South Dakotans and the End of Life

Public Discussions and Personal Thoughts

A

South Dakota Issues Forums®

Report

April 2001

South Dakota Issues Forums® is a project of the Chiesman Foundation For Democracy, Inc., a neutral, nonprofit organization which encourages participation in civic life based on the premise that citizens need to be involved for democracy to work. SDIF serves as a community support and resource for citizen involvement in local, state, and national issues.

South Dakotans and the End of Life

by

Jeanmarie Heriba

Director, South Dakota Issues Forums

All Rights Reserved

This publication may not be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic or mechanical, including photocopying, recording, or otherwise, without prior permission of South Dakota Issues Forums at the Chiesman Foundation For Democracy, 1641 Deadwood Avenue, Rapid City, SD 57702.

The opinions, findings, and conclusions expressed in this report do not imply endorsement by the sponsoring organizations.

Ordering Information

Copies of this report are available from the **Chiesman Foundation For Democracy, 1641 Deadwood Avenue, Rapid City, SD 57702-0352**. The suggested donation per copy is $2.00 plus $1.00 for postage and handling. A free copy of the report is available per individual request.

Why Talk?

Fewer than 10% of us will die suddenly from an unexpected event. More than 90% of us will die from a protracted, life-threatening illness.[1] Americans today live much longer with chronic illnesses, and advances in technology have prolonged our dying process. How we as a society want to help people as they come to the end of their lives, and how we as individuals want to experience our dying process, were the topics of public forums held throughout South Dakota in September 2000.

The South Dakota Issues Forums collaborated with individuals and organizations throughout the state to provide citizens the opportunity to be part of a national outreach campaign to get people talking about end-of-life issues. These discussions followed the Bill Moyers series *On Our Own Terms: Moyers on Dying*, which aired on public television in the fall of 2000. The Moyers series looked at the experience of dying in America and explored the controversies in law, public policy, and medicine that are arising in response to efforts to change the experience of dying. One of the goals of the Moyers series' producers was to promote discussion about improving end-of-life care.

In order to make sound decisions, people need to look at an issue in depth and examine the pros and cons of an issue's various approaches. That is what South Dakotans did when they came together in forums to talk about the end of life. They listened to the experiences and expertise of the other forum participants and shared their own opinions and beliefs. The national Issues Forums book *At Death's Door: What Are the Choices?* provided a framework for the discussions. The approximately 230 forum participants deliberated what they liked and did not like about physician-assisted suicide, hospice and palliative care, and sustaining life. The costs and consequences of each choice were considered for their effect on families and society. Reflections at the end of the forums revealed what people learned and what they wanted and needed when experiencing the dying of a loved one.

People came to the forums because they were connected to the issue through their work; were losing or had lost someone dear; had friends or family members coping with a loss; or had viewed the Moyers series which stimulated them to talk. Doctors, ministers, nurses, educators, caregivers, students, and others participated. Some shared their deepest personal feelings, stating that it was easier to talk publicly with strangers and neighbors than with family. This report reflects how the forum participants were thinking about the end of life when they gathered to discuss this sensitive and inclusive issue. It describes their vision and needs for completing one's life.

What did participants say about end-of-life issues?

Open discussion

Throughout all the forums, participants said death is a topic that needs to be discussed within families and that talking about death can help individuals understand their own feelings and help them make informed decisions. The need for family members to know what a patient wishes when reaching the end of life was one of the most often-heard reasons for family discussions. Though one's reactions may be different when actually faced with the end of life, as one person noted, most said that discussion and knowing a loved one's desires would ease the difficulty of future decision making for family members. There is a general unwillingness to face the issue due to personal discomfort and fear, the participants felt.

Citizens of Philip, South Dakota, deliberate the issue

Making death a more open topic in our society would help educate people about end-of-life issues and was something participants wanted to see happen. "Don't hide it under the basket anymore," reflected the opinions of many of the forum participants. "It is too important a topic," they said. Openness would benefit those dealing with a loved one's sudden or anticipated death and would make it easier for people to validate feelings of grief, participants felt.

Physician-assisted suicide

"Societal attitudes in regard to death and dying must continue to be addressed."

"These are not abstract issues for a lot of us."

The deliberation of physician-assisted suicide brought out strongly-held beliefs among the participants. Most of those who favored physician-assisted suicide cited the underlying value of personal freedom in making their own decisions. They felt that it is a right to be able to choose how one dies. Having the option of physician-assisted suicide would make some people comfortable knowing it is available, even if they probably would not use it, some thought. Some said it would be an option for those whose pain or depression may not be possible to control. There were family members and healthcare workers who told of witnessing unnecessary suffering, and who thought physician-assisted suicide would help prevent it. A few people mentioned that this choice would save healthcare dollars and family resources. One participant pointed out that "money spent on a dying patient could help others survive." Those in favor of the choice to end life were divided on the role of the physician or others, with some believing that an individual should follow through on his own without drawing others into the decision. One participant said, "I don't want anyone to be prosecuted for helping someone die."

