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Reflections on End of Life: Comparison of American Indian and Non-Indian Peoples in South Dakota

SUSAN L. SCHRADER, MARGOT L. NELSON,
AND LUANN M. EIDSNESS

During the past century, dramatic changes have occurred in the way death is experienced in the United States.¹ A death in 1900 typically occurred as a result of sudden illness and injury among the young at home.² Today, Americans are more likely to die from long-term, chronic illness in later life, often in institutional settings. In addition to the many cultural transformations and medical advances that occurred during the last century, new philosophies and responses to end of life (EOL) have also evolved. For example, the health care community may be more apt to approach death as a natural part of life instead of as the enemy or a sign of failure. Palliative care encompasses physical, psychosocial, and spiritual dimensions to promote quality of life at EOL, and by using a team approach, hospice care is typically provided during the last six months to terminally ill people and their families, whether in the home or an alternate setting.³

Previous research has been conducted to understand Americans' preferences for EOL care. A nationwide study, *A Means to a Better End*, reported that 70 percent of Americans would prefer to die in their homes, free of pain, and surrounded by their loved ones.⁴ However, only 25 percent of Americans (and 19.3% of South Dakotans) actually die at home under these preferred conditions.⁵ It appears that what Americans want at EOL is not what they are getting.

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In the late 1990s, Life's End Institute (LEI) of Missoula, Montana, used research as a tool to understand the paradox between what Missoulaans wanted at EOL and what actions they engaged in to ensure their wishes were known and honored.⁶ Community-based research generated responses from Missoula and its subpopulations (for example, American Indians, school-age children, clergy, and lawyers). Other states (Michigan, North Carolina, Nebraska, Massachusetts, and Idaho) have conducted community-based studies by using the LEI tool, but none of these Web-based reports appear in the peer-reviewed literature.⁷

Other research has examined the knowledge and preferences about EOL care among racial minorities and the discrepancies that people of color often experience in palliative and hospice care. When racial comparisons have been made, most studies have targeted American blacks and whites.⁸ Other studies examining palliative care and advance directives have focused on Asian/white comparisons.⁹ Multiethnic approaches (including multiple racial classifications) have also been used.¹⁰

From a review of the literature, only four articles address American Indian perspectives on EOL. Joseph Carrese and Lorna Rhodes examined sharing negative information (including EOL diagnoses) with Navaho patients.¹¹ Christine DeCourtney et al. described the creation of a culturally sensitive palliative care program in rural Alaska, and Emmanuel Gorospe and James Hampton offered commentary on palliative care for American Indians.¹² This dearth in the literature is especially critical, given that more than one thousand tribes inhabit the United States.¹³ Variations pertaining to EOL wishes among these populations have not been addressed.

LifeCircle South Dakota: Partners Improving End-of-Life Care is a statewide collaboration among health care and academic institutions. The statewide research, *South Dakota's Dying to Know (SDD2K)*, provided an understanding of South Dakotans' knowledge, attitudes, and preferences about EOL care.¹⁴ In the prairie state of South Dakota (population 754,844), the largest minority population is American Indian (8%).¹⁵ About 5 percent of South Dakota households are headed by persons self-identifying as "American Indian only."¹⁶ Most American Indians in South Dakota are of the Lakota, Nakota, or Dakota tribes of the Sioux Nation. This study brings into greater clarity the EOL wishes of American Indians residing in South Dakota and compares those perspectives with non-Indian residents.

METHOD

Procedure

The Augustana College Institutional Review Board for Human Subjects approved the study design, and permission was given by LEI to adapt its community-assessment questionnaire. Key questions drove the research:

- What are South Dakota residents' attitudes toward death and dying?
- How much advance planning and preparation have they done?

- What do South Dakota residents want at EOL?
- What do they know about hospice?
- Considering EOL issues, are there differences in EOL preferences among American Indians based on sex and age?
- Are there significant differences in EOL preferences between American Indians and non-Indian peoples in South Dakota?

The random sample size of ten thousand was derived from the 2000 US Census (showing 290,245 households).¹⁷ To ensure a satisfactory representation of American Indians, an additional 204 households where heads of households reported their race as “American Indian only” were included. The cover letter, twelve-page questionnaire, and self-addressed, stamped envelope were mailed in August 2005. To enhance the return rate, a follow-up postcard was sent one week later, and five \$100 prizes were randomly awarded to those returning the questionnaires. Altogether, 2,533 surveys were returned, a response rate of 24.8 percent. Three percent of the respondents (71) identified themselves as American Indian. Data were entered into the computer using the Statistical Package for the Social Sciences, and an interdisciplinary team analyzed the data.¹⁸

