

# Analyzing the attitudes and practices of residents of Lucas County, Ohio in regard to advance care planning

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MEDICAL UNIVERSITY  
OF OHIO

COLLEGE OF GRADUATE STUDIES

FINAL APPROVAL OF SCHOLARLY PROJECT  
Master of Science in Biomedical Sciences  
Concentration in Physician Assistant Studies

Analyzing the Attitudes and Practices of Residents of Lucas County, Ohio in Regard  
to Advance Care Planning

Submitted by

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Analyzing the Attitudes and Practices of the Residents of Lucas County, Ohio in  
Regard to Advance Care Planning

Over the last 100 years, there has been a move toward the mechanization of medicine. This has resulted in the use of artificial means to prolong life, when in the past, death would have been inevitable. Historically, debate over the use of these artificial means to continue life beyond the loss of competence has resulted in numerous court cases and the institution of advance care planning legislation in all 50 states (Sabatino, 2003). Field and Cassel (1997) stated "...people have come both to fear technologically over treated and protracted death and to dread the prospect of abandonment and untreated physical and emotional distress." Advance care planning legislation provides the public with the legal opportunity to create documents that state their wishes for healthcare, the refusal or acceptance of life sustaining treatments during the end of their life, once they have lost the capacity to communicate.

Nevertheless, the institution of this legislation has not motivated the majority of Americans to create such documents and a study conducted in 2003 found that only 15-25% of all Americans have completed the process of advance care planning, with higher completion rates in older adults (Kahana, Dan, Kahana, & Kercher, 2004). This lack of document completion has been attributed to lack of public knowledge, fear of the limitations instituted by these documents, denial of the urgency for document completion and the misconception that these documents are unnecessary (Ulrich, 1998).

As Americans, our society values independence and autonomy, our ability to make informed decisions for ourselves. With the onset of medical illness it becomes increasingly difficult to maintain this control. Consistent with the ethical principal of informed consent for all health care procedures, advance care planning documentation allows one to retain autonomy,

even when the capacity to communicate decisions about treatment has been lost. Two types of documents are part of advance care planning, the living will and the durable power of attorney for health care. Living will documents contain choices about specific treatments one wishes to receive or refuse if he/she becomes no longer able to make decisions for him/her and his/her illness is likely to cause death within a short period of time. Durable power of attorney for health care documents authorize one to appoint another person to make medical decisions for him or her if he or she lose the ability to communicate (Lo, 2000).

Field and Cassel (1997) believed that people in the United States have not discovered how to talk realistically and comfortably about the end of life. They concluded that continued public discussion is essential to develop a better understanding of the dying process and the options available. Conversations between health care providers and patients are important but cannot fully provide all the resources necessary to make it possible for one's wishes to be fully upheld at the time of death (Field & Cassel, 1997). In America today, people can receive information about advance care planning from a variety of sources. It therefore becomes important to ensure that information about advance care planning legislation conveyed to the public is accurate and comprehensive so that informed decisions can be made by patients.

The purpose of this study was to assess the attitudes of the residents of one metropolitan community in northwest Ohio with regard to advance care planning and to determine where these residents are receiving their information. A further goal of this project was to determine the comfort level these residents have in discussing their wishes for future health care with their family members and with their health care providers. It was hypothesized that differences in attitude about advance care planning would exist between the residents of Lucas County, Ohio,

in relation to various demographics such as gender, age, marital status, race, religion, education, income, and previous life experiences.

## Literature Review

### *History of Advance Care Planning*

The history of advance care planning roots itself in numerous court battles both on the state and the national levels throughout the United States. The first of these court cases, in 1975, occurred prior to any legal decisions with regard to the rights of patients. Karen Quinlan was a 21-year-old young woman from New Jersey who had suffered irreversible brain damage secondary to anoxia from an overdose of alcohol and medication. It was the wish of Karen's parents to have the respirator that was sustaining her life removed (Pence, 1995).

Two important legal precedents were strongly influential in the outcome of the Karen Quinlan case. Just two years prior to 1975, the Supreme Court decision in *Roe v. Wade* stated that abortion was illegal only if it was performed on a viable fetus. This decision did not give personhood to a fetus but did allow murder charges to be brought against any medical professional that was responsible for the death of a fetus after viability. The second influential statement came from the American Medical Association (AMA) in 1975. The position of the AMA at this time stated that withdrawal of a respirator was equivalent to euthanasia and murder. After a lower court decision to maintain the respirator, stating that Karen's own wishes were not known and therefore treatment should continue in the best interest of the patient, it was finally the New Jersey State Supreme Court which applied the right to privacy to this case and ruled in favor of allowing Karen's parents to make medical decisions (Pence, 1995).

During this same time, the state of California passed the first legislation in this country establishing the rights of patients and their surrogates to forgo life-sustaining treatment through the formulation of written directives. This was called the Natural Death Act of 1976 and though

more restrictive than current laws, it paved the way for other states to formulate similar legislation (Hammes & Briggs, 2002).

Between 1981 and 1983, a report from the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research emphasized the obligation of health care providers and health care institutions to respect the rights of individuals who have expressed their wishes for end of life care. This report also recommended that states adopt the Uniform Determination of Death Act that had previously been proposed by Harvard Medical School. This Act outlined a whole brain approach for the determination of death stating that an individual who has sustained either irreversible cessation of circulatory or respiratory functions or has sustained irreversible cessation of all functions of the brain including the brain stem is dead (Mappes & Degrazia, 2001).

Between the mid 1970's to 1980's most states created living will legislation and between the early 1980's and 1990's durable power of attorney for health care legislation was enacted (Sabatino, 2003). Even with these new laws a 1986 survey found that only approximately 10% of the population had these documents (Braun, Onaka, & Horiuchi, 2001).

