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Key Finding of the 2022 Nebraska End-of-Life Survey: A Report for Nebraska Hospice and Palliative Care Association

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nhpca
NEBRASKA HOSPICE & PALLIATIVE CARE ASSOCIATION

University of Nebraska Omaha

University of Nebraska Medical Center

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INTRODUCTION

The 2022 End-of-Life survey is a continuation by the Nebraska Hospice and Palliative Care Association (NHPCA) to understand the knowledge, beliefs, and actions of Nebraskans and their end-of-life (EOL) wishes. Previous surveys conducted in 2003, 2006, 2010, and 2017 helped to inform the 2022 survey. Results of previous surveys can be found on the NHPCA website.

The University of Nebraska-Lincoln Bureau of Sociological Research contracted with NHPCA to prepare, distribute, and enter survey data for a random sample of Nebraskans 19 years of age and older. Survey invitations were sent to 3,000 Nebraskans 19 years of age and older in one of six regions to ensure adequate representation across the state. Weighting was used to make certain of adequate representation by age and sex. Weighting was not used for oversampling for race or ethnicity. Behavioral health regions are shown on page five highlighting the statewide nature of this survey. Surveys were evenly distributed and completed throughout these regions.

Respondents were provided with two options for completing the survey: online using a Qualtrics survey or on paper. 635 adults completed the survey. 490 were completed on paper and 145 surveys were completed online. The response rate for the 2022 survey was 21%.

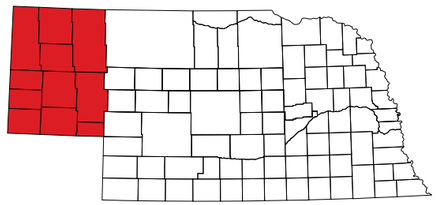
Secondary analysis of the data was completed by University of Nebraska at Omaha, Creighton University, and University of Nebraska Medical Center faculty, staff, and doctoral students. Findings from this analysis are on the pages that follow.

Included in this report are key findings from the 2022 survey. Respondent demographics, knowledge of hospice care and knowledge of palliative care are presented separately. Also presented are respondents' desired preference for where to receive hospice care, knowledge of payment sources for hospice care and palliative care, and their interest in learning more about hospice care and palliative care. We also include highlights of respondents' attitudes about death and illness along with the completion of EOL planning documents. Information about income is presented based on a combination of Internal Revenue Service Tax Brackets from 2022, the 2022 Federal Poverty level, and average Social Security payments for 2022.

Because the 2022 survey took place at the end of a global pandemic, we have included select items from the 2017 survey to compare with the 2022 results. The purpose for including this additional information is to see if any changes in awareness of services and/or usage occurred between the two time periods. This issue, raised by a member of this team and the nursing community, emphasizes the importance of EOL care in relation to the pandemic. What do people know and how does this influence their attitudes about EOL care?

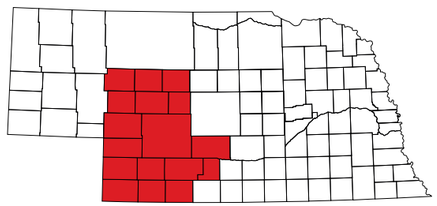
While no definitive conclusions can be drawn from these results, they do offer insight into the attitudes of responding Nebraskans to the state of hospice care and palliative care and provide a roadmap for future survey questions.

DEFINITIONS OF REGIONS AND NUMBER OF RESPONDENTS



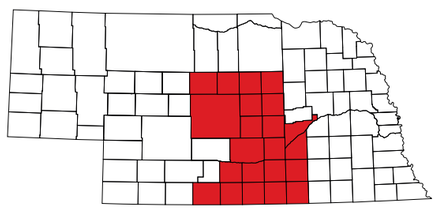
REGION 1 — PANHANDLE (N=97, 15%)

Banner	Garden	Sioux
Box Butte	Kimball	
Cheyenee	Morrill	
Dawes	Scotts Bluff	
Deuel	Sheridan	



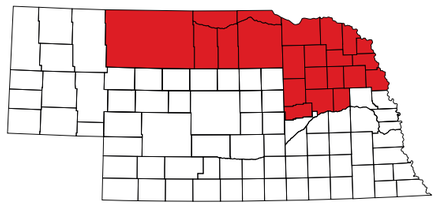
REGION 2 — SOUTHWEST (N=95, 15%)