Participants

A demographic profile of the full sample, the American Indian and non-Indian subsets, and general South Dakota population for 2005 is presented in table 1.¹⁹ Compared to non-Indian respondents, American Indians were less likely to be married/cohabiting (49%), live in an urban area (that is, Sioux Falls or Rapid City) (4%), and reside east of the Missouri River (35%). American Indian respondents were more likely to live in larger (5+ persons) households (22%) with someone with a chronic illness (46%) and have a household income below \$30,000 a year (72%). American Indian respondents were significantly more likely to have experienced a death of a loved one in the last five years (87%). By self-report, 69 percent of American Indian respondents had health insurance, and 32 percent rated their health as “very good” or “excellent.” American Indian respondents were more likely to be female (69%) and have less education compared to the non-Indian respondents. American Indian and non-Indian samples were similar in levels of employment (56% working full time) and in age.

RESULTS

Framework for Analysis

As we see in figure 1, the data from *SDD2K* are framed in a typology to reflect respondents’ attitudes and actions in four areas: spirituality, family, health care, and self. This framework enabled researchers to recognize the centrality of spirituality and family among the Lakota people and to examine more closely the interface that American Indian people in South Dakota

Table 1
Impact of Race on Key Demographics

	South Dakota Pop. (2005)	Total Sample	American Indian Sample	Non-Indian Sample	Sig.
Sample Size	746,033	2,533	71	2,462	
Indicator					
Married/Cohabiting	56%	70%	49%	70%	.001*
Urban (50,000+)	—	27%	4%	27%	.001*
Reside east of Missouri River	—	72%	35%	73%	.001*
Household 5+ person	—	9%	22%	9%	.001*
Chronically ill household member	—	23%	46%	22%	.001*
< \$30,000/year household income	—	36%	72%	35%	.001*
Experienced death in last 5 years	—	76%	87%	75%	.013*
Health insurance	—	90%	69%	91%	.001*
“Good” or “excellent” health	—	52%	32%	53%	.001*
Sex (Female)	51%	54%	69%	54%	.009*
≤ H.S. degree	45%	28%	26%	28%	.052
Full-time Employ.	76%	56%	56%	56%	.291
Age (under 45)	—	28%	36%	27%	
(45–59)	—	37%	40%	37%	
(60+)	—	35%	24%	36%	.114
Median	37	54	51	54	

Note: “Sig.” refers to the probability that differences are statistically significant (*) using chi square, where $p \leq .05$.

have with the health care system (for example, physician, health care settings and programs, and responses to pain or treatment). Responses pertaining to individuals’ attitudes, preferences, actions, and definitions of a “good death” comprise the typology’s fourth dimension.

Spirituality

Ten items were used to describe views of aging, dying, death, and spirituality/religiosity (see table 2). The vast majority of American Indian respondents felt it was very important to be at spiritual peace at EOL (96%). Most American Indian respondents valued getting old (89%), felt dying was an important part of life (87%), and were comfortable thinking about life after death (82%). Nine of ten American Indian respondents said it would be somewhat or very important to receive comfort from religious/spiritual services or persons and to know how to say goodbye (96%). Seventy-three percent of American Indians agreed that caring for the dying is a rewarding experience. In their

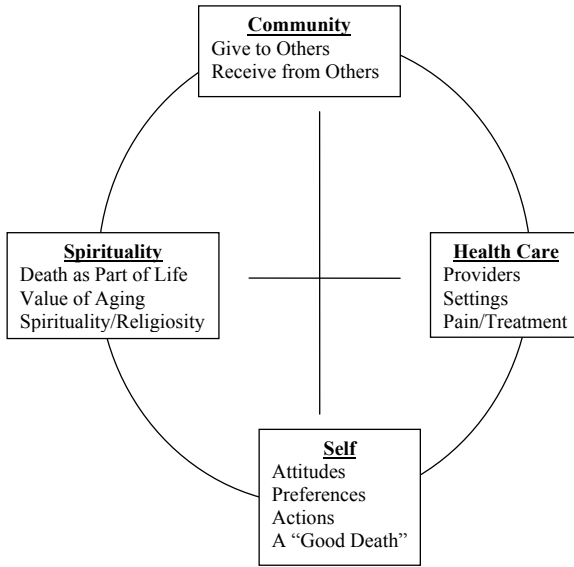


FIGURE 1. Typology of EOL Attitudes and Actions among American Indian and Non-Indian South Dakotans.

self-assessment of their own religiosity, 30 percent of American Indians said they were very religious and regularly attended religious or spiritual services (29%); yet half said they found strength in religion or spirituality daily.

Bivariate analyses were completed on the American Indian sample to explore differences by sex and age. With the exception of American Indian women being significantly more likely to find daily strength in their religion/spirituality compared to American Indian men, there were no significant differences among American Indians by sex. Middle-aged American Indians were significantly more likely to consider themselves very religious, compared to younger and elder Native peoples. Additional bivariate analysis was done, comparing American Indian and non-Indian peoples. The data suggest that American Indian South Dakotans were significantly more likely to value being at spiritual peace, and non-Indian South Dakotans were significantly more likely to be regular in their attendance at religious or spiritual services.

