Managed Death in a PACE: Pathways in Present and Advance Directives

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Objectives: To test the effect of an innovative method of documenting present and advance health care wishes on the rates of completion and the qualitative choices of health care wishes.

Design: Interventional prospective cohort (pre- and post-).

Setting: Program for All-inclusive Care of the Elderly (PACE) site in St. Louis, MO.

Participants: Enrolled PACE participants.

Intervention: A documentation tool that captures both present and advance directives in a framework of “pathways,” blending goals of care with typical procedure-oriented directives.

Measurements: Data from medical records to calculate rates of health care wishes (HCW) completion, proportions of qualitative choices, and compliance with wishes at death.

Results: Baseline prevalences of present directives (PD) and advance directives (AD) were 77% and 36%, respectively, while Do Not Resuscitate (DNR) wishes were documented in 48% of PD and 26% of AD. After implementation of the Pathways Tool, completion rates increased to 99% for both PD and AD. Documented DNR wishes decreased to 38% of PD and increased to 66% of AD. Qualitative choices for care (Longevity vs Function vs Palliation) changed toward a palliation pathway for AD (from 9% to 53%). The rate of dying at home increased from 24% to 65%. Compliance with end-of-life wishes increased from 72% to 96%. These are statistically significant.

Conclusion: Introduction of a novel pathways method of documenting HCW in a PACE site was associated with increased completion, preferences toward less invasive levels of care at life’s end, and increased compliance with participants’ wishes and deaths at home. Future research to validate the methodology employed in this intervention should be conducted in other long-term care settings. (J Am Med Dir Assoc 2006; 7: 339–344)

Keywords: End-of-life; advance directives; health care wishes; present directives; pathways

The majority of individuals in the US elderly population have not completed health care wishes such as advance directives (ADs), which provide health care direction for the end of one’s life should one become unable to express his or her own decisions.1,2 New community-dwelling enrollees in our Program for All-inclusive Care of the Elderly (PACE) site fit this pattern with about 10% having any type of advance care planning documented on admission (on-site estimates, R. Schamp, unpublished data, 2005). Multiple authors have enumerated barriers to this process,3,4 which include ethnic patterns,5 family dynamics,6 marital status,1 and age. Physician attitudes and beliefs are also factors in determining whether patients complete advance care planning.8 The Patient Self-Determination Act9 (PSDA) of 1990 sought to address these barriers by legislating availability and encouraging completion of advance directives in health care facilities. Passage of the PSDA brought an increase in the number of individuals who have completed advance directives.10–12 But the reality remains that most elders in our country die in circumstances contrary to personal wishes or generally accepted descriptions of a “good death.”13
PACE enrolls community-dwelling elders with certified levels of frailty of at least nursing home level of care, replicating the model of comprehensive community-based care pioneered by On Lok in the 1970s. The Balanced Budget Act of 1997 established the PACE model as a permanently recognized provider type under both Medicare and Medicaid programs. Alexian Brothers Community Services in St. Louis, MO, became the first permanent provider of the PACE model in November 2001. About 40 sites across the United States have enrolled approximately 10,000 participants (National PACE Association, personal communication, February 2004). To enroll in PACE, participants must be at least 55 years old, live within the catchment area, and be frail enough to qualify for nursing home placement by a state-determined “level of care” system. In practice, nearly all PACE participants are dually eligible for Medicare and Medicaid.

Most PACE participants remain enrolled until death, with an average length of stay of about 48 months (R. Schamp, unpublished data, 2003). The predominant “death trajectory” is one of slow gradual decline, often without clear indicators of impending death. This pattern emphasizes the need to prepare for death and the relevance of documented health care wishes for PACE participants, caregivers, and health care providers.

Medical training, reimbursement patterns, and societal expectations have emphasized improving quality of care for the living, not the dying. For people whose death is more or less predictable due to age or disease process, opportunities to identify, document, and follow health care wishes for end-of-life care already exist. But these opportunities remain underdeveloped, especially as patients progress through a continuum of settings, such as private practice, acute care, or long-term care. Deficiencies in end-of-life care along this continuum include 5 factors occurring alone or in combination: (1) directives not initiated; (2) directives initiated but the medical/procedural language and orientation of the directives limit guidance in many circumstances; (3) documented directives inaccurately reflect patients’ values and goals of care, which may change over time; (4) health care providers passively or actively disregard directives, even when appropriate and expressed; and (5) outcomes of, or compliance with, directives are seldom monitored or reported so consequences remain anecdotal and expire with the patient. Systematic opportunities for improvement in managing the dying processes, especially in institutional settings exist, but lack data to drive process changes. The pre-death processes of routine modern medical care are thus poorly managed.

