

# Knowledge, Attitudes & Preferences Related to Advance Directives Among Patients of a Managed Care Organization

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## Purpose

We conducted a survey to assess the knowledge, attitudes and experiences related to Advance Directives (ADs) among adult health plan patients of all ages.



## Methods

Surveys conducted by phone and mail of a random sample of patients (age 20 – 80+) stratified by age decade.

## Data Collected

- ❖ Knowledge of AD terms and logistics
- ❖ Experiences related to ADs
- ❖ Attitudes toward ADs and end-of-life (EOL) care decision-making
- ❖ Preferences regarding initiation of EOL care planning

## Analysis

- ❖ Descriptive statistics used to summarize variables
- ❖ Chi-square tests run to assess differences by age

## Survey Response n=187

- ❖ 40% response to telephone survey (n=70)
- ❖ 36% response to mail survey (n=117)

## Responders' Knowledge of Terms

- % aware of terms related to EOL care planning:
  - ❖ Living Will – 99%
  - ❖ Health Care Directive – 58%
  - ❖ Durable Power of Attorney for Health Care – 58%
  - ❖ Advance Directive – 42%

## Knowledge of Terms (cont'd)

- ❖ 66% reported that they most closely associate with the term Living Will when they think about providing directions for EOL care.
- ❖ Subjects age 20-29 (36%), 40-49 (46%) and 80+ (42%) were less likely to have heard of the term Health Care Directive compared to those of other ages (30-39 57%; 50-59 89%; 60-69 78%; 70-79 62%; p=0.0005).

## Knowledge of AD Logistics

### Agree with statements:

- ❖ "A patient has the right to accept or refuse treatment." – 94%
- ❖ "A patient has the right to accept or refuse life-sustaining treatment." – 81%
- ❖ "More than one person may be named to speak on your behalf." – 72%

### Disagree with statements:

- ❖ "Creating an EOL care document requires a lawyer." – 62%
- ❖ "Once documented, EOL decisions cannot be changed." – 92%

## Experience

- ❖ 32% reported having completed an AD and 5% stated they were in the process.
- ❖ The likelihood of having completed an AD increased incrementally with age (p<0.0001).
- ❖ Of those who had not created an AD, 44% reported having talked with someone about their EOL care wishes.

## Attitudes

- ❖ 77% *disagreed* with "It is up to my doctor to decide if I should receive life-sustaining treatment if I cannot speak for myself."
- ❖ 87% *agreed* with "I believe that my wishes should determine what life-sustaining treatment I should receive."
- ❖ 65% *agreed* with "I prefer my family decide what kind of medical care is best for me if I should become unable to communicate my wishes."
- ❖ 42% *disagreed* and 43% *unsure* with "My physician clearly understands my wishes for life-sustaining treatment."

## Preferences

- ❖ 54% reported preferring to discuss EOL care decisions with their family versus a health care provider
- ❖ 38% reported no preference between family or health care provider when discussing wishes
- ❖ 62% felt that it was up to them or the person for whom the AD was created to bring up the subject of EOL care wishes
- ❖ Overall, 70% reported they would feel "comfortable" if their provider brought up the subject of an AD
- ❖ Those 60+ years old were more likely to report being "very comfortable" with their provider bringing up the subject of an AD compared to those under 60 (60% vs. 39%, p=0.0157).

## Conclusions

- ❖ More than half the subjects associated with the term "Living Will," despite the term "Health Care Directive" used under Minnesota law since 1998.
- ❖ Subjects appear to be familiar with their rights regarding EOL care planning, however about 1/3 reported they believe or were not sure that initiation of an AD requires involvement of a lawyer.
- ❖ About 1/3 of the population completed an AD – similar to estimates in the literature.
- ❖ Of those who have not completed an AD, <1/2 report that they have talked with someone about their wishes.
- ❖ Subjects feel it is their responsibility to raise the issue, however, most would feel comfortable if their provider brought up the topic.
- ❖ Age differences found in two areas:
  - Having completed an AD
  - Comfort level with provider initiation of topic

## Implications for Practice

- ❖ There is much room for improvement in increasing the number of patients who complete an AD, or at the minimum, engage in a discussion of their wishes.
- ❖ Ways to involve health care providers in the process should be explored as it appears that patients are receptive to physician-initiated discussions of ADs.