It was not until the case of Nancy Cruzan in 1990 that national legislation regarding end of life planning was enacted. Nancy Cruzan was 24 years old in 1983 when she entered a persistent vegetative state after a motor vehicle accident. Though Nancy was not dependent on a respirator for survival like Karen Quinlan, Nancy's parents desired to remove her feeding tube arguing that this was what Nancy would have wanted. As a result of a 7-year court battle in the state of Missouri, the United States Supreme Court made its first decision on death and dying stating first of all that persons have the ability to make choices or refuse medical treatment even if it would result in death, second that "clear and convincing evidence" was needed for a

person's wish to be honored if he/she has lost decision making capacity, and lastly that artificial nutrition and hydration was considered a medical treatment. The United States Supreme Court did not define what constitutes clear and convincing evidence; they left that up to the state. Five months after the Supreme Court decision, the state of Missouri did allow Nancy's feeding tube to be removed, allowing her previous verbal wishes, which were relayed by her family and close friends, to constitute clear and convincing evidence (Pence, 1995).

The Nancy Cruzan case resulted in the federal government establishing the Patient Self Determination Act in October of 1990 which required all health care institutions including hospitals, nursing homes and health maintenance organizations that receive federal funding either through Medicare or Medicaid, to inform all patients of their right to formulate advance directives, living will and durable power of attorney for health care documents as outlined by each state. This act, which is further supported by the Joint Commission for Accreditation of Health Care Organizations, required these institutions to ask about ownership of these documents, provide information about what advance directives are, and forced these institutions to incorporate advance directives into the medical record of patients. It further outlawed discrimination by these health care institutions based on a person's ownership of these documents and protected health care providers when following through with patients written directives (American College of Physicians, 1998; Patient Self Determination Act, 1990). It is interesting to note that this legislation did not, however, formulate federal regulations on the various components of advance directives, leaving that decision up to the individual states (Patient Self Determination Act, 1990).

It was not until 1992 that the AMA council on Ethical and Judicial Affairs was prompted to change its position on end of life treatment. The AMA position now states that it is "ethically

possible to withdrawal respirators and feeding tubes from irreversibly comatose patients.” It further states that there is no ethically significant distinction between withholding and withdrawing life sustaining treatment (Mappes & Degrazia, 2001).

Current professional ethics manuals now also support advance care planning discussions. Published in 1998, the 4<sup>th</sup> edition of the American College of Physicians Ethics Manual encourages physicians to routinely raise issues of advance care planning with competent adult patients during outpatient visits and to document these conversations in the medical record (American College of Physicians, 1998). Under the guidelines for the Ethical Conduct of Physician Assistants, last revised in 2002, it is the duty of a physician assistant to “protect and foster informed consent.” Physician assistants also have an “obligation to optimize care at the end of life and facilitate discussion with family members.” Physician assistants further have an obligation to always include the physician in all near death planning and to be aware of the medical, legal, social and ethical issues involved in ethical decision making. Like the American College of Physicians Ethics Manual, this document also encourages advance directive discussions to occur with routine patient visits (American Academy of Physician Assistants, 2002).

A 1997 report from the Institute of Medicine also addresses the issue of advance care planning. The goal of this report was to improve care at the end of life by strengthening popular and professional understanding of what constitutes “good care” at the end of life and to encourage a wider commitment within society to caring for people as they die (Field & Cassel, 1997).

*The Process of Advance Care Planning*

Pence (1995) stated that “today, people have come to believe that the definition of death is not a matter of discovery but rather, to a significant extent, a kind of decision that families and their physicians make.” Advance care planning is an organized approach to the initiation of these discussions about end of life issues. It can occur within the family unit or with a health care provider and not only includes the formulation of specific documents collectively called advance directives, but also includes the initiation of a deeper understanding about the values, goals, and preferences for health care that a particular individual holds (Hammes & Briggs, 2002). Health care providers have an ethical and legal responsibility to undertake advance care planning with their patients. These discussions improve the communication pathway between patient and provider and formulate a more holistic approach to patient care. Emanuel, Von Gunten and Ferris (2000) suggested five steps that a physician may go through in the process of advance care planning with a patient. These steps include introduction of the topic, engaging in structured discussions about advance care planning, documenting patient preferences either on formal advance directive forms or in the patient’s medical record, reviewing and updating the directives routinely on patient visits, and applying these documents in actual circumstances.

All 50 states now have legislation that allows for the completion of advance directives, either in the form of a living will, a durable power of attorney for health care or both. Living will documents inform physicians about specific conditions under which a person would or would not want medical support continued and may in fact outline specific medical treatments a patient may or may not want to receive. These documents are valid for either the withholding or the withdrawal of these treatments and may include cardiopulmonary resuscitation, artificial ventilation, antibiotic medications, cardiac medications, dialysis and artificial nutrition and

hydration. Living will documents can only be used when a patient is in a terminal condition or in a persistent vegetative state (Lo, 2000).

A durable power of attorney for health care, also known as a health care proxy, assigns another adult person to make health care decisions on behalf of the patient if they are no longer able to make medical decisions for themselves. These documents do not require a patient to be in a terminal condition or a persistent vegetative state, just to have lost the capacity to make medical decisions. Most states do not allow the patient's physician, the hospital or nursing home administrator or any other person directly responsible for the patient's care to be named as a surrogate (Lo, 2000).