Arthur	Gospel	Keith	Red Willow
Chase	Grant	Lincoln	Thomas
Dawson	Hayes	Logan	
Dundy	Hitchcock	McPherson	
Frontier	Hooker	Perkins	



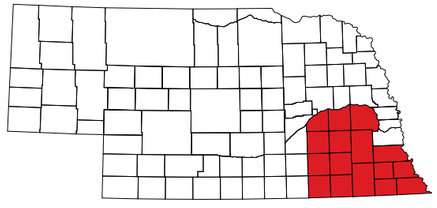
REGION 3 — SOUTH CENTRAL (N=104, 16%)

Adams	Franklin	Hamilton	Merrick	Webster
Blaine	Furnas	Harlan	Nuckolls	Wheeler
Buffalo	Garfield	Howard	Phelps	
Clay	Greeley	Kearney	Sherman	
Custer	Hall	Loup	Valley	



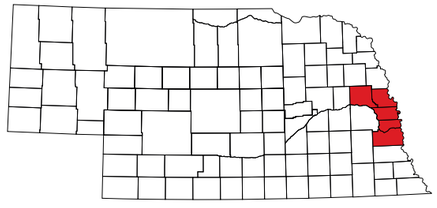
REGION 4 — NORTH (N=110, 17%)

Antelope	Cedar	Dixon	Nance	Thurston
Boone	Cherry	Holt	Pierce	Wayne
Boyd	Colfax	Keya Paha	Platte	
Brown	Cuming	Knox	Rock	
Burt	Dakota	Madison	Stanton	



REGION 5 — SOUTHEAST (N=125, 20%)

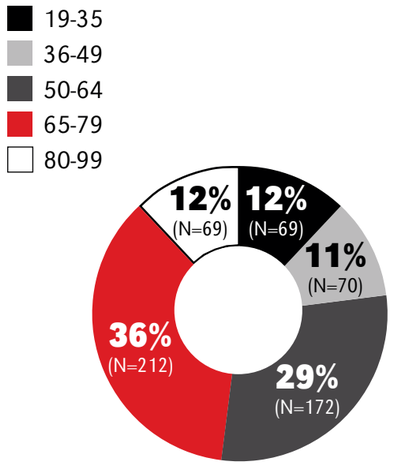
Butler	Lancaster	Richardson	York
Fillmore	Nemaha	Saline	
Gage	Otoe	Saunders	
Jefferson	Pawnee	Seward	
Johnson	Polk	Thayer	

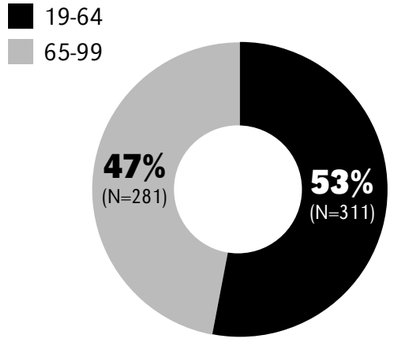


REGION 6 — MIDLAND (N=104, 16%)

Cass
Dodge
Douglas
Sarpy
Washington

AGE





GENDER

FEMALE
66%
(N=392)

MALE
34%
(N=203)

CURRENT MARITAL STATUS

Single/never married	**12%**	(N=70)
Married/domestic partnership	**59%**	(N=355)
Separated/divorced	**13%**	(N=74)
Widowed	**17%**	(N=99)

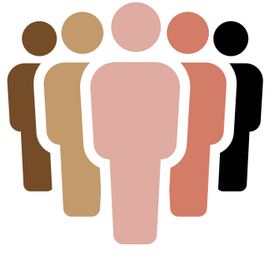
LIVING ARRANGEMENTS

31% (N=184) of respondents live alone

47% (N=279) of respondents live with another person

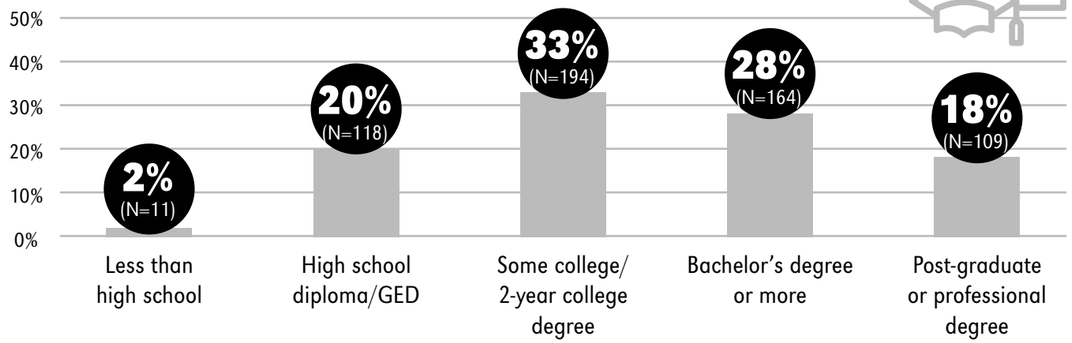
23% (N=130) of respondents live with 2 or more persons

