COMMUNICATING ADVANCE DIRECTIVES FROM LONG-TERM CARE FACILITIES TO EMERGENCY DEPARTMENTS

Merril A. Pauls, MD, CCFP(EM), MHSc,* Peter A. Singer, MD, MPH, FRCPC,† and Isser Dubinsky, BSc, MD, CCFP(EM), FCFP‡

*Department of Emergency Medicine, Queen Elizabeth II Health Science Centre and Department of Emergency Medicine, Dalhousie University, Halifax, Nova Scotia; †Sun Life Chair in Bioethics and University of Toronto Joint Centre for Bioethics, Department of Medicine, University of Toronto University Health Network, Toronto, Ontario; and ‡Department of Emergency Medicine, University Health Network, and Department of Family and Community Medicine, University of Toronto, Toronto, Ontario, Canada

Reprint Address: Dr. Merril Pauls, MD, CCFP(EM), MHSc, Queen Elizabeth II Health Sciences Centre, Halifax Infirmary Site, Room 3–021, 1796 Summer St., Halifax, Nova Scotia, Canada, B3H 3A7

Abstract—Many residents of long-term care (LTC) facilities are transferred to Emergency Departments without advance directives (AD). The goal of this study was to describe an ideal model for the transfer of AD from LTC facilities to Emergency Departments. Health care providers were asked to describe their ideal model for the completion and transfer of the ADs of LTC residents. A grounded theory methodology was used to identify significant themes. The model we present as a result of this analysis acknowledges the importance of simplifying and standardizing ADs, but focuses more attention on the process of completing and transferring the AD. A key feature of this model is an emphasis on the education of LTC residents and their relatives about ADs and advance-care planning. This education should involve a variety of resources used in creative ways; it should begin as soon as LTC placement is being considered, and the emphasis should be on providing information and discussing options rather than pressuring residents to make a decision. © 2001 Elsevier Science Inc.

Keywords—advance directive; emergency department; long-term care facility; advance-care planning; health care provider

INTRODUCTION

Advance-care planning (ACP) describes the process whereby patients, in consultation with their health care providers, family members and significant others, make decisions about their future health care (1). A written document, called an advance directive (AD), can take the form of an instruction directive (living will), a proxy directive (durable power of attorney for health care), or a combination of the two (2,3). In the United States, the Patient Self-Determination Act mandates that health care organizations that receive federal funding must advise patients of their right to make end-of-life decisions in advance. In Canada, a majority of provinces have legislation recognizing ADs.

Advance directives have received considerable attention in the Emergency Medicine literature. Although many authors feel that an AD can provide direction in difficult situations and promote patient autonomy, potential problems have been identified with their use (4–9). A majority of states and at least one province (British Columbia) have established Emergency Medical Services (EMS) protocols that recognize out-of-hospital Do Not Resuscitate orders, one type of AD (10–12).

One patient group in which ADs can serve a valuable purpose is residents of long-term care (LTC) facilities. Long-term care residents are frequently transferred to the Emergency Department (ED), and decisions regarding the initiation of life-sustaining treatments are often re-
quired (13–15). Over 50% of LTC residents who present to the ED require admission to hospital, and mortality rates are 10–20% during the admission (13–16). Two to 4% of patients transferred from LTC facilities will die in the ED (13–15). Unfortunately, only 4–8% of LTC residents transferred to an ED are accompanied by an AD (13,14,17).

Different approaches have been suggested to improve the transmission of ADs across health care settings (18–22). Most have focused on the development of a special form or transfer sheet (18,20). The Physician Orders for Life-Sustaining Treatment form developed in Oregon is an example of this approach. The developers of this form demonstrated that after its introduction into a number of LTC facilities, the incidence of unwanted resuscitation declined (23). However, the authors of this study, and other commentators, have suggested the results were due to more than just the form (23–25). They recognized the importance of the education around end-of-life care that preceded the introduction of the form, and the supportive environment that exists toward ACP in Oregon (23).

There is increasing recognition that ACP is a complex dynamic process, and that improving our ability to carry out LTC resident’s treatment wishes in the ED requires more than just a better transfer form (24,26). It requires greater insight into the ACP process in which LTC residents and their families engage and a clearer understanding of how health care providers can promote the expression and transmission of residents’ treatment wishes.

