

## Principal Investigators:

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## Research Questions:

- 1) What are South Dakota residents' attitudes toward death and dying?
- 2) How much advance planning and preparation have they done?
- 3) What knowledge and attitudes do people have regarding hospice?

## Methods:

- Survey instrument adapted from Life's End Institute (Missoula, MT)
- Survey sent to 10,204 random SD households in August, 2005
- Oversampling of Native American households
- 24.8% return

## Sample Profile (n=2,533):

54% female      66% married  
96% Caucasian      77% employed  
Average age of 54  
50% reported "good" or "excellent" health

## Mission of LifeCircle South Dakota is to assure that...

- People of South Dakota receive the care they need to complete their lives and die peacefully;
- Their loved ones receive support;
- And health care providers improve their skills in palliative care.

## What are South Dakota residents' attitudes toward death & dying?

### The majority are comfortable talking about death and dying

88.8% Are "very comfortable" or "somewhat comfortable" talking about death

### There are some things worse than death

- 74% Dying in pain
- 73% Physical dependency on others
- 72% Not being able to communicate preferences for care

### Specific concerns expressed about dying

- 42% Care providers won't believe and treat my pain
- 34% I will be a burden to my family or friends
- 31% I am afraid of addiction to pain meds
- 16% "Good patients" don't talk about pain

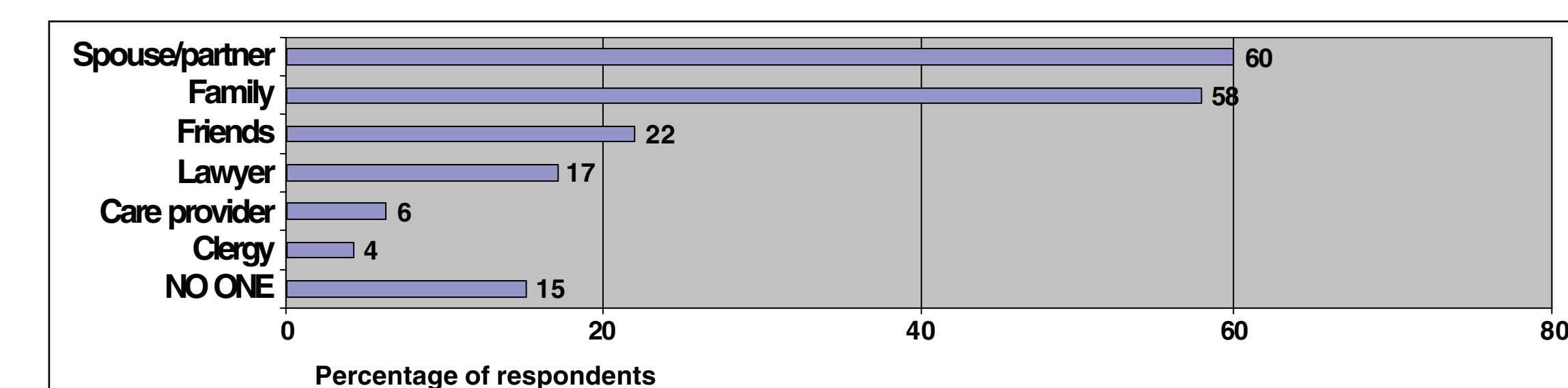
### Preferences about how to die

- 75% Do not want artificial nutrition
- 74% Do not want artificial hydration
- 71% Say it is "very important" to be off machines that extend life
- 23% May want assistance with suicide

## How much advance planning and preparation have they done?

- 49% Organ and tissue donation card
- 39% Advance directive (health care power of attorney or living will)
- 13% Funeral pre-plans