To address these 5 potential deficiencies, we instituted an innovative method (Pathways Tool) of assessing and documenting health care wishes (HCW) for enrollees and began monitoring the outcomes. The purpose of this study was to determine the effect of using the Pathways Tool upon the rates of completion of health care wishes and whether the distinction of “present” versus “advance” directives might be associated with differing qualitative choices expressed. We also examined secondary outcomes of compliance with the expressed wishes.

**METHODS**

**Participants and Setting**

Our study population included a convenience sample of all enrolled participants in an underserved urban community outpatient PACE site (Table 1). This is an elderly (average age 76.3 years), frail, and medically complex population with an average of 8 chronic medical conditions and limitations in 3 activities of daily living (ADLs). Over 50% of these participants have dementia. A level-of-care score, as measured by the Missouri State Department of Health and Senior Services, reflects the functional and frailty status of enrollees. Missouri Medicaid regulations required a level-of-care score of 18 or higher for nursing home eligibility. This sample’s average level-of-care score was 30, indicating functional deficits considerably greater than what is needed for nursing home admission. Despite high level-of-care needs, about 90% of PACE participants continue to live in the community with about one third of them living alone.

The St. Louis University School of Medicine Institutional Review Board granted approval for this study. No outside funding was received.

**Terminology**

Documented health care wishes of participants in this PACE site, as identified by chart abstraction, were classified by a system of present and advance directives developed for the Pathways Tool. Wishes were denoted as “Present Directive,” referring to wishes in a present state of health and function, or as “Advance Directive” applicable in a terminal condition with no hope of recovery and no longer able to express one’s wishes. This distinction between present directive (PD) and advance directive (AD) is important because

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>&gt; 65 y</td>
<td>133 (83)</td>
</tr>
<tr>
<td>≤ 65 y</td>
<td>27 (17)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>119 (74)</td>
</tr>
<tr>
<td>Male</td>
<td>41 (26)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
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<tr>
<td>African American</td>
<td>109 (71)</td>
</tr>
<tr>
<td>White</td>
<td>44 (29)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>≥ 12 y</td>
<td>41 (67)</td>
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<tr>
<td>&gt; 12 y</td>
<td>20 (33)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
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<tr>
<td>Married or widowed</td>
<td>108 (70)</td>
</tr>
<tr>
<td>Single, separated, or divorced</td>
<td>47 (30)</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
</tr>
<tr>
<td>Baptist</td>
<td>63 (46)</td>
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<tr>
<td>Roman Catholic</td>
<td>36 (26)</td>
</tr>
<tr>
<td>Other</td>
<td>37 (28)</td>
</tr>
<tr>
<td><strong>Diagnoses</strong></td>
<td></td>
</tr>
<tr>
<td>&gt; 5 diagnoses</td>
<td>113 (73)</td>
</tr>
<tr>
<td>≤ 5 diagnoses</td>
<td>42 (27)</td>
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the wishes documented had often been obtained in a context of one or the other. For example, PDs were often obtained in the context of a hospital admission to guide care in relatively acute situations. As such, these PDs are not necessarily appropriate for application to outpatient or long-term care settings or for a terminal illness, for which a properly understood AD is suited. Furthermore, directives produced in the context of an acute care episode may be affected by the urgency and anxiety of the situation.

The PDs and ADs were further classified according to general goals of care, ie, whether wishes were unrestricted, restricted, or comfort only. Unrestricted wishes were represented by the Longevity Pathway and typically described as “full code,” including all invasive procedures and supportive technology to maintain life, including advanced cardiac life support (ACLS), surgery, ventilator support, dialysis, etc. Restricted wishes were represented by the Function Pathway and reflected individualized choices that may or may not include cardiopulmonary resuscitation (CPR), but typically limited some invasive procedures with the emphasis on retaining functional status. Comfort only wishes were represented by the Palliation Pathway and were generally taken to mean using pain medicine and limiting procedures to those that promote comfort and always included Do Not Resuscitate (DNR) choices.

**Intervention**

Neither simplified nor complicated procedure-oriented advance care planning instruments support true patient autonomy because of the overall ineffectiveness. Teno and others suggest decreased focus on procedures and increased focus on patients’ values and goals as an alternative course to arriving at patient-centered choices for medical care near life’s end.