Family

“Family” addresses what American Indian respondents might provide to and receive from loved ones at EOL and their concerns and worries in the face of terminal illness (see table 3). Most American Indians said it was somewhat or very likely that they would attend funerals or memorials for loved ones (79%) and would console a friend or relative at the time of death (82%). Eighty-six percent said it was somewhat or very important to give to others in time, gifts, and wisdom and to get outside help so the family wouldn’t have

Table 2
SDD2K Indicators for Spirituality: American Indians by Sex and Age and in Comparison with Non-Indian South Dakotans

Indicators of Spirituality	Overall			American Indian						
	Non-Indian	American Indian		By Sex			By Age			
	Total	Total	Sig.	Male	Female	Sig.	Young	Middle Age	Old	Sig.
1. Somewhat/very important: Being at peace spiritually.	83%	96%	.002*	96%	96%	.70	96%	100%	88%	.15
2. Somewhat/strongly agree: There is a special value in getting old.	86%	89%	.30	77%	94%	.06	92%	89%	82%	.64
3. Somewhat/strongly agree: Dying is an important part of life.	88%	87%	.49	95%	83%	.17	76%	96%	88%	.09
4. Very/somewhat comfortable: Thinking about life after death.	85%	82%	.38	90%	79%	.18	84%	82%	79%	.19
5. Somewhat/very important: Comfort from religious/spiritual services or persons.	88%	91%	.73	86%	94%	.20	92%	92%	88%	.79
6. Somewhat/very important: Knowing how to say goodbye.	94%	96%	.07	95%	96%	.25	96%	96%	93%	.64
7. Somewhat/strongly agree: Caring for people who are dying is a rewarding experience.	68%	73%	.21	68%	77%	.30	76%	75%	71%	.92
8. Consider self as very religious.	34%	30%	.13	23%	33%	.20	28%	39%	18%	.04*
9. Regularly attend religious services.	52%	29%	.001*	32%	27%	.69	20%	32%	35%	.24
10. Find strength 1+ times a day in religion or spirituality.	46%	50%	.76	36%	56%	.05*	36%	64%	47%	.15

Note: "Sig." refers to the probability that differences are statistically significant (*) using chi square, where $p \leq .05$.

Table 3
SDD2K Indicators for Family: American Indians by Sex and Age and in Comparison with Non-Indian South Dakotans

Indicators of Family	Overall			American Indian						
	Non-Indian	American Indian	Sig.	By Sex			By Age			
	Total	Total		Male	Female	Sig.	Young	Middle Age	Old	Sig.
1. Somewhat/very likely: Attend funerals/memorials.	91%	79%	.001*	64%	85%	.04*	72%	82%	82%	.61
2. Somewhat/very likely: Console friends or relatives.	87%	82%	.14	64%	90%	.01*	84%	86%	71%	.41
3. Somewhat/very important: Give to others in time, gifts, and/or wisdom.	90%	86%	.15	96%	80%	.10	92%	93%	62%	.01*
4. Somewhat/very important: Outside help so family won't have to work so hard.	93%	86%	.02*	82%	87%	.40	92%	89%	71%	.12
5. Somewhat/very important: Family and friends visit.	97%	88%	.002*	82%	91%	.23	96%	88%	76%	.16
6. Somewhat/very important: Reviewing life history with family.	71%	85%	.006*	81%	87%	.38	88%	88%	75%	.43
7. Somewhat/very important: Having things settled with family.	99%	96%	.006*	100%	94%	.52	96%	96%	93%	.24
8. Somewhat/very afraid: Dying alone.	45%	56%	.05*	50%	57%	.37	62%	57%	41%	.38
9. Somewhat/very afraid: Being abandoned.	37%	53%	.004*	38%	60%	.07	68%	50%	38%	.14
10. Somewhat/very concerned: Family's money won't last.	63%	68%	.26	77%	62%	.17	76%	68%	53%	.29
11. Somewhat/very important: Not being a burden to loved ones.	98%	97%	.34	96%	98%	.30	96%	96%	100%	.73
12. Somewhat/very important: Be able to stay in own home.	92%	90%	.32	86%	91%	.41	92%	96%	76%	.10

Note: "Sig." refers to the probability that differences are statistically significant (*) using chi square, where $p \leq .05$.

to work so hard, should their death be imminent. In receiving from family and community, American Indian respondents reported the importance of having family/friend visits at the time of death (88%), time to review one's life history with family (85%), and things settled with the family (96%). Even in the face of giving to and receiving from the family and loved ones, Native respondents expressed fears and concerns. For example, more than half were somewhat or very afraid of dying alone (56%) or being abandoned (53%). Sixty-eight percent were concerned that their family's money wouldn't last in the face of terminal illness, and 97 percent of respondents said it was somewhat or very important not to be a burden to loved ones at the time of death. Ninety percent of American Indian respondents wanted to remain in their own homes when dying.

