



United Way End of Life Care Partnership—
Pima County Household Survey: Baseline
Results

Executive Summary

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ASSOCIATES, INC.

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About LeCroy & Milligan Associates, Inc.:

Founded in 1991, LeCroy & Milligan Associates, Inc. is a consulting firm specializing in social services and education program evaluation and training that is comprehensive, research-driven and useful. Our goal is to provide effective program evaluation and training that enables stakeholders to document outcomes, provide accountability, and engage in continuous program improvement. With central offices located in Tucson, Arizona, LMA has worked at the local, state and national level with a broad spectrum of social services, criminal justice, education and behavioral health programs.

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Executive Summary

The End of Life Care Partnership, anchored at United Way of Tucson and Southern Arizona (UW-TSA), contracted LeCroy & Milligan Associates (LMA), Inc., to develop and conduct a survey of a representative sample of Pima County, AZ, residents about end-of-life issues. The primary purpose of the study was to understand residents' attitudes and beliefs about death and dying, their own end-of-life care planning, and their experiences with the death of a loved one (in the past five years and the most significant). The study employed random sampling for 300 telephone interviews and sampled email addresses obtained from an internet survey company for 300 online surveys to obtain a sample of 600 adults that was representative of full- and part-time residents of Pima County with respect to age, gender, and Hispanic ethnicity.

Exhibit ES-1. Characteristics of Pima County Residents and Survey Respondents

	Pima Co. %	Sample %
AGE		
18 to 24 years	15%	15%
25 to 39 years	24%	24%
40 to 54 years	21%	22%
55 to 64 years	16%	16%
65 years and over	24%	24%
GENDER		
Male	48.7%	47.7%
Female	51.3%	51.5%
NonBinary	N/A	0.8%
ETHNICITY		
Hispanic	69% ^a	69%
Non-Hispanic	31% ^a	31%

^aPima Co. Hispanic percentages were calculated by averaging percentages of individuals and households.

NOTE: Percentages may not sum to 100% due to rounding.

The survey instrument comprised questions from existing surveys on end-of-life care and new questions developed by the research team from LMA and staff from UW-TSA. The survey instrument was tested and then translated into Spanish. The survey was fielded by a third-party survey research firm in October 2019. LMA cleaned and analyzed the data with input from UW-TSA. The descriptive results presented in this report provide baseline measures with which future survey results can be compared.

Thoughts about Death and Dying

Several findings about how respondents think about and understand issues associated with death and dying are worth noting. Most respondents said that it's important to talk about death and dying with family and friends (77%) and with a primary care provider (70%), and 82% of respondents said they're somewhat or very comfortable talking about death and dying. However, 53% of respondents said they talk about death and dying with family or friends *rarely*



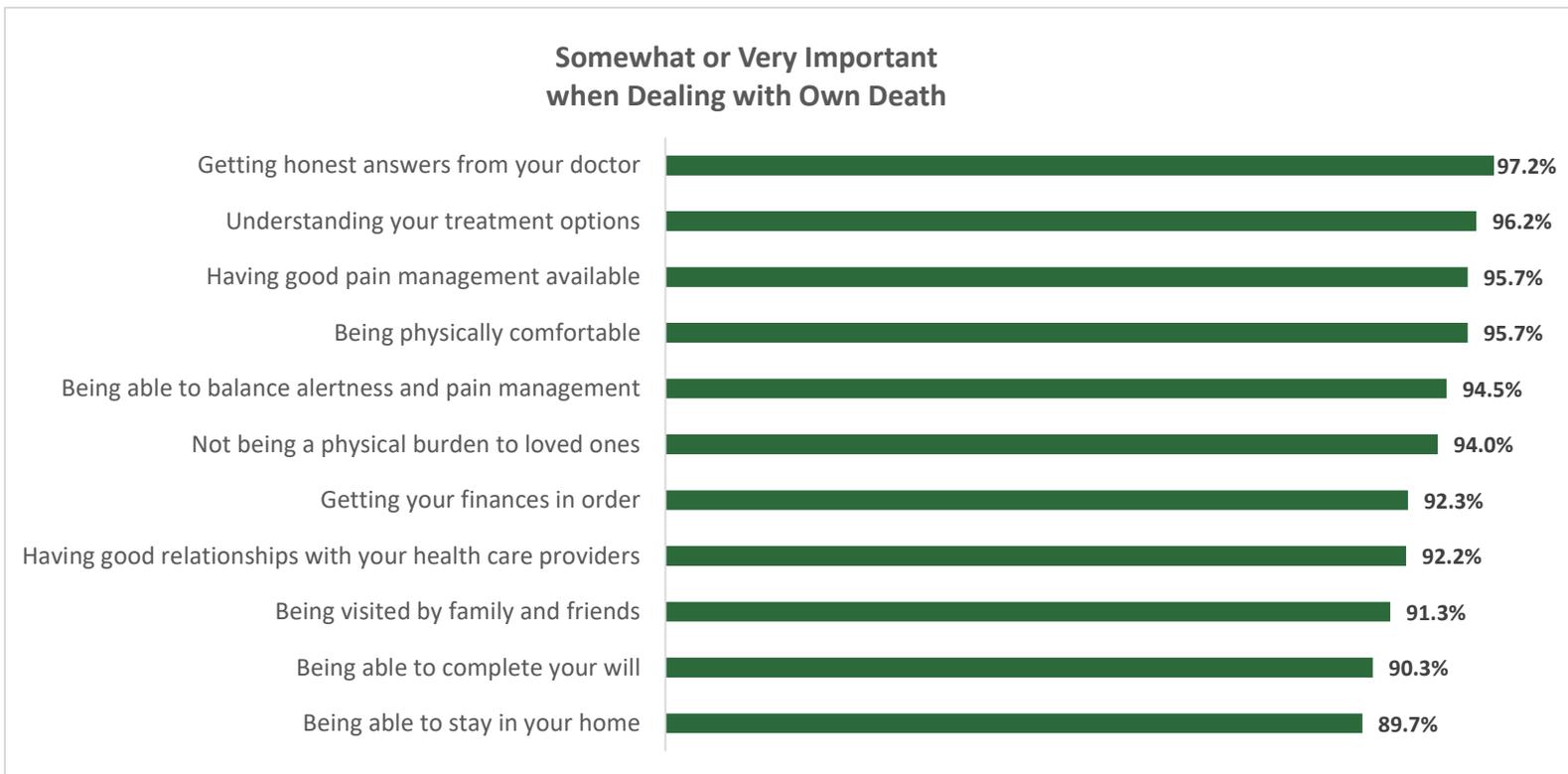
or *never*. Hispanics and non-Hispanics were equally likely to say that it's important to talk about death and dying and that they are comfortable doing so. Older respondents reported higher levels of comfort than younger people with talking about death and dying.