RACE

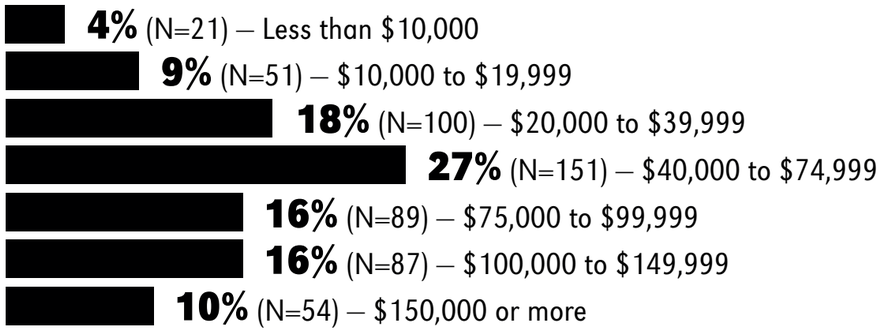


93%	(N=557)	White, non-Hispanic
1%	(N=6)	Black, non-Hispanic
3%	(N=20)	Hispanic
2%	(N=13)	Other

HIGHEST LEVEL OF EDUCATION COMPLETED



HOUSEHOLD INCOME



RELIGIOUS OR SPIRITUAL

53%	(N=334)	Yes
40%	(N=254)	No
7%	(N=47)	No response

HOSPICE CARE

hos·pice
noun

(as defined in the 2022 survey)

Hospice care is a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible. The services are provided by a team of health care professionals who maximize comfort for a person who is terminally ill by reducing pain and addressing physical, psychological, social, and spiritual needs. To help families, hospice care also provides counseling, respite care, and practice support.

KNOWLEDGE OF HOSPICE CARE

2022 | **97% (N=633)** had heard a little or a lot about hospice care

2017 | **96% (N=1,078)** had heard a little or a lot about hospice care

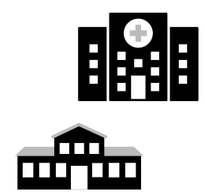
Those having **experience with hospice care** (46% of respondents) indicated the **experience was very positive** 69% or **somewhat positive** 26%.

74% of respondents (N=625) indicated hospice care support would be wanted if a person was dying

DESIRED LOCATION OF HOSPICE CARE

(Note: data is limited to those who said yes to wanting hospice care)

2022		2017	
91%	own home	**88%**	own home
33%	assisted living	**32%**	assisted living
24%	hospital	**26%**	hospital
24%	nursing home	**23%**	nursing home
26%	hospice facility	**38%**	hospice facility
2%	other	**2%**	other
3%	telehealth *(new to 2022)*		



PAYMENT OF HOSPICE CARE

61% of respondents indicated either did not know or were not sure if Medicare or other insurance would pay for hospice care (N=386)

EXPERIENCE WITH HOSPICE CARE

46% of respondents (N=286) have had experience with hospice care

★★★★★

95% of respondents (N=264) have had a very or somewhat positive experience with hospice care

PALLIATIVE CARE

pal·li·a·tive
noun

(as defined in the 2022 survey)

Palliative care is specialized medical care for people living with serious illnesses. This type of care is focused on providing relief from symptoms and stress of the illness. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

KNOWLEDGE OF PALLIATIVE CARE

2022 | **50% (N=309)** had heard a little or a lot about palliative care

2017 | **39% (N=436)** had heard a little or a lot about palliative care

62% of respondents (N=376) indicated that if they were seriously ill, they would want palliative care

PAYMENT OF PALLIATIVE CARE

81% of respondents indicated they either did not know or were not sure if Medicare or other insurance would pay for palliative care (N=498)

