

Culturally Acceptable Advance Care Planning and Advance Directives for Persons Experiencing Homelessness

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Although the process of dying is a universal human experience, it often magnifies individuals' unique cultural differences. Persons experiencing homelessness (PEHs) have unique barriers, challenges, and wishes for end-of-life care. There is insufficient evidence about how to provide culturally congruent advance care planning (ACP) through advance directive (AD) completion for PEHs. This study addressed this knowledge gap, and its findings serve as the basis for developing additional strategies to promote a satisfying ACP experience for this population when they complete an AD. The purpose of this study was to discover if an AD form recreated for PEHs would positively affect their completion of the AD as well as their overall experience with ACP. Guided by the culture care theory and qualitative ethnonursing methodology, 38 individuals (30 PEHs and 8 student nurses) were interviewed. Data were analyzed using the 4 phases of ethnonursing analysis. The 3 themes abstracted were (1) "it needs to be done," (2) the presence or absence of trusted family support, and (3) ACP for PEHs is facilitated by an AD workshop. Nursing interventions based on study findings can be used to help promote a dignified, meaningful ACP experience for vulnerable populations.

KEY WORDS

advance care planning, advance directive, culturally congruent care, end-of-life, homeless persons

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he importance of advance care planning (ACP) and advance directive (AD) completion has been increasingly recognized in health care literature. 1-5 While the AD completion rate is low among the general population, it is even lower in disadvantaged populations such as persons experiencing homelessness (PEHs). 1,2 The purpose of this article is to describe a nursing intervention to facilitate ACP for PEHs by means of a recreated AD and AD workshop. Following is a description of the study's origins, design, setting, and implementation, as well as perspectives on its limitations and the future implications of its results for nursing practice.

BACKGROUND AND SIGNIFICANCE

The US Department of Housing and Urban Development's Office of Community Planning and Development estimated that 500 000 people in the United States experience homelessness on any given night. This number, which fluctuates throughout the calendar year, can be as high as a few millions. Homelessness—which can last from 1 night to decades⁴—is a complex, fluid phenomenon that can happen to anyone; there is no single definition or characteristic that describes all PEHs. The multifactorial causes of homelessness act concurrently and can include lack of holistic mental health services, substance abuse, increasing poverty, and a decrease in affordable housing.⁸ It is estimated that more than one-third of the American population is only 1 to 3 paychecks away from missing a rent or mortgage payment and becoming homeless.8 Experiencing homelessness is negatively correlated with the quality of one's health and health care services. 1,5,8

The life expectancy for PEHs averages 12 years less than the general population, with proportionately higher rates of injury and mental and physical illness. ^{9,10} In addition, PEHs experience many barriers to accessing care, especially end-of-life (EOL) care. End-of-life care is "the support and medical care given during the time surrounding death." Advance care planning is described as a process that helps people "in understanding and sharing their personal values, life goals, and preferences regarding future medical care." Effective ACP helps PEHs receive EOL care that is consistent with their values and preferences. Factors that may hinder the ability of all individuals, and especially PEHs, to

350 www.jhpn.com

Ethics Series



complete ACP include certain demographic variables, comorbidities, lack of care continuity, discrimination, mistrust of the health care system, low health literacy, a desire for aggressive interventions, and a lack of trusted surrogates. ^{12,13} In addition, the combination of limited literacy and complex AD design may jeopardize the ability of PEHs to make decisions about EOL care. ¹⁴

Persons experiencing homelessness share concerns regarding EOL care with the general population, such as having unfulfilled and inadequate pain control. However, as a cultural group, PEHs have some unique fears regarding EOL: concems about dying anonymously or unacknowledged, being estranged from family and friends, being subject to medical maltreatment because of the stigma of being homeless, and lacking finances to pay for health care and funeral expenses. ^{9,12,13} Persons experiencing homelessness tend to choose more vigorous life-sustaining treatments when facing EOL than do other nonhomeless populations. ^{1,10}

The literature describes a surrogate decision maker as one who can be trusted to make sound decisions and is emotionally stable, able to speak to physicians, calm in a crisis, and available when needed. Some PEHs struggle to identify a surrogate who meets these criteria. ^{2,4,12,13} Without trusted surrogates, written documentation may be the only means to direct health care providers should PEHs become ill and/or unable to express their wishes.