States differ on what deems a particular document valid in the eye of the courts. Some states only require the document to be witnessed by two persons who are not family members or the named surrogate while others require the document to be notarized. There are no states that require the documents to be drafted by a lawyer to demonstrate validity (Lo, 2000). States also have the authority to further limit document validity by requiring specific state issued forms be used (Sabatino, 2003)

Following the Supreme Court's ruling stating that "clear and convincing evidence" is all that is necessary to follow a patient's wishes, the most commonly cited advance directive in the hospital setting still results from prior conversations with family members or health care providers when documents have not been completed. Though these oral directives offer a patient the advantage of informality and may be less intimidating, not all states recognize this as a legal form of communicating ones wishes (Lo, 2000). Any physician who is following the directives on a written document is free from civil and criminal charges related to taking another person's life and most attorneys inform their clients that the formulation of written directives is the safest

way to ensure one's wishes will be followed and to abdicate liability from providers (Sabatino, 2003).

### *Importance of the Value History*

Patients can refuse treatment for any reason; it doesn't have to be a good reason. From the medical ethics standpoint, advance directives are intended to be instruments of communication, not private expressions of a patient's wishes which are made known when the document is invoked (Ulrich, 1998). Hammes and Briggs (2002) state, "One of the central themes of the national recommendations is the need to shift the focus of attention from the completion of the advance directive document to the process of advance care planning." Individuals have many values which are involved in advance directive completion. These include the value for life, desired quality of life, wanting to spare family members from difficult decision making, remaining in control during times of disability, desire to avoid degrading therapies, affirmation of religious beliefs and the desire to remaining communicative (Miles, Koepp, & Weber, 1996).

Most state documents do not allow for individuality when completing these forms. For this reason, Ulrich (1998) suggested that it may be helpful for patients to include further content in their advance care planning discussions or documentation to ensure that those making health care decisions for them understand their values. He suggested that these documents include an explanation of the reason for writing such a document, an expanded explanation of why particular treatments are refused or accepted and an explanation of the desired outcome after treatment is initiated stating that only treatments that will result in the desired outcome should be used.

Miles, Koepp, and Weber (1996) stated that advance directive discussions have been shown to “catalyze important, memorable and therapeutic discussions between patients, providers and family members about emotionally and conceptually difficult issues.” These discussions and not just the act of document completion have demonstrated improved physical symptoms, decreased depression, increased patients beliefs that physicians understand their preferences, increased patients beliefs that physicians care, better preparation for death, and decreased the burden on loved ones (Hammes & Briggs, 2002).

#### *Sources of Advance Care Planning Information*

Public educational efforts regarding advance care planning began six months following the enactment of the Patient Self Determination Act (PSDA) in October of 1990 when, as outlined by this document, educational materials were developed and a national campaign was implemented to inform the public of the option to execute advance directives and the right to participate in health care decision making. This information was distributed to hospitals, nursing homes, medical professionals and legal professional. The PSDA (1990) also called for distribution of advance directive information to all social security recipients and a page with information regarding advance directives was added to the Medicare handbook.

According to a longitudinal study completed in 1994, however, there was no significant change in the knowledge base within the community regarding advance care planning before and after the implementation of the PSDA (Jacobson, White, Battin, Francis, Green, & Kasworm, 1994). According to this study, and corroborated by studies conducted in 1997 and in 2000, most people reported that the primary source of advance care planning information came from the media through stories which appeared in the newspaper or on television (Jacobson et al., 1994; Nolan & Bruder, 1997; Waters, 2000). Less than 10% of individuals surveyed in the 1994

study cited a health care professional as the source of their advance care planning information and a 1999 study found that a significantly larger percentage of patients had completed documentation following discussions with their attorneys than following discussions with health care providers (Jacobson et al., 1994; Mansell, Kazis, Glantz, & Herren, 1999). These statistics are rather surprising considering over 90% of patients surveyed by Nolan and Bruder (1997) felt that physicians should be responsible for the initiation of advance care planning discussions.

#### *Factors Associated with Advance Care Planning Completion*

Though advance care planning is grounded in the American value of autonomy and independence, it has been found that information may need to be tailored to specific ethnic groups within American culture. Minority populations within the United States, specifically African Americans, Asians, and Hispanics are less likely to have completed advance care planning documentation (Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002; Baker, 2000; Waters, 2000; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). Baker (2000) concluded that these differences between cultural groups stem from both a distrust of the medical establishment within the United States and also cultural differences in which these individuals rely more on family opinion than their non-minority counterparts. Baker also provided evidence that these individuals are more likely to desire rather than refuse life-prolonging treatments.

Previous studies have found that socioeconomic status and income had little influence on advance directive completion while patient age, marital status, education, and disease severity were influential to document completion. Jacobson et al. (1994) found within a survey of persons over the age of 18, those with documents were more likely to be over 51 years of age and were more likely to have graduated from high school and have additional years of education. A 2003 study of community dwelling older adults found a completion rate over 50% in adults

age 65-99 with higher completion rates among white and unmarried individuals. Current health status was not influential in document completion (Kahana et al., 2004). This finding refutes a 1998 study which stated that persons who perceive themselves to be in poor health and those who had previous experience with life prolonging technology were more likely to have completed these documents (Morrison et al., 1998).

Lack of education specific to advance care planning has not been proven to be a factor in document completion. Nolan and Bruder (1997) found that 59-63% of Americans understand how to issue advance directive documents in their respective states. They also found that 85% of persons felt that the document was a way of obtaining desired treatments and that 67% felt that the document was a way to avoid unwanted treatment (Nolan & Bruder, 1997). These numbers, however, do not correspond to the number of people actually claiming to have these documents.