DIFFERENCE BETWEEN HOSPICE CARE AND PALLIATIVE CARE

64% either did not know the difference between hospice care and palliative care or were not sure of the difference (N=618)

EDUCATION OF HOSPICE CARE

40% of respondents (N=252) are very interested or somewhat interested in learning more about hospice care

9% very interested
31% somewhat interested

EDUCATION OF PALLIATIVE CARE

42% of respondents (N=259) are very interested or somewhat interested in learning more about palliative care

9% very interested
33% somewhat interested

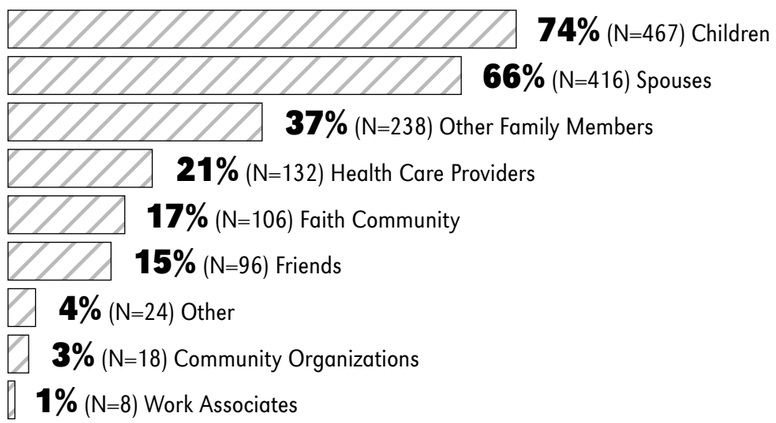
DEATH AND ILLNESS

87% of respondents indicated they are very comfortable or somewhat comfortable talking about death

82% of respondents indicated they strongly or somewhat agree that they would want to have someone tell them if they had six months or less to live

98% of respondents indicated it was very important or somewhat important to have honest answers from their doctor

89% of respondents (N=545) said they expect someone to know what they want when they die



2022 **82% (N=510)** also expect someone to know about their illness

Most frequently selected persons who should know about their illness:
Spouses – 56%
Children – 58%
Other family members – 40%

2017 **80%** expected someone to know about their illness

Most frequently selected persons who should know about their illness:
Spouses – 55%
Family (including children) – 52%
Friends – 13%

2022 **43% (N=254)** are very afraid or somewhat afraid of dying alone

2017 **48% (N=513)** are very afraid or somewhat afraid of dying alone

2022 **69% (N=410)** are very afraid (28%) or somewhat afraid (41%) of dying painfully

2017 **74% (N=791)** are very afraid or somewhat afraid of dying painfully

POSITIVE AND NEGATIVE EXPERIENCES WITH HOSPICE

POSITIVE

> Comfort, pain control, hospice staff visits, and conversations.

> My mom died in comfort with her loved ones surrounding her.

NEGATIVE

> Did not control pain like I thought they should.

> Lack of dignity handling the deceased body of my loved one.

FIRST TIME COMPLETIONS FOR HEALTH CARE DIRECTIVES

- **47%** (N=285) have heard about and completed a Health Care Power of Attorney
- **46%** (N=278) have heard about and completed a Living Will
- **29%** (N=170) have heard about and completed NETO, POLST, DNR/DNI
- **55%** (N=318) have signed up to have organs/tissues donated

UPDATED HEALTH CARE DIRECTIVES

- **43%** (N=262) have updated their Health Care Power of Attorney
- **39%** (N=245) have updated their Living Will
- **22%** (N=139) have updated their NETO, POLST, DNR/DNI
- **44%** (N=263) have updated their organ/tissue donation forms

WHO YOU WOULD WANT TO INITIATE CONVERSATION ABOUT END-OF-LIFE ISSUES

- **56%** (N=355) Children
- **55%** (N=346) Spouse or partner
- **31%** (N=194) Other family
- **29%** (N=187) Primary care physician
- **22%** (N=139) Lawyer
- **19%** (N=123) Specialty physician
- **19%** (N=120) Clergy or other religious leader
- **13%** (N=84) Financial planner/insurance agent
- **12%** (N=76) Friends
- **7%** (N=44) No one
- **1%** (N=7) Other