Bivariate analysis examined variations among American Indians, based on sex and age. Compared to men, American Indian women were significantly more likely to attend funerals and console the bereaved, and younger and middle-aged American Indians were more likely than elders to find it somewhat or very important to give to others in time, gifts, and wisdom before death. When comparing Native and non-Indian South Dakotans, there were statistically significant differences in fears, with American Indians more fearful of dying alone or being abandoned. Non-Indian peoples were significantly more likely to attend funerals, and report the importance of having family/friend visits at EOL, having things settled with family, and acquiring outside help for the family during the dying process. Compared to non-Indian respondents, American Indians were more likely to find life review with family an important aspect of dying.

Health Care

Questions from the *SDD2K* survey invited respondents to share their perspectives on their relationship with providers (physicians) and health care settings and on the experience of pain. Seven items explored attitudes toward providers (see table 4).

Attitudes toward Providers. American Indian respondents wanted honest answers from their physician (94%) and a doctor to visit at home during a terminal illness (84%). Only 7 percent of American Indians had discussed their EOL wishes with a doctor, and 28 percent would prefer that the doctor initiate an EOL conversation with them. Thirty-nine percent said they would avoid checkups because they were afraid the doctor would find "something serious." Fifty-five percent of the American Indian sample indicated that they would trust a physician to provide information on EOL issues, while 67 percent somewhat or strongly agreed with the statement, "I am afraid my doctor may not believe I am in pain and treat my pain." There were no statistically significant differences in the American Indian sample based on sex or age.

Statistically significant differences between American Indian and non-Indian respondents were identified for four items. American Indians were significantly more likely to avoid checkups and doubt that their doctor will believe and treat pain. Indians were significantly less likely to trust their

Table 4
SDD2K Indicators for Health Care: American Indians by Sex and Age and in Comparison with Non-Indian South Dakotans

Indicators of Health Care:	Overall			American Indian						
	Non-Indian	American Indian		By Sex		By Age				
A. Attitudes toward Providers	Total	Total	Sig.	Male	Female	Sig.	Young	Middle Age	Old	Sig.
1. Want honest answers.	94%	94%	.52	90%	96%	.37	96%	96%	87%	.45
2. Want provider to visit at home.	82%	84%	.40	76%	87%	.22	96%	81%	69%	.06
3. Talked to physician about EOL wishes.	6%	7%	.42	9%	6%	.52	4%	8%	12%	.64
4. Prefer that physician initiate EOL talk.	39%	28%	.03*	14%	35%	.06	24%	35%	24%	.63
5. Avoid checkups	18%	39%	.001*	41%	40%	.56	36%	46%	35%	.67
6. Trust physician to provide information about EOL.	76%	55%	.001*	59%	54%	.46	48%	50%	76%	.14
7. Somewhat/strong agree: I am afraid my doctor may not believe I am in pain and treat my pain.	41%	67%	.001*	82%	60%	.07	67%	68%	69%	.99
B. Health Care Settings										
8. ER visits in last year.	17%	33%	.001*	33%	33%	.60	40%	29%	31%	.66
9. Hospital overnights in last year.	13%	21%	.11	18%	23%	.82	24%	18%	24%	.90
10. Somewhat/very afraid: Dying in an institution.	53%	55%	.39	52%	57%	.45	60%	64%	33%	.13
11. Trust hospital to provide information about EOL.	26%	20%	.15	32%	15%	.10	40%	4%	18%	.006*
12. Not heard of hospice.	3%	14%	.001*	24%	11%	.36	20%	7%	19%	.26
13. Know someone who has used hospice.	68%	36%	.001*	32%	38%	.40	32%	44%	29%	.52
14. Know Medicare covers hospice.	24%	13%	.08	5%	17%	.17	21%	7%	12%	.36
15. Want hospice if terminally ill.	67%	56%	.007*	45%	62%	.40	62%	61%	44%	.52
16. Want hospice at home.	74%	64%	.05*	48%	71%	.06	79%	68%	35%	.01*
17. Trust hospice to provide info on EOL.	35%	28%	.11	27%	28%	.59	32%	35%	12%	.22

Table 4 (cont.)

