cognitive impairment (Forbes et al., 2000). The result may be a long period during which treatment decisions depend on a directive, if they are to incorporate respect for resident autonomy (Forbes et al., 2000; Teno, 2000; Volicer et al., 2002). Happ et al. (2002) identify nursing home admission, acute illness or hospitalization, and decline toward death as identifiable transition points during which ACP documentation should be revised and updated (p. 831).

Literature Review

The Patient Self-Determination Act (PSDA) of 1991 was a catalyst that increased NF involvement in ACP (Blatt, 1999; Bradley, Walker, Blechner, & Wetele, 1997; Forbes et al., 2000; Miles, Koepp, & Weber, 1996). This Act required all institutions receiving Federal Medicare and Medicaid reimbursement to inquire about the person’s ACP, offer the option to complete ADs, and if completed, to incorporate the documents into the medical record and
plan of care (Miles, Koepp, & Weber, 1996). Studies show that, although the intent of the PSDA was to promote and preserve personal autonomy and increase the use of ADs, there has been limited effect (Carney & Morrison, 1997; DesRosiers & Navin, 1997; Murphy, Sweeney, & Chirboga, 2000; Tilden, Nelson, Dunn, Donius, & Tolle, 2000).

As noted by Tilden et al. (2000), the public, health care professionals, and state legislative bodies recognize the urgent need to increase the dialogue with persons about their treatment preferences. A number of studies and project reports document these efforts. For example, Molloy et al. (2000) carried out a randomized controlled trial of a systematic ACP intervention in Canadian nursing homes. The objectives were to determine the effect of the intervention on resident and family satisfaction and to increase the number of completed ADs. Registered nurses attended training to become health care facilitators (HCF). This introduced them to a specific approach to educating staff, residents, and families on a range of health care options in the event of life-threatening illness. The HCFs, coordinated the “Let Me Decide” program implementation in their NF. The outcome was an increase in AD completion and reduction in health services utilization without affecting satisfaction or mortality (Molloy et al., 2000, p. 1441).

In Texas, the state legislature passed an updated Advance Directive Act effective September 1, 1999. This revised act clarified the right of patients to either request or reject treatment. For ease of understanding by laypersons, detailed instructions and definitions were provided. The definitions include information on life-sustaining treatment, including artificial nutrition and hydration; and, in addition, terminal and irreversible conditions are defined separately. The act requires all Texas hospitals, NFs and assisted living facilities to adopt and maintain policies pertaining to implementation of ADs. Written notice of these policies must be made available to all patients and/or their families on admission or initiation of care services (Kyba, 1999).

An Advance Care Planning Project in Texas

Such changes in ACP laws and the promising results of the Molloy et al. study encouraged the Texas Partnership for End-of-Life Care (TxPEC) to partner with the North Texas Alliance of Nursing Homes to implement a demonstration project, designed as a continuous quality improvement (CQI) program. TxPEC is a statewide consortium of professionals and citizens whose goal is improving end-of-life care for Texans of all cultures and communities. The steering committee for this project consisted of representatives from medicine, nursing, social work, LTC administration and regulation, and academia.

The ACP initiative promoted an ongoing process that includes residents and their family or surrogates in designating the type of care desired at the end of life. Phase I consisted of data collection to establish the baseline level of documented ACP in the nine participating NFs. A train-the-trainer educational program was developed for health care providers from the participating NFs. The NFs selected staff representatives and designated a facility coordinator to attend the training and then implement the program at their facility. The program included pre/post attitudinal testing, presentation of the pre-implementation data collection results, educational sessions (a legal update, teaching the ACP/AD module, overview of palliative care and hospice, assessing resident decision-making capacity) and an interactive workshop that included role playing to simulate resident and family encounters involving ACP discussions. A standardized notebook of information and a CD containing documents and the power point presentations were provided to each facility for the subsequent facility training.

This project continues with Phase II implementation and ongoing data collection consisting of the participating NFs self-reporting ADs completed over time. This project is a quarterly basis. Phase II objectives include assessment of:

1. Resident/family satisfaction.
2. Family perception of resident comfort in the last month, week, and days of life.
3. Staff perceptions of barriers to implementing ACP at each facility.
4. Staff perceptions about the strengths and weaknesses of the ACP process.
5. Status of liability claims.

These data will be used to judge the effectiveness of the educational intervention. Feedback from the initial NFs will also be used to assist TxPEC with expanding this pilot project as a systematic intervention in other Texas LTC settings.