Despite these challenges, research demonstrates that many PEHs show a strong interest in discussing EOL care and engaging in ACP when given the opportunity. ^{1,9,10,12,14,15} Following AD completion, PEHs often report reductions in anxiety and depression regarding EOL and EOL care. ¹⁰ In addition, completing an AD may be empowering for these individuals, increasing their self-esteem and confidence in their coping abilities. ^{1,12,15} Recent literature has shown that counselor-guided interventions had a significant impact on AD completion. ^{1,10} Advance directives written at lower reading level increased completion and individuals' satisfaction with the experience. ¹⁴ Given their willingness to participate, the numerous barriers to ACP, and the potential for positive results, PEHs exhibit a great need for dignified, meaningful ACP and assistance in completing ADs. ^{1,3-5,8-10,12}

Nurses are uniquely positioned and have an ethical responsibility to help individuals make decisions about future health care that aligns with their values, beliefs, and goals. The facilitation of ACP discussions, which may include the completion of an AD, is inherent in nursing practice. It is through ACP that nurses provide advocacy, support self-determination, and develop synthesis of personal and family values and beliefs regarding medical treatment that is integrated into the plan of care. ¹⁶ Leininger ¹⁷ explained that nurses can provide culturally congruent care only when they understand the culture care needs of the people they serve.

Research demonstrates that nurses' attitudes toward PEHs directly affect the quality of care these persons receive and their willingness to seek health care services. ¹⁸ In order to provide culturally acceptable care for PEHs, nurses need formal education in providing care for such vulnerable populations, personal and professional experiences caring for PEHs, and opportunities to reflect on such care. ^{16,19}

Reflecting on the Culture Care Theory (CCT), ¹⁷ Mixer et al¹⁹ explained, "Professional nurses have a duty to provide culturally congruent care that is satisfying, meaningful, and beneficial; fits well with people's daily lives; and, in this context, helps them face the end of life." Knowing the values, beliefs, and practices of persons and families experiencing EOL challenges is essential to delivering quality health care, addressing health disparities, and helping persons achieve a dignified death. Currently, there is insufficient evidence about the ACP culture care needs of this population. Research is needed to address this knowledge gap and develop strategies to promote a meaningful and dignified ACP experience for this undeserved cultural group. Therefore, the purpose of this study was to discover if a recreated AD form for PEH with student-guided ACP within the environmental context of a local ministry center would positively affect their completion of the AD as well as their overall experience with ACP.

Theoretical Framework and Methods

The CCT of diversity and universality²⁰ and modified ethnonursing research method²¹ provided the theoretical framework and methodology for this study. The following 3 research assumptions derived from the CCT guided this research: "Care is the essence of nursing and [its] distinct, dominant, central and unifying focus," "care is essential for people's well-being, health, healing, growth, and ability to face death," and "culturally congruent nursing care occurs when people's [EOL] culture care values, expressions, and patterns are known and used in meaningful ways by nurses."17,19 The ethnonursing research method enables the researcher to enter the world of PEHs respectfully as they participate in ACP by completing an AD. The people's (emic) and nurses' (etic) ways of knowing guide discoveries from this cultural group that will facilitate the provision of culturally congruent nursing and interdisciplinary care for this unique population.²¹

Leininger¹⁷ developed tools (referred to as *enablers*) to explicate culturally embedded data by encouraging participants to tell their stories. *The Sunrise Enabler*, a cognitive map of the theory, was used to explore the dimensions of ACP for PEHs in this study. These dimensions included technological, religious/philosophical, kinship/social, political/legal, economic, and educational factors as well as cultural values, beliefs, and lifeways.²² Data from these factors were synthesized and analyzed, and then the researchers used the CCT's decision and action modes to formulate nursing care recommendations.²⁰

Ethics Series

Recreated Advance Directive Form

With permission from the originator of the SELPH Living Will document, Dr Song, University of Minnesota, researchers revised the AD form to further promote cultural acceptability for PEHs. Revisions were based on feedback from PEHs and student nurses who had previously participated in AD workshops, the literature, the health literacy expert, and social service experts who work with the local PEHs population. Wording and flow were revised. The entire document is organized based on progression. Open-ended questions regarding quality and meaning of life were placed first to ease PEHs into difficult decision making. Then, the document progresses to decisions about EOL care and ends with decisions about after-death wishes. A table was inserted with check boxes that guide PEHs in making health care decisions. The table follows severity of condition from better to worse. The recreated form also provides a checklist to describe an ideal surrogate decision maker to assist PEHs with choosing their surrogates. Lastly, the recreated form is shorter than the original to decrease fatigue and promote serviceability (see Supplemental Digital Content 1, http:// links.lww.com/JHPN/A22).