The St. Louis PACE interdisciplinary team developed a system (Pathways Tool) of documenting health care wishes for both PD and AD. This system presents 3 “pathways” of care (after Gillick), which reflect fundamental values of the palliative care movement because of the overall ineffectiveness. Teno and others suggest decreased focus on procedures and increased focus on patients’ values and goals as an alternative course to arriving at patient-centered choices for medical care near life’s end.

The St. Louis PACE interdisciplinary team developed a system (Pathways Tool) of documenting health care wishes for both PD and AD. This system presents 3 “pathways” of care (after Gillick), which reflect fundamental values of the participants and/or their caregivers through the prioritization of goals of care: longevity, function, or palliation. These priorities and pathways were explained to participants and caregivers by trained social workers, using the color-coded Pathways Tool.

The Pathways Tool is composed of separate PD and AD forms, each with introductory paragraphs that describe the clinical and personal contexts for either PD or AD. Aside from these 2 contextual statements and the background color, the forms include identical choices of General Wishes and optional Specific Wishes.

The General Wishes choices describe the value-oriented goals of care: pathways of Longevity, Function, and Palliation. The general wish for the Longevity Pathway specifies the instruction to “prolong life; treat everything, including CPR and 911.” Two Function Pathways allow wishes to restrict interventions at 2 intermediate levels of intensity. The more intense wish instructs health care professionals to “treat and attempt to cure if my recovery is likely, but reassess often.” The less intense Function Pathway is a wish to “limit to less invasive and less burdensome treatments.” The Palliation Pathway specifically states to “provide comfort care only, no CPR, no 911, no hospitals.” The Pathways are color-coded (stoplight-fashion) with green for unrestricted/longevity choices, yellow for some restrictions or function emphasis, and red for comfort/palliation.

General wishes may be sufficient in themselves to guide care. However, participants have the option to identify Specific Wishes. These are intended to note exceptions or clarification to the General Wishes, and include typical procedure-oriented choices such as cardiopulmonary resuscitation, mechanical breathing, blood transfusion, surgery, hemodialysis, artificial nutrition/hydration, and pain management. These interventions are ordered by increasing invasiveness and are color-coded to reflect the same general priority of the General Wishes. When appropriate, the option to specify a therapeutic trial of a particular procedure is available on these forms, with instructions to withdraw the procedure if it provides no clear improvement.

**Procedure**

Charts were abstracted at baseline, August 2003, to identify existing health care wishes, which were coded into a format comparable to the Pathways Tool. Participants were then given the opportunity to complete the Pathways Tool by staff social workers during periodic assessments.

Repeat analysis of documented HCW was performed after 12 months to assess the completion rate and distribution of the Pathways selected in PDs and ADs. We also measured the prevalence of DNR requests for both PD and AD status. DNR choice by itself does not require a palliation pathway—participants may choose DNR and retain other interventions, such as hospitalization or surgery. Because of turnover of participants in this program, the post-intervention group is a subset of participants from the baseline analysis. We show the descriptive characteristics of these participants in Table 1. We performed a retrospective analysis of records of participants who died to assess location of death. The Pathways Tool does not explicitly identify a wish to die at home (however, most elders prefer death at home and not an institution). Repeated discussions with families and participants, especially when they’ve selected a DNR status, confirm their preference to die at home with loved ones near. Besides location of death, we analyzed whether PD or AD was operative at the time of their final decline and if the participants’ wishes for end-of-life care were met.

These gross measures of compliance with expressed health care wishes suffer from missing data in about 10% of cases. We assumed unwitnessed deaths did not have CPR or other procedures performed. We also assumed, unless we know otherwise from record review, that deaths in a hospital did have CPR. Deaths were judged to be fully compliant, partly compliant, or noncompliant with wishes.

**Statistical Analysis**

We performed a paired samples t test on our primary outcome data for 2 reasons: our data is in ordered categories and we are interested in the change between categories after...
intervention. The paired samples t test considers changes in values on a case-by-case basis. The mean values computed reflect trends in the data: higher values indicate a trend toward palliation and lower values show a trend toward longevity. Missing and incomplete categories were excluded from the nonparametric and parametric analyses. Pearson chi-square test was chosen to analyze secondary outcomes for significance.

RESULTS

Descriptive Characteristics

The demographics of this population (Table 1) are typical for both PACE and long-term care populations.

