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End-of-life planning in a rural elderly cohort

Alyce S. Ashcraft, PhD, RN, CNE, FNGNA, ANEF *, Donna C. Owen, PhD, RN, CNE

Texas Tech University Health Sciences Center, School of Nursing, 3601 4th Street, Lubbock, TX 79430, USA

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A B S T R A C T

Relationships between end-of-life (EOL) planning and demographic and health related variables for individuals living in three rural West Texas counties were examined using a prospective cohort study design. Project FRONTIER, a longitudinal community-based participatory research project, served as the database for this study. Abstracted data from 692 older adults focused on demographic variables, medical conditions, and EOL planning. EOL planning activities included completing a will (39%), a durable power of attorney (32%), advanced directives (14%), talking with family about EOL wishes (31%), and designating a decision maker (55%). The mean EOL Planning Index was 1.6 (SD = 2.58) with higher numbers indicating greater level of planning. Regression findings supported significantly higher levels of EOL planning influenced by age, education, non-Hispanic ethnicity, chronic disease, depression, and communication with family about nursing home placement. Aging rural adults and their healthcare providers would benefit from learning more about EOL planning.

The United States (US) has 46.2 million rural residents (14.6% of the 316 million US residents) spread across 72% of the nation's land.[1,2] Rural residents suffer from "triple jeopardy," a combination of growing old, residing in a remote area, and managing health concerns at a distance with fewer local health services and care providers.[3] Rural end-of-life (EOL) services (palliative care, hospice, home health, and nursing home) are fewer and scattered.[4,5] Living in a rural setting means relying on limited or contracted community resources because of migration of residents, particularly younger generations, to urban areas.[6] This leaves fewer health care providers, agencies, and services to sufficiently prioritize EOL planning as a meaningful health care issue for rural Americans. This study examined relationships between end-of-life (EOL) planning and demographic and health related variables for individuals living in three rural West Texas counties (Table 1).[7–10]

Advance directives (ADs) were developed to indicate EOL preferences to health care providers and include wills, durable power of attorney, and do not resuscitate/do not hospitalize orders. Statistics on AD completion vary but it is estimated between 18% and 30% of Americans have completed an AD, with only one in three individuals with a chronic condition completing an AD. Fifty-five percent of patients with cancer have ADs but 14%–24% of severely or terminally ill patients without cancer have an AD. ADs are more frequently completed in nursing homes, with a 60%–70% completion rate, and one study found greater completion rates in urban versus rural nursing homes.[11] Advance directives focus on the completion of written legal documents, not necessarily the communication to health care providers of what is in the document. AD completion is influenced by personal preferences, cultural beliefs, health conditions, and trust in the individuals and institutions that will provide care.[12] Despite overwhelming support from health care providers and the public, the completion of ADs remains low because it is difficult to predict future circumstances and changes in treatment preferences and values over time.[13]

End-of-life planning has shifted from completion of AD documents to ensuring communication with family members and health care providers. End-of-life planning is not "one shot and it's done." It is an iterative process that evolves over time with each visit to the health care provider and each crucial conversation with family about preferences as death comes closer.[14] A systematic study of advance care planning revealed an increase in studies since

* Corresponding author. Tel.: +1 806 743 9202.
E-mail address: alyce.ashcraft@ttuhsc.edu (A.S. Ashcraft).

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Table 1
Description of Cochran, Parmer, and Bailey Counties.[7–10]

Characteristic	Cochran county	Parmer county	Bailey county
Area (square miles)	775	882	827
Population	3127	10,269	7165
Density population per square mile	4	11.6	9
Distance to Lubbock (miles)[a]	56	92	70
Hispanic or Latino (any race)	1661	6069	3971
Median household income	$40,406	$44,925	$41,075
Individuals living below poverty level	15%	19.6%	11.1%
Employed	50.7%	64.1%	56.2%
Unemployed	11.2%	3.5%	5.3%
Number of health care/social assistance establishments	9	9	15
Number of health diagnosing and treating practitioners and other technical occupations	3	121	60
Legal occupations	0	6	14
Cattle and calves in 2012	22,733	413,269	98,976

[a] Lubbock is the closest metropolitan city.