Most participants, however, felt that physician-assisted suicide was not something they would want legalized. Some called on their religious beliefs in guiding them to reject this choice, feeling that "we will die when God is ready for us." The Hippocratic Oath taken by doctors was mentioned as being antithetical to physician-assisted suicide, and participants were unsure how this personal choice and "doing no harm" could be balanced. Inability to regulate the practice was a major concern and many felt that it would open the door to abuse. As one person phrased it, "Too much can be justified once the door is opened to assisting a death." Many of the forum participants felt that if doctors did a better job of keeping patients pain free, the discussion of physician-assisted suicide would be moot. "It seems to me people want a sense of control and want the option of assisted suicide, but maybe they're really just asking for better listening and responsiveness from their healthcare providers," stated a participant.

"I believe physician assisted suicide is a symptom of our society doing a poor job of caring for dying patients."

Sustaining life

"I want to have total control over the treatment I do and do not receive—including treatment that may kill me or sustain my life."

Deliberation of sustaining life as another approach to the end of life uncovered the tension between patient autonomy and what others may feel is in the best interest of the patient. A few participants said that only the patient can and should decide when to "pull the plug" and that doctors should abide by those decisions even

Citizens met in many places

if the patient's family members say otherwise. Others felt the reality is that family members sometimes end up making decisions due to a patient's incapacity.

"I'm a believer in miracles."

Those speaking in favor of sustaining life thought this choice gives hope that there may be improvement or a miracle. A young man revealed his personal feelings when he told the group about a relative who suffered from many serious ailments. He said the light in his grandfather's eyes through his pain made him feel that life is very precious and worth the effort to sustain it. Some felt that family members sometimes choose to sustain life because it allows time for the family to adjust. The choice of sustaining life is consistent with what doctors are trained to do, it was noted.

"We have an aversion as a society to let death occur."

Though some participants preferred sustaining life to the other choices of physician-assisted suicide and hospice and comfort care, most believed that this was not the best approach to the end of life. A few participants thought that sustaining life was "the opposite extreme of suicide." Returning to patient autonomy, people thought this choice should not be supported at the expense of patient choice. Ninety-seven percent of the post-questionnaires indicated participants felt it is important that doctors and hospitals honor a dying patient's wish to refuse treatment. Quality of life and financial costs were concerns expressed about sustaining life. Some participants asked about the effect of this approach on organ donation or what happens when hospitals are full of people on life support indefinitely. The age of the patient was brought up, with participants questioning whether care should be the same for those 9 or 90. Those rejecting this approach also brought out the problems of medical burnout and the emotional pain for the patient, the professional, and the family, with one participant stating, "We are fighting something that is natural and we are fighting it too hard."

Hospice and comfort care

It was during the deliberation of hospice and palliative care that participants found common ground for action. In the forums were men who had cared for wives, women who cared for husbands, and adult children who cared for parents through the hospice program. They shared positive experiences and personal stories. Though there were voices for the other choices of physician-assisted suicide and sustaining life, most of the participants found hospice and palliative care to be the preferred option for end-of-life care.

"I wish more attention to be given to 'comfort care'—less to extreme end-of-life measures."

Many of the participants talked about how hospice helps patients complete life by caring for not just physical but spiritual needs, feeling this choice is, "Caring for the person, not just treating a medical problem." They saw positive communication between the caregiver, patient, and other parties as important for helping the patient to grow emotionally and the family to cope after the patient's death. The control of pain, one of the emphases of hospice and comfort care, was one of the most discussed topics in the forums. "Doctors should do all they can to ease the pain and suffering of dying patients," was an opinion expressed by many of the forum participants. It was important to them that everything possible be done to make the dying process as painless as it can be. To die in one's home, pain free and with family was seen by participants as a natural way to die and preferable to suicide or sustaining life.

"Not all people meet the criteria to receive hospice care."

Most of the drawbacks of hospice care that participants cited related to program guidelines and how hospice is administered, rather than to its philosophy. Though a few felt that choosing hospice care meant giving up on the patient, most of the participants noted the need for respite for caregivers, the six-month requirement for

program eligibility, and meeting program criteria as the major difficulties with the hospice program. While hospice care was seen as more cost effective than hospitalization or sustaining life, participants in small towns were concerned about how to provide the required staff. Rural residents said they just do not have the number of ill patients to justify hiring professionals with specific qualifications, as required for Medicare reimbursement.