Setting: Advance Directive Workshop

Institutional review board approval was received. Because PEHs are considered a vulnerable population, verbal consent was given, and pseudo names chosen by PEHs were used. Only the principal investigator (PI), a fellow nursing student, knew which nursing students participated in the study. Signed consent forms were stored in a sealed envelope housed in the office of research files.

The University of Tennessee's College of Nursing (CON) hosts an annual AD workshop with PEHs at the Volunteer Ministry Center (VMC) in Knoxville, Tennessee. Each year, junior-level student nurses, mentored by CON faculty and The University of Tennessee Medical Center's chief of clinical ethics, provide a counselor-guided intervention to help PEHs complete ADs. ¹⁵ For this study, PEHs who completed an AD were asked if they were willing to talk with the PI, a senior nursing honors student, about their experience.

Verbal consent was obtained from PEHs after they completed the AD. After consenting, the participant went to a private room with the PI, who conducted a 15-minute, semistructured interview. For example, PEHs were asked, "You just completed an advance directive, tell me about what this experience was like for you." If participants consented, the PI recorded the interview. If participants preferred no audio recording, the PI took notes during the interview.

Two weeks after the AD workshop, the student nurses who helped PEHs complete ADs were asked if they wished to participate in the study. Those who agreed signed a consent form and participated in a focus group discussion held in a private conference room at the university.

Participants

According to the ethnonursing research method, the philosophical and epistemological sources of knowledge are the people themselves, as they are the experts about what type of care they need. He informants (PEHs) are persons holding the most knowledge for answering the research questions. Selection criteria were PEHs at VMC, English speaking, and mentally capable of participating in ACP through AD as determined by VMC staff. General informants (student nurses) provide broader views of the population and important reflective data that further facilitate the researchers' understanding of people's meanings and experiences related to ACP.

The 30 key informants consisted of 24 men and 6 women, ranging in age from 22 to 62 years. Many participants described experiencing homelessness "off and on," with the length ranging from 2 months to 28 years. The highest level of education varied from completing sixth grade to earning a bachelor's degree. Participants self-described their faith practices as "Protestant," "Catholic," "Pentecostal," "Baptist," "atheist," "no religion," "Lutheran," and "not currently practicing."

Eight of the 14 student nurses conducting the AD workshop consented to participate in a focus group. This group consisted of 1 man and 7 women, all in their early 20s.

Data Collection and Analysis

Data were collected from key informants during interviews following the AD workshop (23 audio recorded and 7 PI took notes) and from general informants during the focus group. Key informants engaged in open-ended interviews using a semistructured guide, which incorporated CCT constructs and purpose of the study. These participants were asked to tell the interviewer about their thoughts and feelings regarding the AD workshop process as well as the AD form. The interviews were recorded, transcribed verbatim, and deidentified through coding. The PI took field notes that described the environmental context of the interview setting, artifacts, nonverbal communication, as well as the PI's thoughts, feelings, and reactions.

During the focus group, general informants were asked to describe their experiences with the recreated AD form and the overall ACP process with PEHs. The PI facilitated the audio-recorded focus group, which lasted approximately 1 hour. The 8 student nurses made up a small, manageable group that enabled each participant's perspective to be heard. Afterward, field notes were documented.

Data were analyzed by the PI and research mentor using the 4 phases of ethnonursing analysis. ²¹ These phases, which incorporate methodological rigor, guided the researchers in using field notes, observations, and interview data to discover if the AD form was culturally acceptable for PEHs and positively impacted their AD completion, as well as the participants' overall perceptions of their ACP experience.