C. Pain and Treatment of Pain	Overall					American Indian				
	Non-Indian		American Indian			By Sex		By Age		
	Total	Total	Sig.	Male	Female	Sig.	Young	Middle Age	Old	Sig.
18. Somewhat/very important: Being free from pain.	98%	96%	.23	91%	98%	.21	100%	90%	100%	.26
19. Somewhat/very important: Know medicine is available for pain relief.	98%	97%	.75	95%	98%	.08	100%	96%	94%	.04*
20. Somewhat/very important: Know treatment options available.	99%	96%	.04*	91%	98%	.09	92%	100%	94%	.27
21. Somewhat/strongly agree: I would only take pain medicines when the pain is severe.	77%	91%	.001*	95%	90%	.60	88%	92%	93%	.62
22. Somewhat/strongly agree: There are other effective remedies for pain besides medicine (e.g., heat, relaxation).	76%	78%	.41	73%	80%	.35	79%	74%	81%	.84
23. Somewhat/strongly agree: I would take the lowest amount of medicine possible to save larger doses for later when the pain is worse.	70%	74%	.28	70%	76%	.43	75%	63%	93%	.12
24. Somewhat/strongly agree: Pain medicine cannot really control pain.	22%	41%	.001*	57%	34%	.07	33%	44%	50%	.56
25. Somewhat/strongly agree: It is easier to put up with pain than with the side effects that come from pain medicine.	32%	43%	.15	48%	40%	.28	29%	48%	53%	.15

Table 4 (cont.)

C. Pain and Treatment of Pain	Overall					American Indian				
	Non-Indian		American Indian			By Sex		By Age		
	Total	Total	Sig.	Male	Female	Sig.	Young	Middle Age	Old	Sig.
26. Somewhat/strongly agree: I am afraid I will become addicted to the pain medicines over time.	30%	58%	.001*	50%	63%	.22	58%	52%	71%	.47
27. Somewhat/strongly agree: I am afraid I would be given too much pain medicine.	25%	43%	.001*	38%	47%	.35	42%	52%	33%	.49
28. Somewhat/strongly agree: I am afraid my doctor may not believe I am in pain and treat my pain.	41%	67%	.001*	82%	60%	.07	67%	68%	69%	.99
29. Somewhat/strongly agree: "Good" patients avoid talking about pain.	16%	30%	.006*	48%	22%	.10	21%	33%	40%	.52

Note: "Sig." refers to the probability that differences are statistically significant (*) using chi square, where $p \leq .05$.

physician to provide information on EOL issues and were less likely to want the doctor to initiate EOL conversation.

Health Care Settings. Ten items defined attitudes toward health care settings. About one-third of American Indian respondents had received medical services through an emergency room, and 21 percent had been hospitalized overnight in the last year. Fifty-five percent of Native respondents were somewhat or very afraid of dying in an institution, and 20 percent trusted the hospital to provide information on EOL issues. A series of questions focusing on hospice revealed that 14 percent of American Indian respondents had never heard of hospice, 36 percent knew someone who had used hospice support, and 13 percent were aware that Medicare covers hospice. A definition of *hospice* was included in the survey, and, thereafter, 56 percent wanted hospice if they were dying, preferably at home (64%). Twenty-eight percent trusted hospice programs to provide information on EOL issues. With the exception of young Indian respondents trusting hospitals to provide information on EOL issues and wanting hospice care if dying, there were no other statistically significant differences by sex or age among Indian respondents.

There were statistically significant differences between American Indian and non-Indian respondents' use of emergency rooms as well as on most

items pertaining to hospice. For example, non-Indian respondents were more likely to have heard of hospice and to know of someone who had used hospice. American Indian respondents were less likely to want home hospice care, compared to non-Indian peoples. There were no significant differences in fears of institutionalization or levels of trust extended toward hospices or hospitals as providers of EOL information.

Pain and Treatment of Pain. Twelve items asked about pain and treatment of pain. Almost all American Indian respondents (96%) said it was somewhat or very important to be free from pain at EOL, know that medicine was available for pain relief (97%), and know what treatment options were available (96%). Ninety-one percent of Indian respondents somewhat or strongly agreed that they would only take pain medicines when the pain is severe. Three-fourths of American Indian respondents agreed that other effective remedies for pain besides medicine existed (78%), and they would take the lowest amount of medicine possible to save larger doses for later (74%). American Indian respondents somewhat or strongly agreed that pain medicine cannot really control pain (41%), and that it is easier to put up with pain than the side effects from medications (43%). American Indian respondents also expressed fears about pain, such as addiction (58%), being given too much pain medicine (43%), and doctors not believing them and treating their pain (67%). Thirty percent of Native respondents somewhat or strongly agreed with the statement, “‘Good’ patients avoid talking about pain.”