All were welcome at the public forums

How did the forum participants envision their end-of-life care?

When these South Dakotans shared their feelings and experiences about end-of-life issues, several themes became apparent in all the forums. Beyond the choice deliberations, people revealed a desire for a system that is responsive to their needs. Participants were adamant that several factors were necessary when considering these very sensitive and serious issues.

People who came to the forums strongly value ***personal control*** over their own deaths. Patient autonomy over how one experiences the end of life was viewed as a human right. Participants felt strongly that patients should make their own decisions about their care.

The death of a loved one is sometimes made more emotionally draining due to a lack of knowledge about the loved one's final wishes. Some are not in a position to exert personal control over their dying, and ***families want to honor the dying person's wishes***. The participants said family members and friends must be aware of the dying person's own vision of death.

A death free of pain and needless suffering was described as very or somewhat important by 85% of the participants who completed post-forum questionnaires. Ninety-nine percent of the post-forum questionnaires showed dying patients who are forced to endure needless pain and suffering was a concern for the forum participants.

The cost of end-of-life care was a major concern of the forum participants. They said they ***want loved ones to receive the care they need without destroying their families financially***. They were concerned about the "cost of futile care" and, if caring for a loved one at home, felt that 24-hour-a-day caregiving is overwhelming.

Where from here?

To experience the end of life as envisioned, people asked for the support they need. Most of the participants felt the following actions were necessary for our society to better address end-of-life issues. The participants believed these actions could be taken by individuals, families, organizations, or lawmakers.

- Families and friends need to engage in dialogues and listen to patients describe how they feel about the end-of-life.
- Public discussions involving most age groups could help people overcome a sense of denial or the fear of controversy.
- Take dying "away from the medical setting" changing our current "culture of dying."
- Educate citizens and healthcare professionals about relevant issues. Education could include learning from other cultures to enlarge our views of living and dying.
- Small communities need to determine how they can help each other provide end-of-life care.
- Support caregivers in the form of respite care, tax breaks, or compensation.
- Change government regulations of hospice care to better fulfill the needs of rural South Dakotans.

Forum reflections

At the end of the forums people said they learned things about their own mortality, many saw a deeper need for family discussions, and a few said they intended to investigate making an advanced directive. One man appreciated the other participants' open dialogue stating it helped him "make decisions for my mother." One young woman said she had come to the forum to help her heal. Another, having never heard of hospice before, said she became aware of the program and the type of care it offers. Participants commented that they still needed to talk about dying from "just getting old and wearing out," and other issues such as spirituality. They said the forum was a beginning.

---

[1] *EPEC Education for Physicians on End-of-Life Care* (1999). American Medical Association's Institute for Ethics, supported by a grant from The Robert Wood Johnson Foundation.

Acknowledgments

Many people made the opportunity for South Dakota citizens to deliberate end-of-life issues in the SDIF forum series possible. Many others also played important roles. The South Dakota Issues Forums thanks:

Mr. Steve Aamot, Aberdeen
Dr. Roberta Olson, Brookings
Ms. Ardeth Kocourek, Martin
Mr. David Dick, Philip
Ms. Kim Kanable, Philip
Ms. Noreen Plumage, Pierre
Dr. David Bartsch, Rapid City
Ms. Grace Busskohl, Rapid City
Major Mike Kliewer, Rapid City
Ms. Mavis Jewitt, Spearfish
Ms. June Larson, Vermillion
Dr. Tom Dean, Wessington Springs
Dr. Tony Berg, Winner
Mr. Dave Anderson, Yankton
Mr. Manuel Casias, Yankton

The South Dakota Issues Forums also thanks the following forum moderators and recorders:

Dr. Bob Burns
Mr. Tom Cook
Mr. Ted Dickey
Mr. John Glover
Ms. Jeanmarie Heriba
Ms. Faye Kann
Ms. Angie Kliewer
Ms. Elaine Larson
Ms. Cheryl Lemley
Mr. Roger Porch
Mr. Mark Proctor
Ms. Tracy Russman
Dr. John Usera
Ms. Kristi Wagner

Michelle Russell, Publications Manager for the Chiesman Foundation, created the layout and design for the report.

Sponsors

Sponsors of the *At Death's Door: What Are the Choices?* forum series/report were:

Rapid City Regional Hospital System of Care

Benedictine Health Foundation

Chiesman Foundation For Democracy

Sioux Valley

The Center for Ethics and Caring at Sioux Valley Hospital

If you would like information or help with regard to convening a forum or learning to moderate forums, please contact
South Dakota Issues Forums*® at the*
Chiesman Foundation For Democracy, Inc.*®*

Phone: 605-341-4311
Fax: 605-341-3902
Web site: www.chiesman.org