END-OF-LIFE PLANNING DOCUMENTS

DISCUSSION ABOUT CARE AT THE END

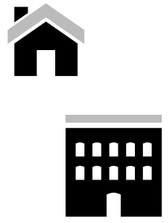
- **53%** (N=338) Have spoken with a spouse or partner
- **45%** (N=285) Have spoken with children
- **30%** (N=188) Have spoken with other family
- **20%** (N=125) Have spoken with lawyer
- **15%** (N=95) No one
- **10%** (N=64) Have spoken with friends
- **8%** (N=48) Have spoken with primary care physician
- **5%** (N=33) Have spoken with a financial planner/insurance agent
- **4%** (N=24) Have spoken with clergy or other religious leader
- **2%** (N=11) Other

WHO YOU WOULD TRUST TO PROVIDE INFORMATION ON END-OF-LIFE ISSUES

- **55%** (N=346) Children
- **52%** (N=328) Spouse or partner
- **42%** (N=268) Primary care physician
- **36%** (N=229) Lawyer
- **30%** (N=193) Other family
- **30%** (N=192) Specialty physician
- **23%** (N=145) Clergy or other religious leader
- **17%** (N=110) Financial planner/insurance agent
- **13%** (N=82) Friends
- **2%** (N=15) No one
- **1%** (N=8) Other

END-OF-LIFE PLANNING DOCUMENTS

DESIRED LOCATION OF DEATH IF TERMINALLY ILL



2022	**76%**	own home
	13%	assisted living
	21%	hospital
	18%	hospice facility
	9%	no preference
	5%	other

2017	**74%**	own home
	9%	assisted living
	18%	hospital
	4%	nursing home
	22%	hospice facility
	9%	no preference
	4%	other

FUTURE PLANNING

22% of respondents N=130 have completed their pre-plans for funeral, burial, or cremation

77% of respondents N=454 have heard about, but not completed pre-plans for funeral, burial, or cremation

21% of respondents (N=128) have updated their plans

LAST WILL AND TESTAMENT

53% of respondents (N=320) have heard and completed a last will and testament

46% of respondents (N=274) have heard about, but not completed a last will and testament

46% of respondents (N=280) have updated their will

ADDITIONAL ANALYSES

PROFILES ON HEALTH CARE DIRECTIVES

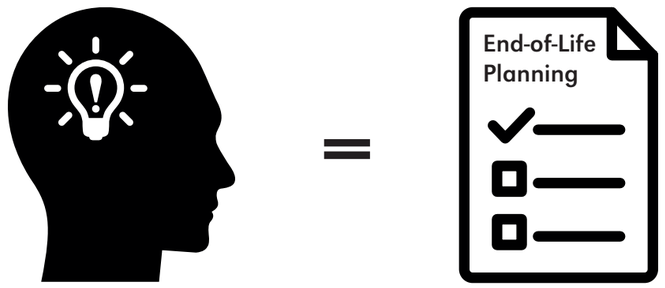
MOST LIKELY TO COMPLETE HCPA, LIVING WILL, OR NETO/POLST/DNR

Older (80+ years of age)
Widowed
In very good health
Living in a 1 or 2 person household
High education

LEAST LIKELY TO COMPLETE HCPA, LIVING WILL, OR NETO/POLST/DNR

Younger (19-35 years of age)
Single or never married
In poor health
Living in a multi-person household
Lower education

Sex, race, region of the state, chronic health condition, and income appeared to be unassociated with likelihood of health care directive completion, although the association with income was complicated. Relative to those making $40,000-$79,999, those with higher incomes were somewhat more likely to complete while those with lower incomes were somewhat less likely to complete except for persons making less than $10,000 who were more likely to complete.



Respondents who have heard a lot about hospice care are also more likely to have completed a HCPA, Living Will, or NETO/POLST/DNR **62%** (N=218)

DISCUSSION

Knowledge of Hospice Care and Palliative Care

The findings from the 2022 survey highlight several important discoveries for NHPCA members and other hospice care and palliative care providers. Like the 2017 survey, 97% of respondents have heard of hospice care compared to 96% in 2017. A positive finding suggesting people are aware of this offering. Awareness of palliative care was much less. 50% of respondents had heard a little or a lot about it. While an improvement from 2017 where 39% of respondents who had heard a little or a lot about it, there is still need for awareness.

There remains a lack of understanding of the difference between hospice care and palliative care. 64% of respondents did not know the difference between these two forms of care. And while hospice care and palliative care work together for people at end of life, there are others, who are not at life's end, that would benefit from the comfort offered through palliative care.