Bivariate analyses revealed no statistically significant differences on pain items among American Indians by sex and age, with the exception of the importance of knowing medicine is available for pain relief (younger American Indian respondents were more apt to say this was important compared to older American Indian respondents). Seven of the pain items were statistically significant when comparing American Indian and non-Indian respondents. American Indians were significantly more likely to fear that doctors would not believe them and treat their pain, addiction, and receiving too much pain medication. American Indian respondents were more likely to agree with the statements, “Pain medicine cannot really control pain,” “‘Good’ patients avoid talking about pain,” and “I would only take pain medications when the pain is severe.” Non-Indian respondents were more likely to want to know that treatment options were available to them when dealing with their own dying.

Self

The *SDD2K* survey invited respondents to consider their own attitudes about dying and death and their preferences at EOL (see table 5). These responses are clustered in this category to depict how people view dying, what their preferences are at EOL, and what actions they’ve completed to ensure that their wishes are honored. Finally, items encapsulate what might be considered a “good death.”

Attitudes about Dying and Death. Ten items invited respondents to reflect on their attitudes toward dying and death. Among American Indian

Table 5
SDD2K Indicators for Self: American Indians by Sex and Age and in Comparison with Non-Indian South Dakotans

Indicators of Self: A. Attitudes about Dying and Death	Overall			American Indian						
	Non-Indian	American Indian		By Sex			By Age			
	Total	Total	Sig.	Male	Female	Sig.	Young	Middle Age	Old	Sig.
1. Somewhat/very comfortable: Talking about death.	89%	86%	.27	77%	90%	.16	80%	89%	88%	.59
2. Somewhat/very likely to: Speak freely to loved ones about EOL wishes.	80%	79%	.46	68%	83%	.13	76%	75%	88%	.53
3. Somewhat/very likely to: Preplan own funeral.	71%	69%	.40	59%	72%	.20	56%	71%	81%	.21
4. Somewhat/very afraid of: Dying from a long-term illness.	64%	70%	.19	73%	68%	.46	76%	71%	56%	.39
5. Not being able to communicate would be worse than death. Percent "yes"	72%	66%	.14	77%	62%	.16	56%	82%	59%	.11
6. Total physical dependency would be worse than death. Percent "yes"	74%	63%	.04*	77%	57%	.09	52%	78%	59%	.14
7. Somewhat/very concerned: That my money won't last.	66%	63%	.39	73%	58%	.19	76%	64%	41%	.07
8. Living with great pain would be worse than death. Percent "yes"	63%	53%	.05*	59%	51%	.36	52%	63%	41%	.36
9. Somewhat/very afraid of: Dying suddenly.	29%	41%	.03*	33%	43%	.33	48%	39%	27%	.41
10. Nothing is worse than death. Percent "yes"	8%	11%	.17	9%	11%	.61	12%	4%	18%	.30

Table 5 (cont.)

B. Preferences	Overall			American Indian						
	Non-Indian	American Indian		By Sex			By Age			
	Total	Total	Sig.	Male	Female	Sig.	Young	Middle Age	Old	Sig.
11. Prefer that family initiate EOL talk.	72%	78%	.16	77%	80%	.50	76%	85%	76%	.71
12. Prefer that spouse initiate EOL talk.	66%	51%	.006*	64%	46%	.13	56%	50%	47%	.84
13. Prefer that friends initiate EOL talk.	26%	29%	.31	18%	35%	.13	32%	35%	18%	.46
14. Prefer that clergy initiate EOL talk.	36%	28%	.10	23%	30%	.36	28%	27%	29%	.98
15. Prefer that physician initiate EOL talk.	39%	28%	.03*	14%	35%	.06	24%	35%	24%	.63
16. Prefer that lawyer initiate EOL talk.	17%	16%	.48	23%	13%	.25	16%	19%	12%	.81
17. Very important to be off machines that prolong life.	70%	71%	.56	67%	74%	.37	76%	67%	73%	.75
18. Somewhat or strongly agree: If I were terminally ill and unable to eat, I would want to be fed through a tube into my stomach.	14%	21%	.15	18%	23%	.84	20%	26%	18%	.26
19. Somewhat or strongly agree: If I were terminally ill and unable to drink, I would want to be given fluids through a tube into my stomach or through intravenous methods.	24%	31%	.32	23%	34%	.45	28%	30%	35%	.30
20. Somewhat or strongly agree: If I were terminally ill, I would want assistance with suicide.	23%	20%	.33	24%	19%	.43	20%	18%	24%	.92

Table 5 (cont.)