During the first phase of analysis, raw data were collected and described. Culture Care Theory constructs, as discussed under the theoretical framework section above, provided the coding structure for analysis. Data were studied for similarities and differences in the second phase. In the third phase, data were scrutinized until saturation was confirmed. The fourth phase involved synthesizing and abstracting themes. Finally, themes were used to identify nursing decisions and actions/interventions for providing culturally congruent ACP with PEHs. ²¹

This study met 4 qualitative criteria for ethnonursing studies: credibility, meaning in context, recurrent patterning, and saturation. Credibility refers to the accuracy of findings. An expert in EOL and culturally congruent care reviewed the transcripts and confirmed the PI's analysis. Findings were traced back to the raw data, creating an audit trail. Meaning in context was confirmed by examining data from the perspectives of PEHs in their natural environment and reviewing field notes. After analysis of 30 key informant interviews, recurrent patterning and saturation were determined to be complete, as no new insights were being discovered. Digital interview files were kept on password-protected computers, and paper files were kept in a locked file cabinet in the researchers' office.

FINDINGS

Three major themes were extrapolated from the data. Within the CCT, data are considered to fall on a continuum between universalities/similarities or diversity/differences. Themes 1 and 3 were universal, and theme 2 was diverse. The themes are reported in a Table along with supporting participant quotes.

Theme 1: It Needs to Be Done

Participants expressed that completing an AD is a task that "needs to be done." Specific key and general informant quotes provided the raw data supporting this theme (Table 1). A male and female key informant reported some of the potential dangers of being homeless: homicide, suicide, drug overdose, and illness or death due to communicable diseases. One individual explained the necessity of completing an AD in a nonemergent situation, as he had been asked about his EOL wishes only while in the emergency room. Other participants felt ADs "need to be done" so that they did not leave a burden for their family. The AD workshop also served as an educational experience for many participants. Some individuals had never heard of an AD, whereas others had heard of it, but were confused about what it was. For example, 2 men thought that an AD dealt only with assets "like cars and houses," which is why they never completed one. Several participants explained that they had thought about ACP in the past but did not have the means to do it.

While some persons described completing an AD as "uncomfortable," "sad," and "depressing," they also described the process as "important" and "a good thing," and some even said they were "glad to get it done." Student nurses confirmed hearing similar responses from the PEHs they had helped.

Theme 2: The Presence or Absence of Trusted Family Support

When asked what was on their mind, the majority of participants were thinking of their families. However, there was diversity in participants' perceived family support. Whereas many PEHs described having trusted family support, others noted that they could not rely on their family (Table 2).

Many of those who trusted family members to support them at the end of their lives believed their death would hurt their loved ones, as they were "a close family." These participants did not want to be a burden on their families, either emotionally or financially. Participants also described thinking about loved ones they lost in the past. For example, some participants distinctly recalled loved ones' cause of death, disposition of the body, memorial/funeral services, and familial traditions. These memories were said to have influenced the decisions they made during the AD workshop. Two participants were able to provide specific EOL wishes based on these family traditions and/or memories. One individual explained that, while he had already had these conversations with his sister, through the AD workshop he was now able to put his wishes in writing. One man talked about how his wife and mother would fight to keep him alive. He used the form to tell them, "I want you to stop fighting for my life." Several participants felt they could trust their family to support them and respect their decisions.

In contrast, several participants said they could not trust their family to support them or carry out their wishes at the end of their lives (Table 1). These individuals often were estranged from their families, with some reported fighting and having "falling outs." One participant reasoned that if her family does not care for her now, why would they start to care at the end of her life? Several participants did not think their family would approve of or follow through with their instructions for the dispositions of their bodies. One participant chose not to designate a surrogate because she did not trust anyone in her support system to make those decisions. She described that she was worried about not having a surrogate. Student nurses offered her potential alternative surrogates, such as a health care professional or ethics committee, who would follow her wishes as designated on the AD. Another woman was concerned that her wishes would not be her families' first priority at the end of her life. For many, the idea of being "dependent" on someone else was a frightening prospect.