1999 investigating the importance of EOL communication and concluded interventions with direct discussion of EOL planning beyond AD completion resulted in greater concordance between patient preferences and EOL care received.[15] In our study, EOL planning was conceptualized not only as document completion but also included communication about EOL planning between residents and health care providers as well as residents and family members.

Methods

The longitudinal epidemiological study Project FRONTIER (Facing Rural Obstacles to healthcare Now Through Intervention) was developed by Texas Tech University Health Sciences Center (TTUHSC) researchers to measure the physical, mental, and cognitive health and factors influencing the change in residents of three rural West Texas counties (additional information about Project FRONTIER is available at http://www.ttuhsc.edu/ruralhealth/researchgroup/frontier.aspx).[16] Data abstracted from Project FRONTIER were used to examine relationships between EOL planning and demographic and health related variables for individuals living in the three Project FRONTIER counties.

The Project FRONTIER protocol consisted of a medical exam, blood draw, interview, and cognitive testing. Any person 40 years of age or above and living in one of the participating counties was eligible to participate.[17] After receiving Institutional Review Board approval, subjects were recruited into the FRONTIER study using whole-county encatchment methodology and included visits to county leaders, churches, and social groups as well as community presentations, telephone calls, door-to-door recruitment, and posting/mailing of flyers.[16] Questions were administered in English or Spanish at the discretion of the participant. The cohort selected for inclusion in our study were those subjects who had enrolled in the FRONTIER study between 2008 and 2011 and had completed the EOL survey questions.

Interview questions were specifically developed at the beginning of Project FRONTIER by a group of TTUHSC scientists with interests in rural health. One investigator (A.A.) participated in the inclusion and design of questions related to EOL in the FRONTIER Questionnaire. In our study, demographic and EOL survey items were selected from the FRONTIER data set. The questions chosen for our study were selected based on the existing survey items available to us for study. Some variables were measured with embedded scales while others consisted of single or grouped questions. Other data available included demographic variables (gender, age, education, ethnicity, literacy) and medical conditions (cancer, cardiovascular, diabetes, dementia, depression). Depression was measured by the 15-item Geriatric Depression Scale (Thurston rating scale) where a score of more than seven suggested depression.[18,19]

An EOL Planning Index indicative of level of EOL planning was constructed for this study. The Index used the five survey questions that addressed wills, alternate decision-makers, durable power of attorney, advance directives, and communication with physician and family. The 5-item scale had a Cronbach's alpha of 0.75, which is acceptable for this newly created scale.

Willingness to be cared for away from home was determined by asking subjects to indicate to what extent they were willing to be cared for by family at home, in the homes of family, and at nursing homes near or far from their current living location. Seven survey items described the extent to which subjects were willing to accept help from others, including using a nursing home and living with relatives. In order to address the study purpose, a dichotomous variable was created that indicated willingness to be cared for at home or cared for away from their home.

Results

The sample that served as the basis of our study on EOL planning was interviewed a single time between 2008 and 2011 and consisted of 692 subjects who completed the EOL portion of the FRONTIER survey, with approximately equal numbers from Cochran and Parmer County (Table 2). There were more females than males interviewed (3–1) and participant age averaged 60 years with over 35% of the population having some higher

Table 2
Demographics and health care background items.

Characteristics	*N* (%)
Participants from three counties	692
Cochran county	338 (49%)
Parmer county	345 (50%)
Bailey county	9 (1%)
Gender	
Male	215 (31%)
Female	477 (69%)
Age	
Mean ± SD	61 (±12.6)
Range	40–95
Education level	
High school or less	448 (65%)
College or higher education	239 (34%)
Refused	5 (1%)
Ethnicity/race	
Hispanic	324 (47%)
White	305 (44%)
Black	27 (3.9%)
Native American	17 (2.4%)
Asian	3 (0.4%)
Other	16 (2.3%)
Primary language	
English	422 (61%)
Spanish	270 (39%)
Self-reported illness	
Cancer	86 (12%)
Prostate cancer	8 (1%)
Diabetes	140 (20%)
Taking medications	128 (18%)
Not taking medications	12 (2%)
Mycardial infarction	51 (7%)
Angina or CAD	43 (6%)
History of stroke/mini-stroke/TIA	23 (3.3%)