The purpose of this study was to describe an ideal model for transmitting a patient’s treatment preferences from the LTC facilities in which they reside to EDs. Most current models are focused on a single element (the transfer form) of a much larger process. We wanted to understand that larger process and to understand it from the perspective of those who are intimately involved in it. For this reason, we chose as our participants the health care providers who are involved in the care of LTC residents when they become acutely ill and are transferred to an ED.

MATERIALS AND METHODS

The goal of the study was to understand the ACP and transfer process from the perspectives of the health care providers and to allow them to fully describe their ideal model, so a qualitative methodology was used (27). Semi-structured focus group interviews were carried out with ED nurses, ED physicians, paramedics, LTC nurses, and LTC physicians. These groups were chosen because they interact with LTC residents during the ACP process and when they are transferred to EDs. The emergency care providers were recruited from six academic centers that provide adult emergency care and are affiliated with the University of Toronto. Paramedics were recruited from the Metro Toronto Ambulance Service. LTC providers were recruited from LTC facilities that transfer residents to the above hospitals. In each location, a volunteer cohort of providers was recruited through poster advertising and word of mouth.

Seven focus group interviews were conducted between June 1998 and April 1999, involving 35 participants. The number in each group ranged from four to 10. Two different focus groups were conducted with Emergency Physicians (EPs), while every other group was interviewed once. The first EP group interview was carried out as a “pilot” interview, but the question guide remained unchanged for subsequent groups, and so both EP groups have been included in the data analysis.

One of the authors (M.P.) moderated all of the focus groups by using a semi-structured interview guide. The key themes addressed were:

1. Participants’ perception of their current role in caring for LTC residents and in engaging in ACP with these residents.
2. Their ideal model for transmitting a patient’s treatment preferences.
3. Their reflections on some current models for transmitting treatment preferences.
4. Any problems they foresee with the implementation of their ideal model.
5. Suggested methods for evaluating their ideal model once implemented.

All conversations were tape-recorded and transcribed. The transcripts were reviewed by a single analyst (M.P.), who extracted all of the ideas offered by the participants and organized them into broad categories and themes by using a grounded theory approach (28). A second analyst (I.D.) reviewed and independently extracted themes in one of the transcripts to confirm the validity of the concepts and to assess interrater reliability. The analysis was also reviewed with the third author (P.A.S.) at a number of stages.

The findings were then compared among groups to identify similarities and differences. The similarities were used to build the framework for a model for transmitting treatment preferences. The final model was reviewed with participants from the original focus groups to confirm that the model accurately represented the ideas they expressed.

Written informed consent was obtained from all participants, and this study was approved by the University of Toronto’s Committee on the Use of Human Subjects.
RESULTS

The demographic characteristics of the participants are listed in Table 1. The model that emerged from the data had two main components: what the transfer document should look like and the process that would encourage its completion and get it to the right person at the right time. Our participants focused more on process issues than form issues, but felt both were important. The model is summarized in Table 2.

### Table 1. Participant Characteristics

<table>
<thead>
<tr>
<th></th>
<th>ED* Nurses (n = 7)</th>
<th>ED Physicians (n = 7)</th>
<th>Paramedics (n = 10)</th>
<th>LTC Nurses (n = 7)</th>
<th>LTC Physicians (n = 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>0/7</td>
<td>4/3</td>
<td>8/1</td>
<td>0/7</td>
<td>4/0</td>
</tr>
<tr>
<td>Age mean (range)</td>
<td>40.3 (35–46)</td>
<td>38 (31–50)</td>
<td>36.8 (32–45)</td>
<td>43.6 (29–55)</td>
<td>52 (37–68)</td>
</tr>
<tr>
<td>Education</td>
<td>RN (7)</td>
<td>TNCC (7)</td>
<td>CCFP (EM) 4</td>
<td>RPN 1</td>
<td>CCFP 4</td>
</tr>
<tr>
<td>Experience (years)</td>
<td>BScN 1</td>
<td>FRCP 3</td>
<td>Level 2, 4</td>
<td>Level 3, 5</td>
<td>BScN 1</td>
</tr>
<tr>
<td>mean (range)</td>
<td>11.3 (3–24)</td>
<td>8.7 (3–16)</td>
<td>12.7 (8–20)</td>
<td>13 (6–20)</td>
<td>25 (8–43)</td>
</tr>
</tbody>
</table>

* ED = Emergency Department; LTC = long-term care.