TABLE 1 Study Themes With Supporting Quotes

Theme 1: "It Needs to Be Done"

- "...it was a good experience, and something that's important, and needed to be done." (KI)
- "...it's good to have... in case anything happens. I mean people die down here all the time." (KI)
- "...I educated myself, and I really needed to get it done 'cause... I don't have no power of attorney or whatever." (KI)
- "...it was a great experience. I like it. I wanted to put in on paper, but I just didn't know how to go about it, and you guys brought it here and I did it." (KI)
- "...he wanted full resuscitation, full everything, no matter what circumstance it was, because he was so afraid of dying and expressed that to me." (GI)

Theme 2: Presence or Absence of Trusted Family Support

Trusted Family Support Quotes	No Support Quotes
"I know that I have the 2 surrogates that I have picked, they know what's best, they really know me and know what I would want." (KI)	"I was just concerned mostly that if something were to happen to me or I was to die or something, would anybody even care? Would anybody be there to, to care enough to bury me properly? Or go by my wishes?" (KI)
"I was just thinking about my family and how it would hurt them, you know if something happened, 'cause we're a close family." (KI)	"What if I don't have anyone? I wouldn't want to be truly dependent on anyone else." (KI)
"how my decisions on this would affect my family if they take care of me and all that, with my family and friends having to take care of me. That's how I made my decision on all that. I've already talked to my sister about all of this stuff." (KI)	"Well, I just hope everything turns out well and everybody will cooperate No fighting and no arguing. I don't like that. I want everyone talking and getting along and fellowship and including me. I don't want to be left out you know, I want to be first. I don't like being last." (KI)
"he was more using this form to like communicate with his wife and mother he was just like, tell 'em that I want them to stop fighting [for his life]" (GI)	"he got sad throughout the process, like realizing that he doesn't have anyone to be his surrogate." (GI)
	''[she] had a big falling out with her family making comments about, well he's the reason I'm here anyway.'' (GI)
	"She didn't want to put her son down as a surrogate because she didn't really trust him." (GI)

Theme 3: ACP for PEHs Is Facilitated by an AD Workshop

- "I really think you guys did a very good job on this [AD]... I don't see too many things that could be changed. Everything... that y'all ask is, is real... so I don't see nothing that could change on it." (KI)
- "I like it. Y'all did good. It went well how y'all did it." (KI)
- "...I was just shocked that you all did it... it's very good the way you all did it, 'cause some people are not prepared to do this and... if nobody don't bring it to our attention, we're not gonna go looking for them to fill it out. So, I'm grateful y'all did come in." (KI)
- "Yeah, that was understandable. It actually was one of the more simpler forms I found." (KI)
- "The neighbors seemed to really like the chart [on the AD], how they could see kind of a progression." (GI)
- Abbreviations: ACP, advance care planning; AD, advance directive; GI, general informant (student nurse); KI, key informant (PEHs); PEHs, persons experiencing homelessness.

354



Theme 3: Advance Care Planning Is Facilitated by an Advance Directive Workshop

Participants reported that ACP at the AD workshop overall was a positive process. They described the workshop as "fun," "eye-opening," and "important." Many said the student nurses did a "good job" and did not have any recommendations for improving the process. Universally, participants expressed gratitude that the AD workshop was offered. For some, it was the first time hearing about ACP and ADs. Others described the workshop as a "relief" because they had wanted to do it for a while, but did not have the resources to do so. Several participants said this workshop was their first opportunity to participate in ACP in a nonemergent situation.

Participants found the student nurses to be a positive asset for the AD workshop. The student nurses were able to assist each participant individually by adapting to their specific needs. Participants said the students answered their questions while being "patient," "attentive," and "caring." Student nurses answered participant questions about legal aspects of the form, lifesaving measures (such as cardiopulmonary resuscitation and mechanical ventilation), and how to choose a surrogate decision maker. One individual explained how glad he was that people cared enough to help him, and this showed him he was not "worthless."

Both participants and student nurses found the form to be culturally acceptable. Overwhelmingly, participants described the form as "self-explanatory," "easy," "real," "professional," and "excellent." When asked about the table portion, most participants and student nurses agreed that the table was "helpful" in making decisions. Some participants and student nurses gave practical suggestions for further refining the form to improve its clarity. The AD form, with participant suggestions, is provided as an online resource for journal readers.

DISCUSSION

As one of the few studies to examine culturally congruent EOL care planning for PEHs, researchers used the ethnonursing method, guided by the CCT, to discover nursing care that is satisfying, dignified, and meaningful; fits with people's lives; and helps them face EOL. The PEHs described the process—ACP through AD completion—as crucial to ensuring their EOL desires would be respected and carried out. These findings are consistent with other studies showing that PEHs value AD completion. While no AD form is perfect, a form tailored to the population's unique needs can make a positive impact on the ACP experience. The form should be simple and concise, flow in an orderly fashion, and give participants the chance to express themselves, providing space for elaboration when they are deeply touched or have specific instructions.