Phase I Data Collection

The TxPEC steering committee identified several documentation variables to examine during Phase I to establish the pre-intervention baseline. The data collection objectives were to determine the:

1. Percentage of residents with documented ACP in their medical records.
2. Percentage of residents with completed ADs, and the type of AD: Directive, Medical Power of Attor-
ACP documentation:

- Directive to Physician and Family or Surrogates (Directive): Informally termed a living will, it instructs the physician and family how the resident wishes to be cared for in the event he/she has a terminal or irreversible condition and is no longer able to communicate his/her wishes.
- Medical Power of Attorney (MPOA): Authorizes a surrogate or proxy to make all health care decisions for the resident who is incapacitated and unable to consent or communicate his/her wishes.
- Texas Out-of-Hospital Do-Not-Resuscitate Order (OOH-DNR): Physician’s order directing health care professionals and emergency medical personnel acting in out-of-hospital settings to withhold CPR.
- Do-Not-Resuscitate (DNR) Order: Physician’s order directing health care professionals within the facility to withhold CPR.

In addition, a limited review of progress notes was performed to identify a fifth type of ACP: documentation of discussions and residents’ admission orders for palliative care or hospice service. Time constraints prohibited more than a cursory search in each chart for this latter documentation. The majority of NFs did not keep records regarding the number of CPRs done in the facility nor were there comparative data available comparing deaths in the facility with deaths following transfer to a hospital.

In total, 1128 charts were reviewed in the nine NFs, which ranged in size from 42 to 209 residents. Table 1 summarizes the findings of the chart reviews identifying the five types of ACP documentation for each NF. Note that resident charts could include from one to all five types of ADs. The percentage of residents having non-resuscitation orders was influenced by the way facilities documented DNR status. Policies varied among facilities; some used both the OOH-DNR and Physician DNR orders, and some used only the OOH-DNR form to document in-facility resuscitation status. Table 2 lists the overall percentage of charts having each ACP documentation type.

Table 1: Summary of Chart Reviews for Presence of ACP Documentation For Each Nursing Facility

<table>
<thead>
<tr>
<th>Facility</th>
<th># charts reviewed</th>
<th>Directive</th>
<th>MPOA</th>
<th>OOH-DNR</th>
<th>DNR</th>
<th>Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>199</td>
<td>77</td>
<td>72</td>
<td>104</td>
<td>97</td>
<td>11</td>
</tr>
<tr>
<td>#2</td>
<td>118</td>
<td>49</td>
<td>51</td>
<td>37</td>
<td>67</td>
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<td>#6</td>
<td>209</td>
<td>88</td>
<td>96</td>
<td>136</td>
<td>131</td>
<td>30</td>
</tr>
<tr>
<td>#7</td>
<td>183</td>
<td>87</td>
<td>57</td>
<td>101</td>
<td>109</td>
<td>0</td>
</tr>
<tr>
<td>#8</td>
<td>113</td>
<td>35</td>
<td>31</td>
<td>71</td>
<td>83</td>
<td>4</td>
</tr>
<tr>
<td>#9</td>
<td>53</td>
<td>37</td>
<td>32</td>
<td>25</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total #</td>
<td>1128</td>
<td>494</td>
<td>477</td>
<td>620</td>
<td>593</td>
<td>62</td>
</tr>
<tr>
<td>Overall Percentage</td>
<td>44%</td>
<td>42%</td>
<td>55%</td>
<td>53%</td>
<td>5%</td>
<td></td>
</tr>
</tbody>
</table>

Facility Range: 42-209 31-70% 27-65% 31-72% 2-73% 0-14%

Table 2: Percentage of Charts with ACP Type Documentation

<table>
<thead>
<tr>
<th>ACP Type Documentation</th>
<th>Range</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directive to Physician and Family or Surrogates (Directive)</td>
<td>31-70%</td>
<td>44%</td>
</tr>
<tr>
<td>Medical Power of Attorney (MPOA)</td>
<td>27-65%</td>
<td>42%</td>
</tr>
<tr>
<td>Texas Out-of-Hospital Do Not Resuscitate Order (OOH-DNR)</td>
<td>31-72%</td>
<td>55%</td>
</tr>
<tr>
<td>Do not resuscitate order (DNR)</td>
<td>2-73%</td>
<td>53%</td>
</tr>
<tr>
<td>Hospice Plan of Care Documentation</td>
<td>0-14%</td>
<td>5%</td>
</tr>
</tbody>
</table>

Discussion and Recommendations

The nine participating nursing facilities used a variety of procedures to track and document ACP. Healthcare provider documentation varied from interdisciplinary flow sheets to a disjointed process of each discipline documenting in its own section of the chart. In some cases the chart had a sticker indicating the resident’s resuscitation status, but it was often not clear to whom the directive applied.
but a signed physician’s order confirming this status was not easily located.