Baseline Completion Rates and Qualitative Choices

Baseline prevalence of documented health care wishes was 77% for PD and 36% for AD for 160 PACE participants. We found various documentation formats, including prevalent use of a “Therapeutic Support Level” (TSL) form typically used in hospitals. This form therefore was functionally a PD carried forward from an acute care setting. Some of these TSL forms identify health care wishes in terms of “unrestricted,” “individualized therapy” specifying procedures to be omitted or “comfort measures only.” We found these TSL wishes had been practically interpreted as ADs in many cases. We also found Durable Power of Attorney (DPOA) formats that sometimes spelled out specific wishes, living wills, and other, irregular expressions of health care wishes. In addition, we noted discrepancies within the same charts (eg, CPR vs DNR wishes in same record in different locations or forms) and missing data. A minority of records had both a PD and an AD documented. Variations such as these are typical for chart data in long-term care environments.

Table 2. Comparison of Health Care Wishes Pre- and Post-Pathways

<table>
<thead>
<tr>
<th>Present directive†</th>
<th>Pre-Pathways n (%)</th>
<th>Post-Pathways n (%)</th>
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<tbody>
<tr>
<td>Longevity/full code</td>
<td>32 (26)</td>
<td>22 (16)</td>
</tr>
<tr>
<td>Functional/restricted</td>
<td>70 (57)</td>
<td>100 (71)</td>
</tr>
<tr>
<td>Comfort/palliative</td>
<td>21 (17)</td>
<td>19 (13)</td>
</tr>
<tr>
<td>Missing or incomplete</td>
<td>37</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advance directive*</th>
<th>Pre-Pathways n (%)</th>
<th>Post-Pathways n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Longevity/full code</td>
<td>3 (5)</td>
<td>9 (6)</td>
</tr>
<tr>
<td>Functional/restricted</td>
<td>49 (86)</td>
<td>57 (41)</td>
</tr>
<tr>
<td>Comfort/palliative</td>
<td>5 (9)</td>
<td>74 (53)</td>
</tr>
<tr>
<td>Missing or incomplete</td>
<td>103</td>
<td>0</td>
</tr>
</tbody>
</table>

Do not resuscitate

<table>
<thead>
<tr>
<th>Present directive†</th>
<th>Pre-Pathways n (%)</th>
<th>Post-Pathways n (%)</th>
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<tbody>
<tr>
<td>77 (48)</td>
<td>61 (38)</td>
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<table>
<thead>
<tr>
<th>Advance directive*</th>
<th>Pre-Pathways n (%)</th>
<th>Post-Pathways n (%)</th>
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<tbody>
<tr>
<td>42 (26)</td>
<td>106 (66)</td>
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* P < .001.
† P < .05.

Fig. 1. Death by location pre-/post-pathways.

Post-Intervention Completion Rates and Qualitative Choices

Overall, these baseline rates of documented health care wishes are higher than the comparable population norm. The most striking change following institution of the Pathways Tool is the increased rate of completion of directives: 99% for both PD and AD.

The second change noted was the shift in the pattern of choices expressed. Following the Pathways intervention, the proportion of participants choosing a Longevity or Palliative Pathway for a PD dropped slightly while more participants expressed preferences for a functional outcome. The chief shift in the AD pattern following the intervention showed a larger proportion (53% vs 9%) who chose the Palliative Pathway (Table 2).

Calculating the mean pathway choice of this population, which reflects qualitative trends in the data and where Longevity = 1, Functional = 2, and Palliation = 3, we found the PD to shift slightly after introduction of the Pathways from 1.830 (SD .61) to 1.961 (SD .36) (P < .05). The shift in the AD choices is more pronounced, from 1.982 (SD .60) to 2.593 (SD .53) (P < .001). The participants’ choice of DNR status following the introduction of the Pathways Tool revealed a shift against choosing DNR for PD and toward choosing DNR for AD with a greater than doubled rate of participants (26% vs 66%) choosing no resuscitation in a terminal condition.

Compliance With Wishes

Deaths prior to the pathways (n = 33) had a low rate (24%) of dying at home, while deaths post-pathways (n = 49) had a higher rate (65%) of dying at home (P < .001) (Figure 1). The provider compliance rate for end-of-life wishes for deaths occurring prior to the introduction of the Pathways Tool was 72%, compared to 96% post-implementation (P < .05) (Figure 2).

DISCUSSION

This study reports efforts to reduce the insufficiencies of care at the close of life for patients within one model of...
long-term care. We used the Pathways Tool to clarify patients' values and goals of care by distinguishing between present and advance directives.

Documentation of HCWs (present or advanced) is limited in our native population of frail, poor, community-dwelling elders. Discrepancies accumulate when HCW are obtained and documented by multiple professionals over time, and without careful management, HCW can become conflicting or nonreflective of actual wishes.