Up to the present time, no single advance directive document has been able to be created which fulfills all requirements across the 50 states (Sabatino, 2003). This stems from many states restricting the application of advance directives to situations of terminal illness, not allowing severely debilitated, non-terminal patients to be covered by these documents. Advance directives from pregnant patients also may not be honored. Some states combine living will and durable power of attorney for health care documents into a single form while others leave the documents separate. Differences even exist with regard to requirements for validity in which some states find the signatures of two adult witnesses acceptable while others require notarization of the document (American College of Physicians, 1998). Many states also will not recognize the validity of documents created and conforming to another states statute (Sabatino, 2003). In 1993, the National Conference of Commissioners on Uniform State Laws drafted the Uniform Health Care Decisions act recommended uniformity in advance directives across states

and the creation of a single statute in each state that would provide for one comprehensive document. This has yet to be adopted (Gunter-Hunt, Mahoney, & Seiger, 2002). The independent organization, Aging with Dignity, has tried to create a comprehensive document with its *5 Wishes* form but it only conforms to the requirements of 35 states (Sabatino, 2003).

The final factor influential in hindering advance care planning completion stems from personal views. Most people who do not have advance care planning documentation completed state a lack of urgency rather than rejection of the idea as their reason (Miles, Koepp, & Weber, 1996). The few who do oppose advance care planning tend to follow the slippery slope argument. They believe that if society allows removal of life sustaining treatments in the terminally ill, they will eventually allow euthanasia and physician assisted suicide (Pence, 1995).

Without the presence of advance directive documentation, an accepted hierarchy of decision making is in place. Court appointed guardians, if present, are the primary person responsible for medical decision making for a patient if a durable power of attorney for health care has not been completed. Spouses, adult children, parents, adult siblings, close friends and other relatives follow in this order. Decisions made by these persons also follow a hierarchy of understanding what the patient would ultimately have wanted beginning with advance directives and followed by substituted judgment and finally best interest of the patient (Mappes & Degrazia, 2001).

#### *Importance of Research and the Present Study*

The American public values autonomy and independence, the ability to make informed decisions and fulfill their own self-determination. Advance care planning documentation is an extension of this autonomy past the point where a person has lost the capacity to make decisions. Information is available to the public from a number of sources including the health care

establishment and the legal system but little consistency is present across state lines or even across professions. Research into the sources of public information and the attitudes governing the completion of advance care planning documentation will hopefully lead to more appropriate educational efforts and eventually higher document completion rates.

Currently no study has been performed which assesses the attitudes of the residents of Lucas County, Ohio with regard to advance care planning. Sources of advance care planning information and the document completion rates are also unknown for this population. It, therefore, becomes necessary to determine this information so that future community based educational efforts can be tailored to this particular population. The purpose of this study was to assess the attitudes of the residents of Lucas County, Ohio with regard to advance care planning, to determine the comfort level these residents have in discussing their wishes for future health care with their family members and their health care providers and to determine where these residents are receiving their information.

## Method

### *Participants*

The population included in this study consisted of individuals 18 years of age and older who do not receive their mail solely from a P.O. Box. A random sample of 1,000 individuals residing in Lucas County, Ohio was obtained by an independent mailing list provider. The only limiting criterion for participation in this study was age over 18 and residing in Lucas County. Age for this survey was limited to those individuals over 18 due to the fact that advance care planning laws do not pertain to those under the age of 18.

### *Instrument*

Information for this study was gathered through a 26 question survey which was distributed by mail (see Appendix A). This survey contained 10 questions focused on gathering demographic information and 16 questions were used to determine the attitudes about advance care planning held by survey participants.

Survey validity was ensured through evaluation by a group of individuals participating in the Northwest Ohio Coalition for Advance Care Planning who were familiar with Living Will and Durable Power of Attorney for Health Care documentation and the process of completing this documentation. Reliability was ensured by comparing the questions contained in this survey with other public surveys pertaining to advance care planning.

### *Procedure*

Surveys were mailed to a random sample of 1,000 individual residences throughout Lucas County, Ohio during January 2005. Mailings were limited to those 18 years old and older with home mailing addresses. A cover letter (see appendix B) and a postage paid return envelope were included with the survey. Consent for participation was confirmed by individuals

returning the survey and anonymity was ensured through the lack of identifiers on the survey instrument. A reminder postcard (see appendix C) was sent to all participants two weeks following the initial mailing in an effort to increase response rate. Those individuals who were interested in receiving additional information about advance care planning were instructed to contact Barbara Kopp Miller at the Center for Successful Aging at the Medical College of Ohio or to phone the Advance Care Planning Coalition hotline where information was available free of charge.

## Results

### *Demographics*

One hundred thirty-four valid surveys were returned of the 1,000 surveys distributed by mail. Twelve surveys were forwarded, two phone calls were received indicating that the addressee was deceased and a total of 57 surveys were returned undeliverable for various reasons including vacancy, insufficient address and inability to forward. It can therefore be determined that of the 941 potential participants, the response rate was 14.2%.

The information obtained from the first 10 questions of this survey pertained to the demographics of the respondent population. Respondents were 58.2% male and 41.8% female. The average age of the participants was 56.9 years ( $SD=15.3$ ) with the youngest being 19 and the oldest being 92. With regard to marital status, 60.2% were married, single and widowed contained 14.8% of the survey respondents each, and 10.2% of the respondents were divorced. The majority of participants were white (88.7%), with the rest being African American at 10.5% and one respondent choosing not to answer this question. No respondents claimed Asian or Hispanic/Latino as their ethnicity. Eighty-eight percent of respondents were Christian with the rest distributed between Jewish (1.5%), other (1.5%) or no religious preference (9.0%). This notwithstanding, only 43.9% claimed to attend worship services regularly, while 35.1% claimed occasional attendance, 3.0% claimed to attend on holidays only, and 17.4% stated they never attend worship services. Most respondents indicated the highest educational degree obtained was college graduate (34.1%) followed closely by those claiming some college (33.3%). Twenty five percent (25.8%) claimed having a high school diploma or graduate equivalent diploma and just 6.7% stating only some high school as their highest level of education achieved. The majority of respondents were employed fulltime (50.0%), followed closely by those who were

retired (32.6%). The rest were split between part time employment, unemployed, unable to work, student, homemaker and other (5.3%, 3.0%, 4.5%, 0.8%, 1.5%, and 1.5% respectively).