Recording of hospice service orders and plans of care were often located in a separate tabbed section of residents’ charts with a hospice identification sticker placed on the front of each chart with agency contact information; however, the hospice admission information was kept in another location. This made it difficult to identify admission dates and calculate length of stay. The Texas Department of Human Services (2001) has a voluntary palliative care form available for documenting expected outcomes for residents receiving hospice services. This form was found in only one chart during the review process.

Institutionally specific forms, as described by Bradley et al. (1997), were used by some NFs to document ACP discussions. These often included a check box to indicate that ACP had been discussed and/or documents were present in the chart. In addition, many NFs had a separate tabbed section for ACP and AD documentation, located in the front of the chart and brightly colored to ensure that this section was easily identified. Difficulty was encountered locating some of the documentation in the chart (possibly lost or misplaced during resident transfer); or it was hard to read due to document age (yellow, faded); or in poor condition (torn, missing pages, photocopied multiple times).

Based on this experience the following recommendations are offered.

- Use an easily located ACP section in the front of the resident’s chart. This collaborative section would include all ACP documentation done by the physician, nurse and social worker, including summary notes of ACP discussions and the specific documents including directives, MPOA, DNR orders, and OOH-DNR. It could incorporate the use of an interdisciplinary flow sheet to ensure that all health care providers have easy access to documentation by other disciplines and to assist with ready identification of ACP status. It should also include a form or easily identifiable notation stating whether the resident, when actively dying, prefers to remain at the NF rather than being transferred to a hospital. All information should be dated to ensure that the documentation reflects the resident’s current wishes and to track discussions with change in condition.

- The Physicians Orders for Life Sustaining Treatment (POLST) form, widely implemented in Oregon, is one example that incorporates the use of a bright color and front of the chart placement (POLST Task Force, Center for Ethics in Health Care, 2001). This form summarizes the end-of-life treatment wishes of the resident and transforms them into medical orders. A second example, “Long Term Care Advance Proxy Planning,” provides a template, developed by the Veterans Administration, that can be adapted for individual facility use (Volicer et al., 2002).

- Careful handling of AD documents and identification of those documents needing updating or replacement is essential. A master file of originals and/or good quality photocopies is recommended. These documents could then be periodically copied and poor quality or missing chart copies replaced.

- The use of plastic sleeves to hold documents (to reduce wear and tear and assist with locating the documents) and stickers to designate that these items should not be thinned or removed is also recommended.

- Care should be taken to ensure that a copy of each directive is easily located for review before the decision is made to transfer the resident to an acute care hospital. If it is determined that a transfer is appropriate and there is no order to the contrary, a copy of ACP documentation should accompany the resident (Bradley et al., 1997; Miles et al., 1996; Tilden et al., 2000).

- For residents who are terminally ill with end-stage disease or who curative care is no longer appropriate or desired, a palliative plan of care should be completed. An optional form may be available for use within each state (TDHS, 2001).

Many hand-written or typed notes from residents and/or their family members were discovered in the medical records. These notes contained the personal wishes of the residents and expressed their preferences regarding their care. It is important to include these documents in the ACP section of the chart. This will assist health care providers along the continuum of care in developing a better understanding of the residents’ values and choices if they are no longer able to express their own wishes.

Facilities must be familiar with state ACP laws when developing institutional policies and procedures. For example, in Texas, changes to the ACP laws provided new definitions and designated forms for documenting end-of-life choices and surrogates. While out-of-state or older versions of ADs are legally recognized, it is recommended that updating to new forms be included in the ACP process, when possible. This will ensure that the residents’ current wishes are expressed and should avoid possible
confusion in interpretation by health care providers.

Conclusion

ACP in the NF setting is a process of on-going communication with periodic updates of pertinent documents. To preserve autonomy, a process should be implemented to assist with keeping all directives applicable to the resident’s current medical condition and wishes (Blatt, 1999; Bradley et al., 1997; Forbes et al., 2000; Teno, 2000; Volicer et al., 2002). This interdisciplinary process should include procedures to ensure that all communication and conversations concerning ACP are documented on an ongoing basis and in a consistent, easily accessible format.

References


Clinical Research and Education Sections:

Healthcare Ergonomics - It Takes Two to Tango

Treatment Strategies for the Management of GERD in Older Adults - CE Article

The QUEST Process - An Innovative Approach to Improving Patient Care

A Guide to Fall Prevention - Understanding A Fall Prevention Program

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