Dealing with Death and Dying

Several findings about the beliefs and actions respondents think are most important when dealing with death and dying are important for programming and education efforts related to end-of-life care in Pima County. Respondents were asked about the importance of different situations and experiences when thinking about death and dying. *Getting honest answers from your doctor* was rated somewhat or very important by 97% of respondents, followed by *understanding your treatment options*, which was rated as somewhat or very important by 96% of respondents (Exhibit ES-2). More respondents said *getting honest answers from your doctor* is important than any of the other 20 situations or experiences, including *having good pain management available* (96%), *being physically comfortable* (96%), and *not being a physical burden to loved ones* (94%).

Most respondents (87%) said they are somewhat or very concerned that they will have mental deterioration or severe memory loss. Similarly, 87% said they are somewhat or very concerned that they will not be able to communicate wishes or needs to family and friends.

Exhibit ES-2. Percentage of Respondents Who Said the Situation or Experience Would Be Somewhat or Very Important When Dealing with Own Dying (N=600)



End-of-Life Planning

Several findings about respondents' end-of-life planning are worth noting, because they highlight the need for education and services related to planning for end-of-life care and sharing those plans with family, friends, and healthcare professionals:

- Although most respondents said it's important to talk about death and dying, only 61% said they had talked to someone about their end-of-life wishes.
- Hispanics were less likely than non-Hispanics to report that they had talked to someone about their end-of-life wishes.
- Of respondents who had talked to someone about their end-of-life wishes, 97% had talked to family or a spouse or partner, and only 12% had talked to a doctor or healthcare professional.
- When asked what would make it easier to talk to someone about end-of-life wishes, the most common answer was, "I don't need to think about end-of-life issues until I'm older or dying."
- Only about one-third (32%) of respondents said they had written down their wishes for their end-of-life care.
- Most respondents (84%) said there is someone they would trust to make end-of-life decisions for them. Roughly two-thirds (66%) said they have a family member they would trust to make decisions, and about half (51%) said they have a spouse or partner they would trust. Roughly 4 in 10 respondents (39%) said they would trust a doctor or other healthcare professional to make end-of-life decisions for them.

Experiences with the Death of a Loved One

Several findings about respondents' experiences with the recent (past 5 years) death of a loved one and the most significant death of someone close to them highlight the need for end-of-life services and programming and for efforts to increase the frequency with which people's end-of-life wishes are honored:

- Most respondents (79%) have had someone significant in their lives die, and 69% experienced the death of a loved one in the past 5 years.
- Of the respondents who experienced the death of someone close to them in the last 5 years, 39% reported that the person died at home, and 55% reported the person died in a facility. Only 57% of respondents said that the person died where they had wanted to die.
- Most respondents (83%) said the wishes of the person who died were known to people important to them, and 92% said the person's wishes were honored by people important to them at least some of the time.



- About 8 in 10 respondents (81%) who had experienced the death of someone close to them in the past 5 years said the person's wishes were honored by medical providers at least some of the time. Conversely, 1 in 5 of those respondents (19%) said the person's wishes were honored by medical providers *none of the time*.
- More than 1 in 4 respondents (28%) reported that the person close to them who died did NOT know their end-of-life care options.
- Roughly 1 in 4 respondents (26%) reported they did NOT receive the support they needed when someone close to them died. Of those, 1 in 4 (25%) reported they needed therapy or counseling but didn't receive it, and roughly 1 in 4 (26%) reported they needed emotional support or someone to talk to.