### The Form

All of the focus groups emphasized simplicity and accessibility. Our participants felt the form should be one page; use simple, non-medical terms; and be available in many languages. All participants felt that a resident’s wishes regarding cardiopulmonary resuscitation should be the main focus of the form and be displayed most prominently. Paramedics and ED personnel felt that resident preferences for or against intubation, ventilation,

### Table 2. Model Summary

#### The Form

- One or two pages
- Simple language, no technical terms
- Many translations
- Wishes for or against CPR most prominent
- Three or four levels of care from which residents can choose
- Space for additional or alternative instructions
- Brief medical history
- Physician’s signature—to attest to competency of decision maker
- Information about LTC resident—for identification purposes
- Information about substitute decision maker to contact
- Date of completion or latest review

#### The Process

- Completing the Form
  - Educational sessions for LTC residents and relatives about AD and ACP
  - Begin educational sessions as soon as LTC placement initiated
  - Use a variety of learning resources and approaches for educational sessions
  - Make focus of sessions information provision not form completion
  - Hold review sessions yearly and with changes in health status
  - Involve a variety of health care providers in the sessions
  - Remuneration for providers who participate in the ACP process

- Using the Form
  - Completed in advance of the acute illness
  - Kept in accessible, consistent location
  - Implement the model on a regional basis
  - Obtain the endorsement of regulatory and licensing authorities
  - Have mechanisms to hold providers accountable if form not followed
  - Encourage direct communication between health care providers
  - Improve provider education about AD and ACP

* CPR = cardiopulmonary resuscitation; LTC = long-term care; AD = advance directive; ACP = advance-care planning
and intensive care unit (ICU) care also should be prominent. Many focus group participants initially wanted detailed forms that dealt with other interventions, such as antibiotics, feeding tubes, or surgery. However, after some discussion, all of the groups agreed that these decisions could be made less urgently, in conjunction with a substitute decision maker, and so should not be on the form. Some participants were concerned that if the form contained too many specific treatment scenarios it would be confusing for the LTC residents, would increase the chances that inconsistent wishes were expressed (such as wanting intubation and ventilation, but not ICU care), and that residents might unintentionally prohibit treatments that could provide comfort in certain situations.

Most of the participants felt a form that allows residents to choose from different “levels of intervention” would be the best design because it is easier for health care providers to interpret and simpler for the residents to complete. For example, a three level form might include: level one as desiring all appropriate medical care, including full resuscitation; level two as transfer to hospital for active medical care, but no resuscitation; and level three as no transfer to hospital, no resuscitation, comfort care only. Additional space would be provided for additional instructions and to clarify issues such as intubation and ICU care. Most participants felt that specific mention should be made of the supportive care that would be offered when aggressive care is not desired.

Almost all participants stated that the form should be an AD rather than a physician’s order form. At the same time, many participants felt a physician’s signature should be on the form to certify that the patient (or a substitute decision maker) was competent when completing the form and that sufficient education had been provided about the various life-sustaining treatments.

Other features unanimously requested included identifying information about the patient, name and contact number of the substitute decision maker, and signature of the patient or the substitute decision maker. Half the participants wanted to know the date the form was last reviewed by the patient (or substitute decision maker). Some groups discussed formats other than a paper form, such as electronic transfer or fax. This was not seen as offering significant advantages and concerns were raised over confidentiality and a lack of equipment needed for electronic transfer.

One interesting request, made by almost all of the groups, was that a patient’s primary diagnosis or medical history be included on the form. Participants were uncomfortable providing care (or withholding it) if they did not know the medical context, and some even suggested they would not abide by the directive if they felt the wishes were inappropriate.

---

**The Process**

Our participants devoted much of their attention to the larger process of ACP and to clarifying how the form fits into this broader context. They felt the form should be more than just a transfer document used by health care professionals. It should facilitate and simplify the process of eliciting treatment wishes from LTC residents and should be used as an educational resource by LTC residents and their loved ones.