C. Actions Regarding EOL	Overall			American Indian						
	Non-Indian	American Indian		By Sex			By Age			
		Total	Total	Sig.	Male	Female	Sig.	Young	Middle Age	Old
21. Talked to family.	58%	71%	.02*	59%	76%	.12	64%	65%	88%	.18
22. Talked to spouse.	61%	42%	.001*	59%	35%	.05*	40%	46%	41%	.90
23. Talked to friends.	21%	26%	.21	9%	33%	.03*	28%	27%	18%	.72
24. Talked to physician.	6%	7%	.42	9%	6%	.52	4%	8%	12%	.64
25. Talked to lawyer.	17%	1%	.001*	0%	2%	.68	0%	4%	0%	.44
26. Talked to clergy.	4%	6%	.31	0%	9%	.20	8%	4%	6%	.82
27. Completed financial will.	54%	32%	.001*	29%	35%	.42	20%	31%	56%	.05*
28. Completed power of attorney.	35%	28%	.15	24%	30%	.40	12%	27%	56%	.009*
29. Completed advance directive.	34%	25%	.08	29%	24%	.45	12%	19%	53%	.009*
30. Completed organ donor card.	50%	29%	.001*	27%	30%	.51	32%	35%	18%	.46
31. Completed funeral plans.	13%	16%	.27	14%	17%	.53	8%	15%	31%	.14
32. Talked to no one.	15%	16%	.50	4%	22%	.07	20%	19%	6%	.41
D. A "Good Death"										
Somewhat/very important to:										
33. Be at spiritual peace.	96%	100%	.10	100%	100%	.70	100%	100%	100%	.15
34. Not be a burden to loved ones.	98%	97%	.34	96%	98%	.30	96%	96%	100%	.73
35. Have things settled with loved ones.	99%	96%	.006*	100%	94%	.52	96%	96%	93%	.24
36. Be free from pain.	98%	96%	.23	91%	98%	.21	100%	90%	100%	.26
37. Die at home.	92%	90%	.08	86%	91%	.91	92%	96%	76%	.09
38. Be surrounded by family and friends.	97%	88%	.001*	82%	91%	.02*	96%	88%	76%	.44
39. Have hospice care at EOL.	67%	56%	.007*	45%	62%	.40	62%	61%	44%	.52

Note: "Sig." refers to the probability that differences are statistically significant (*) using chi square, where $p \leq .05$.

respondents, 86 percent said they were somewhat or very comfortable talking about death, and 79 percent said it was somewhat or very likely they would speak freely to loved ones about death and dying or preplan their own funeral (69%). Despite this comfort level, fears about dying were acknowledged: fears of dying of long-term illness (70%), not being able to communicate one's wishes (66%), total physical dependency (63%), money not lasting (63%), living with great pain (53%), and dying suddenly (41%). Only 11 percent said that nothing would be worse than death. No significant differences appeared among American Indian respondents by sex and age.

Comparisons between American Indian and non-Indian respondents revealed that American Indians were more fearful of dying suddenly; non-Indian respondents were significantly more likely to say that living with great pain or total physical dependency would be worse than death.

Preferences at End of Life. Who should initiate the EOL conversation? Among American Indian respondents, the majority preferred that family initiate this conversation (78%), followed by spouse (51%), friends (29%), clergy (28%), physician (28%), and lawyer (16%). Other items asked about medical interventions that are often central to the discussion of treatment options for people at EOL: machines that may prolong life (for example, ventilators), artificial nutrition and hydration, and assistance with suicide. Regarding these items, 71 percent of Indian respondents said it was very important to be off machines that extend life, 79 percent agreed they would not want artificial nutrition, 69 percent rejected artificial hydration, and 20 percent would want assistance with suicide. There were no statistically significant differences among American Indian respondents by sex and age. Comparison between American Indian and non-Indian respondents revealed many similarities rather than differences; the only significant differences seemed to revolve around who might initiate the EOL conversation, with non-Indians more likely to prefer that their spouse or physician initiate the conversation.

Actions to Ensure EOL Wishes Are Honored. More than seven of ten American Indian respondents said they had talked to their family about their EOL wishes, with lesser percentages talking to their spouse (42%), friends (26%), physician (7%), clergy (6%), or lawyer (1%). Besides "having the talk," Indian respondents had completed a financial will (32%), completed an organ donation card (29%), designated a power of attorney (28%), signed a living will/advance directive (25%), or completed plans for their own funerals (16%). Comparison of Indian respondents by sex suggests that men are more likely to talk with their spouse about their EOL wishes and women are more likely to talk with friends. Compared to younger American Indian respondents, elders were more likely to have completed EOL documents (for example, will, power of attorney, and living will/advance directive). Again, when comparing American Indian and non-Indian respondents, patterns of actions were similar, with significant differences appearing in the areas of conversation with spouse and lawyer and of completing a financial will and organ donation card (non-Indians more likely to engage in these actions). American Indian respondents were more likely to have discussed their EOL preferences with family. For American Indians and non-Indians alike, about 15 percent had

talked to no one about their EOL wishes.