Over one half of participants (51.2%) made less than \$50,000.

#### *Involvement in Decisions for Loved ones*

Part B of this survey, questions 11-15, began by dealing with the respondent's experience with the death of another person. Ninety-three percent (93.3%) of the 134 respondents claimed having experienced the death of a loved one at some point in their life. This withstanding, just less than half (47.7%), were involved in the end of life decision making for this person.

Furthermore, only 26.8% of loved ones had advance care planning documentation with the majority (65.7%) of these loved ones having both a living will and a durable power of attorney for healthcare. Just over 11% (11.4%) had a living will only, and 22.9% only had a durable power of attorney for health care.

#### *End of Life Document Ownership*

Part B, questions 16-18 and 21-22, continued with questions referring to the participants own health, their comfort level with discussions pertaining to end of life topics and their ownership of various end of life documents.

The majority of participants (56.7%) claimed their current health status as "good" and when combined with those rating their health as "excellent", over ¾ of the survey population was included (78.3%). Of the remaining respondents, 19.4% rated their current health status as fair and 2.2% chose poor. When questioned about having close contact with a health care provider with whom they would discuss their health care if they were to become seriously ill, 81.1% of respondents stated they did. Furthermore, greater than eighty-five percent (85.6%) of all participants stated they were comfortable or very comfortable when talking about death.

When questioned about ownership of various end of life documents 67.7% of participants stated having a last will and testament, only 20.8% had a burial plan or had made arrangements with a funeral home, and 41.1% of respondents had an advance care plan. Eighty percent (80.4%) of the 56 participants with an advance care plan had both a durable power of attorney for healthcare and living will. Just 16.1% had a living will alone while only 3.6% had a durable power of attorney alone.

#### *Comparison of Demographics and Completion Rates*

The present study also attempted to determine if significant differences in advance care document completion rates were present among the various demographic groups found in the sample population. Comparisons were made between those over the age of 65 and those less than 65 years of age, males and females, those of different races, those who had achieved various levels of education, those who made less than \$50,000 and those making greater than \$50,000, and between those who were employed as health care providers and those who were not. The completion rate among those over age 65 was 62.8% while 31.5% of those less than 65 years of age had completed advance care planning documentation. This was the only comparison which produced differences that were found to be significant. No significant differences were found when comparisons were made between those of different gender, those with different educational attainment and those from different economic groups. Additionally, there was not enough diversity in the sample population to perform comparisons among those from different racial groups and the number of respondents who were health care providers was too small for valid comparisons to be made.

#### *Sources of Information*

Both parts of question 20 referred to respondents obtaining advance care planning information. Sixty of the 134 participants (44.8%) claimed to have been presented with advance care planning information. Of these 60 respondents, several sources for information about advance care planning were cited. The respondents' attorney was most frequently cited as the source for advance care planning information (45.0%) followed by the respondents' health care provider (28.3%). Table 1 displays a complete account of the numbers of respondents claiming each of the choices as a source for information. Write in responses to question 20 were also permitted by this survey. Sources such as the media (newspaper, magazines or television) and financial planners or life insurance brokers were cited by a very small number of respondents. A total of 10 respondents choose to write in answers to this question with three citing the media as the source while four cited financial planners.

Data was also tabulated regarding those who were most influential in the completion of advance care planning documentation. Of the 56 participants with an advance care plan, their attorney was cited as the most influential person in document completion (57.1%). Second most influential was the spouse (50.0%). Health care providers were only cited by 3 of the 56 respondents as influential in advance care planning completion (5.4%). (Refer to table 2 regarding specific numbers of those who have been most influential in the completion of these documents.)

#### *Attitudes towards Advance Care Planning*

Within the present study, a positive attitude toward advance care planning was determined to be 3 or 4 affirmative answers to 4 separate questions, numbers 19, 21, and two parts of question 23. Question number 19 stated, "Have you ever discussed, with another person, your wishes regarding the treatments you would want to receive at the end of your life?",

question 21 stated, “Do you have an advance care plan?”, and question 23 gave options regarding best way for participants to know that their future health care wishes would be followed in the event that they were no longer able to communicate. The options which were deemed to signify a positive attitude toward advance care planning included “Putting your wishes for you health care into writing” and “Appointing, in writing, a person who knows you well, to execute your health care wishes on your behalf”. Overall, 41.7% of respondents were found to have a positive attitude toward advance care planning and only 11.3% of respondents answered ‘no’ to all 4 questions pertaining to attitude.

More specific results pertaining to question 19 found that 75.6% of respondents had discussed wishes for end of life care with another person and 98.0% of these discussions were found to be helpful. The majority of these discussions were with either family members or spouses. (68.7% and 65.7% respectively). Only 4% of those who claimed to have discussed their end of life wishes with another person stated that this person was their health care provider. (Specific results regarding who these conversations were with are portrayed in table 3).

Three quarters (75.0%) of participants answering question number 23 felt that a previous discussion about their values with regard to health care with their family members was the best way to have future wishes followed. This was followed by 50.8% of participants stating that appointing another person in writing to execute their health care wishes would ensure their wishes were followed. Forty-eight percent (48.4%) of participants believed putting their wishes in writing would ensure their future health care wishes would be followed and just 28.1% believed that previous discussions with their health care provider would ensure that their wishes were followed.

