# Incorporating patient preferences and priorities into end of life care

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## Background

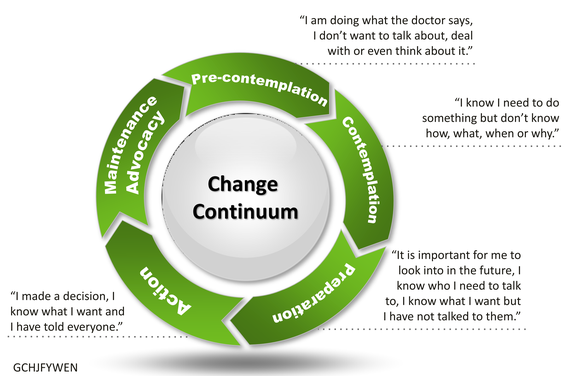
Patients with advanced illness often face painful conversations and difficult decisions. A counseling program was deployed to help patients identify, communicate, and incorporate their personal preferences and priorities into decisions about their care.

## Objective

To evaluate a counseling program on end of life care preferences and priorities by measuring movement along the readiness for change continuum.

## Methods

- **Design:** Program evaluation
- **Population:**
  - Patients with chronic illness living at home in Kentucky, West Virginia, Texas, and South Florida were eligible.
  - Candidates were referred to the program either (1) by their case managers based on clinical conditions and whether the patient appeared to be in their last 12 months of life, or (2) based on identification by an end of life algorithm.
  - Participants must have been cognitively able to verbally consent to participate.
- **Timeframe:** September 2014 to August 2015
- **Program Overview:**
  - Participants are matched with counselors who take a non-directive approach, empowering the participant to become better informed about their condition, and to actively discuss what is important to them with their physicians and families. There are 5 goals of the counseling program:
    1. **Medically informed:** Does the patient know about their condition?
    2. **Priorities and preferences:** Does the patient understand what is important?
    3. **Communication with family:** Does it exist? Positive or not?
    4. **Communication with physician:** Does everyone feel well informed?
    5. **Decision making process:** How are you going to do it? Is it repeatable? Who is involved?
- **Measurements:**
  - Progress on each of the five goals of counseling was measured by net change using the readiness to change continuum.
  - Patients were mailed a satisfaction survey to complete when they reach action and their caregivers are mailed a satisfaction survey to complete when the patient is deceased. Patient and caregiver surveys included the same questions.

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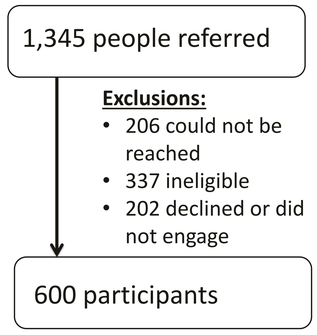
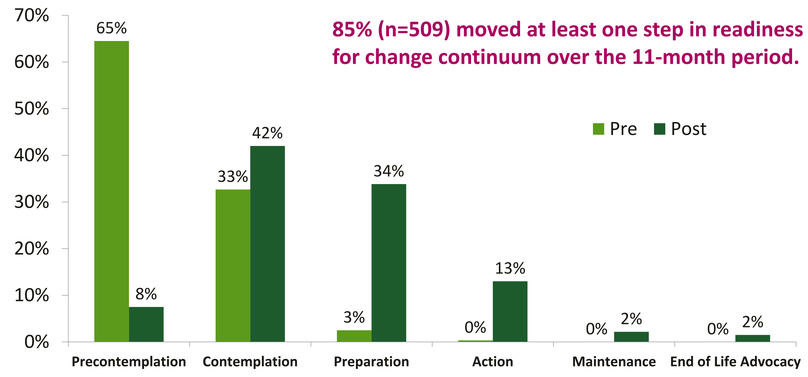
## Results

### Figure 1. Participant Sample




### Figure 2. Distribution of Participants on Readiness for Change Continuum Pre and Post Counseling (n=600)




### Table 1. Patient/Caregiver Survey Results

**Likert scale for responses ranged from 1=Not at all to 5=Always**

| Question | Median Score n=14 |
|---|---|
| The service helped me to focus on what is most important to me as I deal with my condition | 4 |
| Information and services provided by my counselor improved my understanding and sense of control about my treatment | 4 |
| It has become easier to make health related decisions because of the service | 3.5 |
| I have learned how to better communicate health related decisions to my family and friends | 4 |
| Information and services provided by my counselor improved my communications with my medical team | 4 |
| I was satisfied with the services provided | 4.5 |
| I would recommend the service to others in similar situations | 4 |

**Early surveys show high levels of satisfaction.**

### Table 2. Program Goals: Distribution of Participants on Readiness for Change Continuum Pre and Post Counseling (n=600)

| 1 Medically Informed | Pre | Post | Change |
|---|---|---|---|
| Precontemplation | 54% | 12% | -42% |
| Contemplation | 40% | 43% | +3% |
| Preparation | 5% | 30% | +25% |
| Action | 1% | 12% | +11% |
| Maintenance | 0% | 2% | +2% |
| End of life advocacy | 0% | 1% | +1% |

| 2 Priorities & Preferences | Pre | Post | Change |
|---|---|---|---|
| Precontemplation | 56% | 8% | -48% |
| Contemplation | 39% | 43% | +4% |
| Preparation | 4% | 32% | +28% |
| Action | 1% | 14% | +13% |
| Maintenance | 0% | 2% | +2% |
| End of life advocacy | 0% | 1% | +1% |

| 3 Communication: Family | Pre | Post | Change |
|---|---|---|---|
| Precontemplation | 63% | 19% | -44% |
| Contemplation | 31% | 41% | +10% |
| Preparation | 5% | 24% | +19% |
| Action | 2% | 14% | +12% |
| Maintenance | 0% | 2% | +2% |
| End of life advocacy | 0% | 1% | +1% |

| 4 Communication: MDs | Pre | Post | Change |
|---|---|---|---|
| Precontemplation | 61% | 18% | -43% |
| Contemplation | 34% | 36% | +2% |
| Preparation | 4% | 32% | +28% |
| Action | 1% | 12% | +11% |
| Maintenance | 0% | 2% | +2% |
| End of life advocacy | 0% | 1% | +1% |

| 5 Decision Making | Pre | Post | Change |
|---|---|---|---|
| Precontemplation | 66% | 29% | -37% |
| Contemplation | 28% | 37% | +9% |
| Preparation | 4% | 21% | +17% |
| Action | 1% | 10% | +9% |
| Maintenance | 0% | 2% | +2% |
| End of life advocacy | 0% | 1% | +1% |

- **Across all goals, 37-48% of participants progressed beyond the precontemplation stage.**
- **12-16% of participants reached either the action, maintenance or end of life advocacy phase.**
- **The largest observed movement was in defining quality of life priorities (goal 2), whereas the least movement was in articulating a self-defined medical decision making process (goal 5).**

## Conclusions

- A very high percentage of patients progressed in incorporating their preferences and priorities into end of life care as measured by the readiness to change continuum.

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