Student nurses were effective facilitators of the AD workshop. Through educational videos, role playing, and expert support, students became knowledgeable and comfortable assisting PEHs with ACP. One student nurse said, "[I was] a lot more comfortable with it than I thought I would be." Others described how this service-learning experience opened their eyes to the realities of cultural groups different from their own. One student nurse explained, "It really helped in abolishing the different prejudices that you have." Research study results have shown that service-learning experiences with PEHs decrease students' fears about working with this vulnerable population while increasing their sensitivity and advocacy for them. 15,23-25

Culture Care Modes	Nursing Recommendations	
Preservation/maintenance	 Preserve persons' dignity, humanity, and worth Honor persons' values, beliefs, practices, life circumstances, and backgrounds by exhibiting an accepting, nonjudgmental, and culturally sensitive approach Actively listen and be present 	
Accommodation/negotiation	 Adapt care delivery based on individual health literacy level Describe the qualities of a trusted health care surrogate If no trusted surrogate is available, offer suggestions (nonfamily options, friends, health care providers, and hospital ethics committee) 	
Repatterning/restructuring	 Engage all persons (including those representing vulnerable populations) proactively in ACP through AD completion Sit with individuals, answer their questions, and encourage them to express their desired quality of life and end-of-life experiences Use a culturally acceptable, concise AD form that is appropriate for the individual's health literacy level and that provides space for individuals to express themselves, elaborate on their desires, and give specific instructions 	



NURSING PRACTICE IMPLICATIONS

From the qualitative data, the PI derived evidence-based recommendations for providing culturally congruent care for PEHs engaged in ACP. Recommendations are organized based on the CCT theoretical constructs of preservation/maintenance (supporting), accommodation/negotiation (adapting), and repatterning/restructuring (modifying) nursing interventions. ²⁰ Table 2 provides specific recommendations nurses can use to help all people express their values, life goals, and preferences for future medical care through an AD.

The participants of this study clearly demonstrated their desire to engage proactively in ACP and AD completion, despite not having a serious illness or being in the process of dying. These findings may be useful for helping people from other cultural groups with dignified and meaningful ACP. Students and nurses can help individuals participate in ACP and AD completion by using a culturally acceptable AD form and, when appropriate, organizing an AD workshop. Lastly, these findings support the national call for reducing health disparities by providing culturally appropriate services. ^{5,16}

CONTRIBUTION TO NURSING THEORY

This study is one of the first to use the CCT and ethnonursing method in research for PEHs participating in ACP through AD completion. Three culture care theoretical assumptions were adapted for and subsequently supported in this study. Care constructs, as described in the CCT, are embedded in people's cultural practices and are useful for nurses to understand people's care needs. Five care constructs discovered in previous ethnonursing studies also were found to be important for these PEHs and student nurses: honor, acceptance, listening to, communication, and serving others. These care constructs can help nurses understand how to provide meaningful care for PEHs engaged in ACP.

LIMITATIONS

These findings should be considered in light of several limitations. Because all study participants currently reside in East Tennessee, some of their culture care needs might be unique, limiting transferability of these findings to other regions. As only 1 interview was conducted with each participant, the PI did not meet the ethnonursing qualitative criterion of confirmability. Given the fluidity of the population under study, ⁸ it was unrealistic for the PI to reconnect with participants to confirm findings. A \$3 incentive was given for participation in this study, which could be viewed as a potential limitation, as it is possible some PEHs participated only to receive the money. However, the \$3 incentive is the standard amount offered to PEHs when they participate in an annual local study on homelessness.

CONCLUSION

This study filled a gap in literature about the unique ACP needs of PEHs. These findings and evidence-based recommendations could help nurses assist vulnerable populations by providing dignified, meaningful ACP through AD completion. Educators could use similar service-learning experiences to facilitate students' comfort in working with vulnerable populations, their role in advocacy, and the provision of culturally congruent care. While this study had 38 participants, further research is needed with additional participants representing other vulnerable populations and geographic regions to facilitate culturally congruent ACP.

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Ethics Series



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