#### *Initiation of Advance Care Planning Discussions*

The remaining three questions in this survey, questions 24-26 pertain to end of life discussion initiation and comfort level with others asking the participants to complete advance care planning documentation. Eighty seven percent (87.0%) of respondents felt it was their own responsibility to initiate discussions regarding the type of end of life care they would like to receive. Health care providers also were cited as those responsible for initiation of end of life care discussions with 28.2% of respondents citing this group of people (Refer to table 4 regarding the other persons whom respondents felt were responsible for initiating these discussions). Write in answers were also permitted for this question with 32 respondents choosing this option. All respondents who choose to write in an option stated various family members as the responsible party with regard to initiation of discussions about end of life care.

The majority of respondents (77.4%) said they would feel comfortable with health care providers asking them to complete an advance care plan, while 71.4% stated they would feel comfortable with an attorney asking them to complete this form of documentation.

#### *Barriers to Advance Care Planning Completion*

The largest barrier to document completion cited by 29 of the 78 respondents (37.3%) was never having been presented with advance care planning information. Twenty-one percent (21.8%) claimed the document was unnecessary and 12.8% felt they were too young to make these decisions. The average age of those claiming they were too young to make these decisions was 37.4 years with a range from 19-57. Only one respondent stated they would never complete this type of documentation, which equated to 1.3% of all participants who did not already have an advance care plan.

An additional option to write in answers related to reasons for not having advance care planning documentation was also given. Twenty-one respondents choose this option. When

tabulating this information it was found that the majority of participants who wrote in responses cited procrastination (12 respondents) as the reason for not having completed these documents. Additionally, it was cited that children or other family members were uncomfortable in discussing these topics and this is the reason these documents have not been completed.

## Discussion

Few things are known regarding the attitudes of Lucas County, Ohio residents regarding advance care planning or where these residents receive their planning information. The purpose of the present study was to assess the attitudes toward advance care planning of the residents of Lucas County, Ohio, to determine if the population in Lucas County, Ohio closely approximates the national population with regard to ownership of these documents, and to determine where these residents receive their advance care planning information. Furthermore, information regarding the comfort level residents of Lucas County, Ohio have in discussing their wishes for end of life care was desired. It was hypothesized that differences would be present with regard to ownership rates and attitudes towards advance care planning among members of different age cohorts and various other demographics.

### *Advance Care Planning Completion*

In a 1996 study cited by Kahana et al. (2004), it was reported that only 15-25% of all Americans had completed the process of advance care planning. The present study found that of the 134 respondents, 41.1% owned an advance care plan including either a durable power of attorney for health care, a living will or both, with an overwhelming majority of participants owning both documents. At first this stark difference may be alarming however the above comparison represents an 8 year difference between the reported statistics and therefore may not be a reliable comparison. More recent national data would be beneficial for accurate comparison.

Kahana et al. (2004), when surveying only those over the age of 65 in one metropolitan community in northeast Ohio, found completion rates within this population to be almost 60% (59.9%). The current study found those over the age of 65 within Lucas County, Ohio having a

similar completion rate at 62.8% within this age cohort. Jacobson et al. (1994) reported from a survey of persons over the age of 18 that those with documents were more likely to be over the age of 51. The median age of those who had completed advance care planning documentation within this study was 57. With regard to those over the age of 65, completion rates were rather similar when compared to more recent data and therefore it can be assumed that the overall completion rates obtained for this study may be similar to the current national averages.

Many hypotheses can be made concerning the higher completion rates among those over the age of 65. First of all, those over 65 tend to suffer from more chronic illnesses than those less than age 65. These same persons may also be experiencing the death of their peers. Many people also begin to plan for other end of life decisions later in life. All of these things may lead to one considering and eventually completing advance care planning information.

#### *Comparison of Demographics and Completion Rates*

Much controversy has been found through various studies conducted over the years regarding the effect education, socioeconomic status, disease severity, marital status and ethnicity has on completion rates. Jacobson et al. (1994) stated that those with advance care plans were more likely to have graduated from high school and have additional years of education. This, however, did not indicate that a higher level of education was needed to understand advance care planning documentation. This point was addressed by Nolan and Brunder in 1997 when they found that even though persons may not have completed advance care planning documentation, 59-63% of Americans understood how to complete these documents in their respective states and understood that these documents were a way to prevent unwanted treatment. Furthermore, Kahana et al. (2004) found in 2003 that higher completion rates were among white and unmarried individuals over the age of 65 but current health was not

a factor in document completion. This went against a 1998 study by Morrison et al. which stated that persons who perceived themselves to be in poor health or those with previous experience with life prolonging technology were more likely to have completed advance care plans. Perkins et al. (1998) found that minority populations within the United States, especially African Americans, Asians, and Hispanics were less likely to have advance care plans.

According to the United States Census bureau results for 2000, 77.5% of individuals residing in Lucas County are Caucasian, 17.0% are African American, and only 1.2% are Asian. The median income in Lucas County was \$30,004, over eighty two percent (82.9%) had a high school diploma and 21.3% had at least a bachelor's degree. The religious preference among the Lucas County, Ohio population was not reported by the census bureau (United States Census Bureau, n.d.). The demographic results for the sample population of returned surveys very closely matched the Lucas County, Ohio population at large with 88.7% of respondents being Caucasian, and 10.5% claiming African American as their ethnicity however as can be seen, little ethnic diversity is present within this community.