A **“Good Death.”** It appears from the survey items that most respondents weighed in heavily on certain dimensions of what might constitute a “good death.” For example, American Indian respondents said it was somewhat or very important to be at spiritual peace at EOL (100%), not be a burden to loved ones (97%), have things settled with loved ones (96%), and be free from pain (96%). Nine of ten American Indians want to die at home (90%), surrounded by family and friends (88%). Fifty-six percent want hospice care. For most, a good death was a natural death, rejecting machines and medical procedures that might prolong dying.

These items revealed no statistically significant differences among American Indian respondents by sex and age, with the exception of women wanting to be surrounded by family and friends if dying. When comparing Native and non-Indian respondents, American Indian respondents were less likely to find it somewhat or very important to have things settled with family, be surrounded by them, and want hospice care during the dying process.

DISCUSSION

The results from *SDD2K* reveal several patterns of interest. First, the study provides a profile of American Indian respondents’ attitudes, preferences, and actions related to EOL. Further analysis reveals few differences among American Indian respondents by sex and age.

Second, significant differences emerge when considering interactions with health care (physicians and settings) and pain. American Indian respondents were much more likely to be concerned that doctors wouldn’t believe and treat their pain and were more likely to agree that “good” patients don’t talk about pain. This critical element of distrust deserves greater examination, as do the mechanisms that might be developed to repair trust and heal interactions. Other considerations (for example, poverty, alcoholism, and cultural understanding of the body) seem to compound the problems of pain treatment, where American Indian respondents were much more likely to express concerns about addiction, doubt the efficacy of medications in treating pain, and minimize use of medication in the dying process. Further, American Indian respondents were much less likely to be aware of hospice services. All of these factors have potent implications for quality of life at EOL. A qualitative study inviting American Indians’ reflections on pain, symptom control, the “good” patient role, and interaction with the health care team would broaden understandings of these issues.

Third, the importance of spirituality at EOL is a significant contribution to the literature. Although EOL issues do not exclusively pertain to the old, recognizing the merit American Indian respondents place on being prepared for death and being at peace may suggest that spiritual counseling and conversation about these things might be especially important for American Indian elders as they approach their dying and death.

Fourth, a number of similarities among American Indian and non-Indian respondents were revealed in the data as well. Native and non-Indian views of

a “good death” were quite similar. The vast majority of respondents wanted to be at peace, not burden loved ones at EOL, have things settled with family and be surrounded by them at home when dying, be free from pain, and be free from machines and technology that might prevent natural death.

The findings from this research suggest that education addressing the myths and realities of pain treatment and medications is warranted among American Indian populations. More education about and availability of hospice programs and services is also needed. Physicians need to be culturally competent in assessing American Indians’ perspectives on dying, pain, and trust levels with health care providers and settings and to be aware that some Indian patients will be reluctant to share their pain, wishes, and skepticism with the doctor, thereby jeopardizing their treatment and comfort levels.

Other applications from the study warrant consideration as well. For example, transmission of these findings to agencies, such as Indian Health Services and tribal clinics, working with American Indian communities and families is needed. Increasing outreach from hospice programs, educating providers in Indian country to the hospice philosophy, inviting dialogue about traditional healing options that may also support a peaceful and supported death, and examining the changes in institutional structures that may impede quality of care at EOL for American Indian individuals and their families deserve a closer look. Being aware of the problems with communication among patient, physician, and the patient’s family may strengthen providers’ abilities to listen and respond to the needs and preferences of the dying individual. As an example, in 2007, the Wellmark Foundation funded a project allowing the Aberdeen Area Tribal Chairmen’s Health Board in Rapid City to educate and train family members, friends, and community health providers—all of whom may serve as caregivers—in the care of Native Americans with cancer.²⁰

The limitations of the study include, first, the small sample of American Indian respondents ($n = 71$), despite efforts to increase Indian representation in the study. Second, the study design was limited in that American Indian respondents were not asked what tribe they belonged to or whether they lived on a reservation. Because the vast majority of American Indians in South Dakota are Lakota, Nakota, or Dakota, the presumption is that the American Indians in this sample are from the Sioux Nation. Although information about living on a reservation is unavailable, the variables of rural/urban and East River/West River (geography demarcated by the Missouri River, which slices through central South Dakota) allude to a more rural, West River location (the area where most of the South Dakota reservations are located) for American Indian respondents. There is no attempt to generalize findings from this geographically specific study and apply them to other tribes or parts of the country. Additional research using a larger, nationally representative sample is needed to understand American Indians’ knowledge, attitudes, and preferences about EOL and the potential diversity that might be found among different tribes. Third, the extensive written survey may have introduced bias by drawing more heavily from respondents comfortable with this medium.

SDD2K generates information and patterns of attitudes, preferences, and actions about EOL issues among American Indian and non-Indian

respondents in South Dakota. The study should be replicated with larger samples to get a pulse on the patterns of EOL preferences among American Indian tribes in various parts of the country.

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