### Discussed their wishes for end-of-life care with...



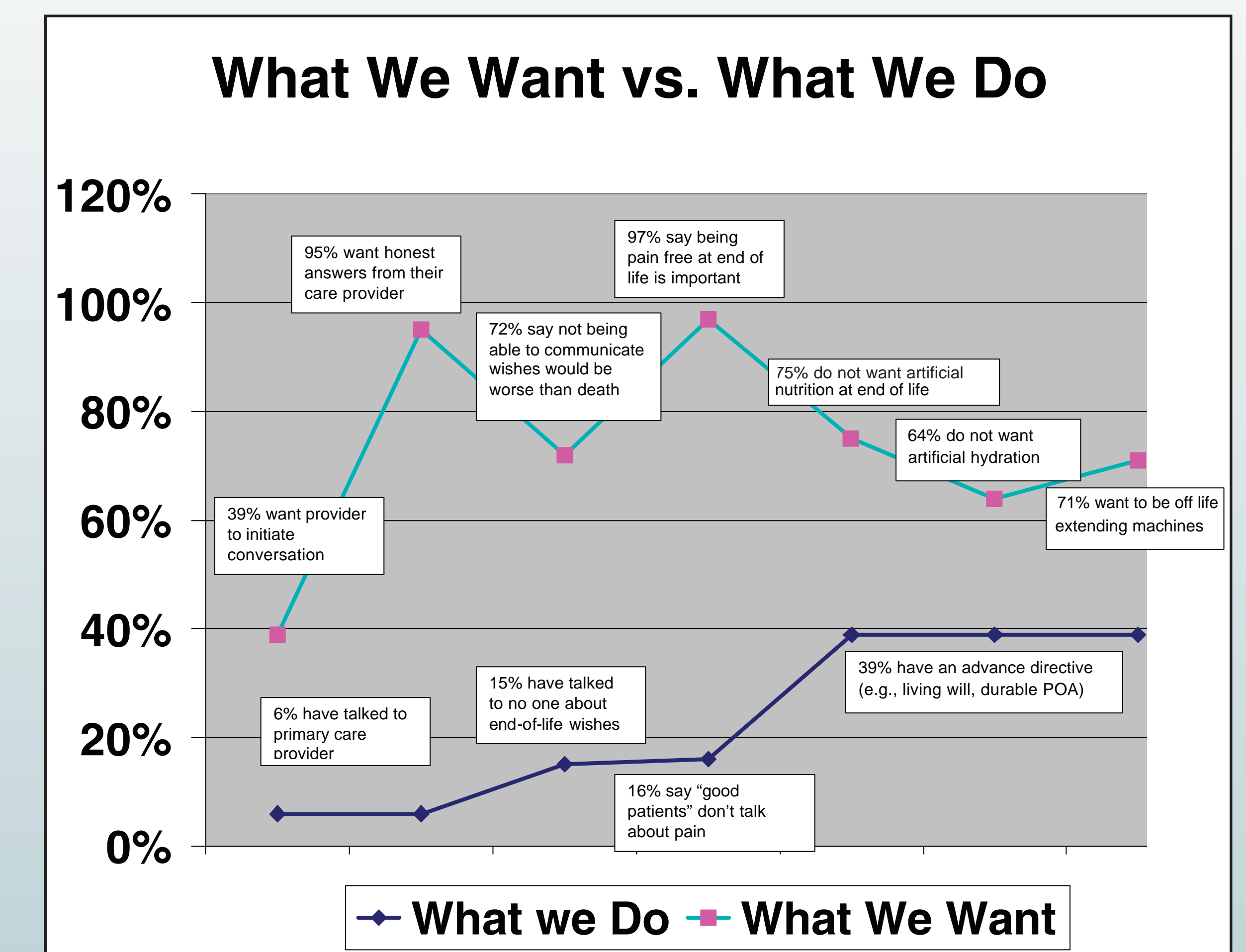
### What South Dakota residents want at end of life...

- 95% Honest answers from primary care provider
- 87% Having things settled with the family
- 86% Understanding treatment options
- 84% Being at spiritual peace
- 83% Not being a burden to loved ones

## What do South Dakota residents know about hospice?

- 50% have never heard of hospice or have heard "a little"
- 67% would want hospice support if dying
- 74% would prefer hospice at home
- 24% know Medicare helps pay for hospice

## Paradoxes: What people want and what they do are sometimes incongruent



## Discussion and Next Steps:

- Many South Dakotans have talked to no one about their preferences at end-of-life
- Most do not want artificial nutrition and hydration at end-of-life
- People are not well-informed about hospice
- Findings are being used to engender community conversations
- Education of legislators and the general public is ongoing
- Research is being expanded to include qualitative research and inter-state comparisons
- Design strategies to close the gaps between preferences and perceived realities in end-of-life care in South Dakota

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