The present study attempted to make many of the same comparisons which had been previously performed however due to the small sample size and the lack of diversity within the respondent population few of these comparisons were able to be made. With regard to age however, the present study did find a significant difference in completion rates between those over the age of 65 and those less than age 65, which was consistent with previously reported data. No other differences were noted when gender, educational background, and income level were analyzed with regard to their influence on document completion. Too little ethnic diversity was present in the sample population for comparisons to be made.

Additionally, comparisons were attempted among those who were employed as health care providers and those who were not. Within Lucas County, Ohio 8.8% of residents are employed in the health care field. Within the sample population 12.2% were health care professionals. Though these percentages were similar, the total number of respondents who were employed in the health care field was too small to produce reliable results for comparison.

### *Sources of Information*

Throughout all 50 states, people can receive information about advance care planning from a variety of sources and none of the 50 states require a lawyer to draft this form of documentation. Following the Patient Self Determination Act of 1990, hospitals, nursing homes, medical professionals and legal professionals were supplied with advance care planning information to distribute to their patients and clients. Information was also distributed to all Social Security recipients and as part of the Medicare handbook. Though a 1994 longitudinal study found no change in the knowledge base within the community regarding advance care planning after the PSDA, this study and additional studies completed in 1997 and 2000 found that most people reported the media as the primary source for their advance care planning information (Jacobson et al., 1994; Nolan & Brunder, 1997; Waters, 2000). Less than 10% of individuals surveyed in the 1994 study cited a health care professional as the source of their advance care planning information and a 1999 study found that a significantly larger percentage of patients had completed documentation following discussions with their attorneys than following discussions with health care providers (Jacobson et al., 1994; Mansell, Kazis, Glantz, & Herren, 1999).

The current study found those claiming to have been presented with advance care planning information totaled 44.8%. As stated previously, 41.1% of respondents actually had

completed these documents. It can therefore be assumed that only 3.7% of those who had been given the information did not complete the documents. The most commonly cited source of information was the respondent's attorney followed closely by the health care provider. Interestingly, however, the health care provider was only cited by 5.4% of participants as being influential in document completion. These percentages closely approximate that found in the many studies previously cited. Many individuals see their attorney for the completion of other end of life documents which necessitate the help of a lawyer. Though advance care planning may be done without the help of a lawyer, the completion of other end of life documents may prompt one to complete this form of documentation.

Also determined from the current study was that 87.0% of respondents believed it was their own responsibility to initiate discussions pertaining to end of life decisions. These statistics are rather surprising considering over 90% of patients surveyed by Nolan and Bruder (1997) felt that physicians should be responsible for the initiation of advance care planning discussions.

It remains unclear what the strongest influence has been for ever increasing completion rates of advance care planning documentation throughout the years. Though health care providers can and do play an integral role in end of life decision making, it remains necessary to support and inform legal professionals with regard to these same issues since many individuals look to them for this form of information.

#### *Attitudes towards Advance Care Planning*

No previous study has ever specifically evaluated the population's attitude towards advance care planning though many people have speculated with regard to what keeps people from completing this form of documentation. The primary form of directive still followed today is the oral directive in which family members convey to health care providers what the patient

had stated previously about their wishes for end of life care (Lo, 2000). Though many health care providers follow these directives they do not ensure legal protection for the clinician.

Though only 41.7% of the population could be deemed to have a positive attitude towards advance care planning it is significant that only 11.3% had what may be considered a negative attitude towards advance care planning and only one respondent stated they would never complete this form of documentation. The percentage deemed to have a positive attitude towards advance care planning was very similar to the percentage which already had completed this form of documentation possibly indicating that those whose attitude was more negative would not desire this form of documentation or choose not to complete the survey.

#### *Barriers to Document Completion*

The majority of people who do not have advance care planning documentation completed state a lack of urgency rather than rejection of the idea as their reason (Miles, Koepp, & Weber, 1996). Lack of document completion has also been attributed to lack of public knowledge, fear of the limitations instituted by these documents and the misconception that these documents are unnecessary (Ulrich, 1998). The few who do oppose advance care planning tend to believe that if society allows removal of life sustaining treatment from the terminally ill, they will eventually allow euthanasia and physician assisted suicide (Pence, 1995).

Multiple previous studies have found that minority populations within the United States are less likely to have completed advance care planning documentation. The current study attempted to determine if ethnicity was a barrier to document completion also within Lucas County, Ohio however due to the lack of ethnic diversity within the sample population, this comparison was not able to be made.

Since never having been presented with information was cited as the greatest barrier to advance care planning completion within the present study, it may be concluded that increasing the percentage of individuals who receive advance care planning at an earlier age would greatly increase completion rates. There will always be persons who reject the idea of advance care planning but encouraging the completion of these documents will better ensure that a person's wishes are followed at the end of life.

With only 11.3% of all survey participants found to have a negative attitude towards advance care planning and only 41.1% of respondents having already completed advance care planning documentation, it can be assumed that other barriers to document completion apart from attitude are present in the remaining 48.6% of participants. Though lack of information regarding advance care planning may be cited by a large portion of participants (37.2% of those without this form of documentation), other barriers must still remain which were not able to be extrapolated from the current study.

#### *Public Education Recommendations*

As stated above, increasing the percentage of persons who receive advance care planning information at an early age may increase completion rates. It also becomes important, however, that those who are distributing this information be aware of the differences in laws from one state to the next. Public education efforts, outside the legal or medical establishment, also may further reach those individuals who are not accessed by either of these two institutions. End of life decision making encompasses professionals from various walks of life and only through collaboration among these persons will a greater percentage of persons consider the care they desire at the end of their life.