**Completing the form.** The importance of education was the dominant theme. All groups agreed that residents and their relatives should be provided with consistent, repeated, simple information about the form and its goals. Almost all of the participants felt the form should be introduced to residents and families when placement in a LTC facility is first initiated.

Because this can be a difficult time for patients and families, the emphasis at this stage should not be on making specific decisions. Rather, the discussion should focus on ACP in general and serve as the start of an ongoing conversation. Many participants suggested that information should be offered in different ways, including books, videos, and discussion groups. Each of these should be culturally sensitive and available in different languages. Participants identified the goals of these educational efforts as 1) explaining the concepts of ACP and ADs; 2) educating patients and their relatives about life-sustaining treatments and possible medical scenarios in which they may find themselves; and 3) clarifying that if no wishes are expressed, aggressive interventions will be undertaken normally. Once the patient becomes a resident of a LTC facility, the same information should be reviewed on an annual basis and whenever there is a change in health status. The physician should play an important role in this process, but other providers such as nurses and social workers may communicate more effectively with patients and their relatives because they interact with them more frequently.

All participants felt that every LTC resident should be exposed to information about ACP, but they recognized that a certain percentage of residents and their families will refuse to engage in the educational process. Our participants felt that this would represent a small minority of all LTC residents.

Many participants suggested that LTC administrators and physicians should be involved in the development of the form so they feel comfortable using it and implementing it. The time that health care providers spend educating patients and filling out the form should be recognized and remunerated. Incentives (both positive
and negative) should be introduced to encourage LTC providers to engage in this process.

**Using the form.** All participants agreed that the form must be filled out in advance and be easily accessible at the time of transfer. The transfer of care from the LTC staff to the paramedics was identified as a particularly stressful time. Special measures were suggested to simplify the transfer of the form from the LTC nurses to the paramedics, including using different colored paper for the form and keeping it in a standardized location. Implementing the same model for an entire region would improve the likelihood that all health care providers who come across the form would recognize it and respond appropriately.

Because, you know, in the heat of the crisis when the nurse that doesn’t normally work there is running around in three circles, if someone said to her, “Do you have the directives form?” that might just be the trigger she needs to go and get it from the chart. (Focus Group 3—ED nurses)

Some participants suggested that obtaining the endorsement of local medical organizations or regulatory bodies would improve provider participation and compliance. All providers should have their responsibilities clearly defined. Some participants suggested that mechanisms be developed to hold providers accountable if they do not fulfill their responsibilities.

Whenever possible, the form should be supplemented by direct contact between providers. Long-term care nurses should communicate directly with paramedics, paramedics with emergency nurses, and LTC physicians should contact EPs when possible. Some participants expressed concerns about physicians’ practices around end-of-life issues. They were concerned that even when ADs are available, physicians may not follow them. They felt that communication with patients and families in the ED needed to be improved and that physicians were often too aggressive in providing treatments, even when patients requested less aggressive care. Many participants felt that more education should be provided to health care professionals (and to physicians in particular) about end-of-life issues and ADs.

Participants were asked to imagine that their ideal model was implemented and to suggest how its effectiveness could be assessed. The number of forms successfully completed, transferred to the ED, and correctly interpreted were all offered as appropriate outcome measures. However, many participants felt that even if no form was completed, the discussion generated by the model, and particularly the education of the family and relatives of the resident, would help emergency health care providers determine a resident’s treatment wishes more rapidly.

**DISCUSSION**

Most current models for transmitting ADs across health care settings are built around special forms and focus on the transfer of written information at the time of an acute illness. Some studies have looked specifically at ADs in the ED, documenting the prevalence of ADs among ED patients and describing the attitude of ED patients toward ADs (13,14,33,34). Few studies have examined the transfer of ADs from LTC facilities to the ED, and none have looked at it from the perspective of the health care providers who are most involved in the transfer process (19,21,22).

The health care providers we interviewed advocated a much broader approach to the problem of transmitting ADs from LTC facilities to EDs than most current models do. They felt that many of the features contained in current models, such as simple forms and a consistent approach, are valuable but need to be supplemented by creative, long-term educational efforts designed to make LTC residents more comfortable with ACP.