While people may have difficulty knowing the difference between hospice care and palliative care, those who know the difference indicated interest in receiving hospice care if dying (74%), and 64% would want palliative care if seriously ill. This initial awareness can be useful in educating the public about these complementary offerings for care.

Location of Care

When asked about the location they would prefer for care, most respondents continue to express a desire to remain in their homes for care, whether the service is hospice care or palliative care for a long-term illness. What is not known is if people have the necessary caregiving support systems in place to ensure this service can be delivered as hoped. This is an area worth further exploration.

Payment Mechanisms

For providers, the lack of knowledge about payment mechanisms is an important discovery. In addition to not knowing the difference between hospice care and palliative care, respondents to this survey are uncertain what mechanism was in place to cover costs. For hospice care, 61% of respondents were not sure if Medicare or other insurance would pay for services, while for palliative care, the percentage of respondents expressing uncertainty was even higher at 81%.

Completion of Health Care Directives

Those responding to this survey had a higher completion rate (52%) for health care advance directives (Health Care Power of Attorney and Living Will) in comparison to the national average of 37% reported by Yadav et al (2017). It is worth noting people most likely to complete a health care directive were older (65-79 years of age), white, widowed, in very good health, and having a college education. They were also more likely to have income above the poverty line. These findings are somewhat similar to previous research conducted in Nebraska (see Kelly, Masters & DeViney, 2013; and Masters, Wylie & Hubner, 2022). Those least likely to have a health care directive were young (19-35 years of age), single, never married, in poor health, living in a multi-person household, and with lower education. Encouraging other groups beyond those who responded to this survey to engage in this planning behavior is an important area for NHPCA to consider. This also highlights the value of normalizing the process, especially for underrepresented groups, so greater access and awareness is offered. Additionally, while not asked as part of this survey, we wonder if the pandemic served as a motivator for Nebraskans to complete one form of a health care directive. An area worth further exploration.

DISCUSSION AND NEXT STEPS

The Role of Others

Family members, especially spouses and children, were identified as being important to initiating conversations about end-of-life (EOL) wishes. Because they are the ones who will be called upon to offer insight as to the patient's wishes in the event of an incapacitating illness, their understanding of EOL preferences becomes more important overall. Interestingly, though 42% of respondents state that they would trust a primary care physician (PCP) to provide information on EOL issues, and 29% say they would want their PCP to initiate this conversation, only 8% indicate having spoken with their PCP about this. An area of opportunity.

End-of-Life Planning

Other non-health care related forms of EOL planning reflect varied completion rates. Over half (53%) of respondents have completed a will, while others have heard about it, but have not taken steps to do anything further. Similarly, while people have heard about preplanning of burial or cremation, only approximately one fourth of respondents have completed plans for their final disposition. Because the cost of body disposition varies (earth burial vs. cremation), encouraging people to act or communicate their wishes is useful.

NEXT STEPS

People know what hospice care is, but are uncertain how it is paid for by programs such as Medicare and other insurance. Further education in this area by providers may be of use and may encourage people to consider this service at EOL.

People also are less familiar with palliative care and how it is different from hospice care. There seems to be confusion between the two which is natural, but is worth differentiating. A marketing campaign by NHPCA may be to communicate a clearer message as to what each service offers and how it is based on diagnosis and prognosis. Rosa et al. call for palliative care as a human right that should be understood and accessible to all. To advance understanding about and access to these services, education, and health equity reform are needed (Rosa et al., 2021).

Finding ways to differentiate hospice care and palliative care is in order. Preliminary work by a doctoral student in the UNO Department of Gerontology is focused on communication strategies to advance conversation. More work and support for this effort is needed.

Improvement in the completion of health care directives will continue to be needed. For respondents, while more than half of respondents have a HCPA, Living Will, or a directive for resuscitation, there is still a need to encourage others, especially those whose health is poor to complete a health care directive. Helping people understand the value of expressing their wishes for EOL care regardless of how extensive the care is, is of foremost importance.

While modest, 15% of respondents have spoken to no one about their wishes for health care. This discovery is concerning, particularly during times of a global pandemic when decisions for such things as mechanical ventilation require extensive thought and communication. As noted by the American Geriatrics Society (AGS) Position Statement on resource allocation, knowing the wishes of people of all ages is critical to ensuring peoples preferences and values are honored (AGS, 2020). Finding ways to encourage Nebraskans to communicate their wishes becomes vital.

Additional insight is needed to understand the needs of people not represented in this survey. This includes people from diverse groups who are less likely to engage in EOL planning.

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