While “getting directives on the chart” is a frequent goal of health care organizations, the utility is limited if these directives are not “managed” as part of care processes. Proper questions include the following: Are these HCW intended to guide present care, eg, as the TSL form guides such care in acute care settings; or are the HCW clearly intended as “advance,” ie, to take effect only in specific circumstances of being unable to express wishes otherwise? As health status changes, wishes may also change.25 Thus, organizations may develop systems to keep directives updated appropriately. In our PACE site, these are addressed at least every 6 months and are adjusted unless the health status declines, in which a trend toward more palliation is observed.

Existing common nomenclatures of health care wishes are almost universally procedure oriented and selection options do not necessarily reflect beliefs and qualitative values about longevity and dying preferences. The Pathways Tool represents an intermediate step toward integrating beliefs and values into health care decision making by more accurately reflecting patient wishes regarding goals of care. Additional study into associations of beliefs and values about end-of-life care may lead to more useful tools.

After introduction of the Pathways Tool in our population, the qualitative choices documented for both PD and AD seemed more “appropriate,” ie, within the realm of both medical realism and consistent with known and expected trends for frail elderly approaching the end of life. In this regard, we observed shifts toward more functionally oriented care for the PD with a preponderance of participants choosing longevity and functional priorities for the present, perhaps indicating engagement with living in the present. Conversely, we saw a clear trend toward less invasive care for the AD, as participants chose palliation and DNR much more often in contexts associated with terminal and irreversible conditions.

After observing conversational dynamics over many months of presenting the tool to participants, we suggest that the Pathways Tool as used by us

1. addresses present directives first, which
2. more effectively presents the subsequent context of advance directives (such as a terminal condition), and
3. allows more participants to feel comfortable shifting their AD health care wishes toward less invasive care (including no resuscitation).

This postulated dynamic of satisfying concerns about current care before addressing advance directives may be worthy of further study.

Coincident with the introduction of the Pathways Tool, educational presentations to the PACE staff emphasized the significance of early identification of participant values and beliefs as part of understanding their priorities for care. This process led to formation of an interdisciplinary task force that developed enhanced processes for care of participants who chose palliation for present or advance directives.

Additional informal findings resulting from the use of the Pathways Tool include the social workers reporting ease of understanding and acceptance of the advance care planning language by participants and caregivers, who had often previously avoided these discussions. Anecdotally, social workers estimate the Pathways Tool took about half the time (20 minutes) to complete than previously used formats for obtaining and documenting health care wishes.

Several factors might limit the validity of our conclusions. Because of the nonconformity of existing forms at baseline, we compressed a variety of HCW formats into an arbitrary (Pathways) grid, although we retained reasonable interpretive guidelines. The retrospective approach allowed for missing and potentially ambiguous baseline data. The Pathways initiative evolved into a facility-wide focus on end-of-life care, which promoted a cultural shift toward greater attention to HCW by all staff. Aside from the increased clarity of the Pathways, this attention may have contributed to the increased compliance with HCW. Finally, we know that proxy choices do not always accurately reflect patients’ wishes.26 We do not specifically address the issue of competency in this study or who completed the HCW as the proxy in this study. Proxies completed HCW for demented patients in this study, reflecting a “real world” environment. These issues may be elucidated further in a controlled study of the Pathways methodology.

CONCLUSIONS

Prior to focused efforts with the Pathways Tool, we saw modest (77% PDs and 56% ADs) success in documentation of health care wishes (“getting directives on the chart”) at this PACE site. The tool, through systematic consistency and ease of use, reduced the barriers to completion of wishes, achieving 99% documentation rates.

Introduction of a 3-tiered value-oriented approach to exploring HCW with participants appears to clarify patient-centered goals of care. Using this approach in both PD and
then AD contexts allows for clearer understanding and separation of the clinical and personal implications.

Use of the Pathways Tool is associated with choosing less invasive goals of care in AD. Corresponding compliance with AD produced more palliative levels of care delivered in the pre-death stages and at the end of life, which is reflected in the marked increase in proportion of deaths occurring at home following this intervention.

Other studies emphasize that intensified efforts toward advance directive education can increase prevalence of advance planning and effectiveness in honoring end-of-life decisions in communities, and perhaps in states. Future research to validate the Pathways Tool should be conducted in other long-term-care settings, such as nursing homes.

ACKNOWLEDGMENTS
The authors thank the social workers at Alexian Brothers’ PACE site for assiduous cooperation and support of this intervention and data collection. We also thank Dan Morris, MS, for assistance with statistical analysis.

REFERENCES