**The Form**

The ideal form that our participants described is similar to other transfer forms developed for the purpose of improving communication across health care settings (18,21,25). One element of the form that our participants felt was important, and which is mentioned in few other models, is having the form available in many languages and using culturally appropriate terms and explanations. Toronto is an extremely multicultural city, and this finding may be a function of the environment in which the participants work. Minority ethnic groups are among those least likely to complete ADs and are more likely to express mistrust of the ACP process, so having culturally appropriate forms available in a patient’s own language may enhance participation in the process (29,30). One version of the form still would have to be completed in the main language used by the health care providers caring for the patient.

**The Process**

**Completing the form.** Our participants felt that educating residents and their families about ACP in a low-pressure, creative way is the key to facilitating the completion of the form. There is evidence from other studies to support these ideas. Improving a patient’s knowledge of ACP, using creative methods to impart information about ADs, and increasing the time that health care
providers and patients spend together all increase the likelihood that an AD will be completed (2,31,32).

A number of excellent resources that discuss ACP from the patient’s perspective already exist, and further resources should be developed (35,36). Emergency Physicians should consider what their role could be in the educational process. All of our participants felt this process should begin long before LTC residents arrive in the ED. Emergency Physicians have a great deal of knowledge and experience with many life-sustaining treatments and should be working with LTC providers to develop educational materials for LTC residents. They should consider becoming more active in the delivery of this information to the LTC residents.

**Using the form.** Many of the ideas contained in our model, such as filling out the form in advance and keeping the form in a consistent place in the LTC facility, have been described previously and implemented in other areas (18,25). Our participants felt these ideas were valuable because they simplify the most stressful aspect of the transfer process, when the ill LTC resident is transferred from the care of the nurses to the paramedics. Because our model is based on the experience of physicians, nurses, and paramedics, it places a high priority on the components of the model that address these practical problems. These include consistent locations for forms and standardization across regions.

One concern that some of our participants expressed is that even if a form is available it may not be followed. A number of paramedics and emergency personnel expressed reservations about abiding by an AD if they felt the treatments requested (or declined) were not “appropriate” to the resident’s medical condition. This was true both in the case where the treatment requests were felt to be overly aggressive in a very ill resident and where they were not aggressive enough in an otherwise healthy resident. A number of nurses also expressed their concerns that physicians may proceed with treatment regardless of the instructions in an AD if they are not familiar with the concept of ACP. Our model seeks to address these concerns in a number of ways. The extensive educational efforts that our model advocates for LTC residents and their relatives should help providers feel more comfortable that the ADs they encounter represent informed decisions and are the product of a sound process. The standardization of the process and the endorsement of the model by regulatory or licensing bodies should also increase their comfort level with these documents, as should improving the education that health care providers receive about ADs and ACP.

**Strengths and Limitations**

The main strength of this study is that the participants were health care professionals involved in the transfer of LTC residents from LTC facilities to EDs. Their suggestions for improving the transfer of ADs are based on personal experience and observations. Therefore, the model we have developed is more likely than other models to address their concerns and may be more readily accepted when implemented. The main limitation is that LTC residents and their relatives were not included in the study. Including their perspective would make the model stronger and increase the likelihood that the model could be successfully implemented and that LTC residents and their families would actively participate. A second concern is that our findings may not be generalizable to other settings. The ideas expressed by the participants are a function of their experience working in an urban Canadian center, although many of them have worked in other settings. Health care providers in other places may have a different experience. Finally, participants in the focus groups were volunteers and thus may have had pre-existing biases.

**CONCLUSION**

Health care providers feel that the key to successfully transmitting residents’ treatment preferences from LTC facilities to EDs is not the form, but the process. Simplifying and standardizing the AD is valuable, but it is more important to educate residents and their relatives about advance care planning and the treatment decisions they will face. This educational process should be creative, start as early as possible, and continue throughout the resident’s time in the LTC facility. This process should increase the number of written directives to which emergency personnel have timely access. However, even when no directive is completed, the process should make it easier for ED personnel to discuss treatment decisions with LTC residents and their substitute decision makers.

**REFERENCES**