#### *Practice Recommendations*

Apart from the American College of Physicians Ethics Manual (1995) and the guidelines for Ethical Conduct of Physician Assistants (American Academy of Physician Assistants, 2002) which state a clinician's obligation to undertake advance care planning discussions with patients, these discussions also help clinician's gain a deeper understanding of the values, goals and preference for end of life care that their patients hold (Hammes & Briggs, 2002). Over 85.6% of respondents stated they were comfortable or very comfortable talking about death. Additionally, 77.4% stated they would be comfortable with a physician asking them to complete this form of documentation. Therefore, it can be determined that health care providers who address end of life issues with their patients will affirm the clinician-patient relationship.

End of life care is a sensitive topic well addressed within the trusted relationship between health care providers and patients. The present study found that survey participants overall felt comfortable with these types of discussions and did have a desire to have this topic addressed by their clinicians. It therefore becomes important for clinicians to address end of life issues prior to a time when these documents would be needed since the patient may no longer be able to express their wishes for themselves at that time. For health care providers to be competent and proficient in the discussion of these issues, they, themselves, must be knowledgeable about this topic, and it should be the responsibility of the clinicians themselves to become educated about the laws which pertain to them and their patients.

#### *Limitations to the Present Study*

Various limitations to the current study should be acknowledged. Of the 1000 surveys which were distributed by mail, only a very small number of surveys were actually returned. It is unknown what specifically lead to this low response rate but it should be noted that a high number of surveys were forwarded to other addresses or were returned undeliverable. Also, no

incentive to return surveys was given and this may have further contributed to the poor response rate.

Due to the voluntary nature of the survey, information obtained in this survey only represents those who choose to respond to the questions provided. A further limitation and possible bias present in this study can therefore be attributed to the fact information obtained represents only those who choose to respond.

Demographically, many of the results obtained were similar to those reported by the United States Census Bureau for Lucas County, Ohio. This withstanding, it is still unknown if the sample population was in fact random. Additionally, due to the homogenous nature of the survey population, comparisons with regard to religious preference and ethnicity were not able to be made.

Furthermore, the unique nature of the survey instrument contributed to some of the limitations encountered with this study. Though the survey instrument was reviewed by the Northwest Ohio Coalition for Advance Care Planning to ensure content validity, reliability can not be assured. The survey instrument also assumed literacy within the sample population and this may have eliminated some potential respondents from participating. Additionally, the uniqueness of the survey instrument made it difficult to correlate the current data with previous research in this area.

Though this survey was conducted in an anonymous manner, there is no way to determine, based on the results received, if respondents were in fact expressing their own views or if they were expressing those views which they felt were most socially acceptable. Furthermore, behaviors do not always correlate with attitudes which may invalidate some of the results obtained.

In retrospect, when reviewing survey responses, the wording of some questions may have lead to various interpretations of what was actually meant by the particular question. This may have lead to inconsistency in the data obtained.

#### *Suggestions for Future Research*

Future research in the area of advance care planning would be of great benefit to the population at large. Additional research targeting those responsible for care of sick individuals, those from different ethnic groups or specific to those responsible for educating the population with regard to advance care planning could determine where educational gaps are and help guide future information based programs. This same research could also detect biases among these populations and help to form a more neutral approach to end of life education. Research to determine the effectiveness of these educational programs would also be beneficial.

Additional studies which encompass larger samples of people, extending outside the confines of Lucas County, Ohio would also be helpful to obtain a better understanding of the national attitudes towards advance care planning. Extending the geographic area sampled would also increase the ethnic and religious diversity within the population surveyed.

After completion of the current survey, the recent media attention surrounding Terry Schiavo brought the subject of advance care planning to the forefront of the public mind. Schiavo was a Florida woman who was the subject of debate regarding the removal of the feeding tube that sustained her life for 15 years after suffering irreversible brain damage. Additional research to determine the attitudes within the community following this case would be interesting and may further delineate the impact the media has on public opinion surrounding end of life care and the protection of one's wishes.

## Conclusion

This study revealed that the majority of individuals in Lucas County, Ohio had very positive attitudes towards advance care planning. In the past, positive attitudes towards advance care planning, knowing how to complete these documents or understanding what the purpose of these documents was did not always correlate well with document ownership. This study, however, found that there were similar results between those with a positive attitude and the percentage of respondents who actually had completed this form of documentation.

It is significant to note that only three respondents stated that a health care provider was influential in the completion of their advance care plan. This is contrary to the fact that over 77% of respondents felt they would be comfortable with health care providers asking them to complete this form of documentation. Additionally, most participants stated that previous discussions about their values with regard to health care with family members would be the best way to ensure future wishes were followed. This confirms that most people believe verbal expressions of their wishes are more powerful than written expressions. If health care providers encourage their patient to discuss their wishes for end of life care and include these discussions as a part of routine office visits, they can improve communication between themselves and their patients and further ensure that a patient's wishes are being respected at the end of life.

The current study found that 41.1% of participants had completed advance care planning documentation. Though this percentage is much higher than the 1996 data reported by Kahana et al. (2004), the extrapolations which can be made concerning the similarities within the current sample population and regional demographics can lead one to believe that national averages may be higher than previously reported. This suggests that the nation at large believes these documents are important to ensure one's wishes are followed at the end of life.

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## Appendix A

This survey will assess your attitudes about end of life issues, such as the kind of care you would want and the protection of your decisions if you are no longer able to communicate. We understand that some of these topics may be sensitive but we greatly appreciate your participation in this study. Your responses will remain confidential and may help advance the care provided throughout Northwest Ohio in relation to Advance Care Planning.

Throughout this survey, please refer to these definitions:

**Advance Care Plan-** The completion of written documents (or the documents themselves) which outlines your wishes regarding your future medical care if you become unable to communicate.

**Living Will-** A written document containing choices about specific treatments (cardio-pulmonary resuscitation, machines to help you breath, tubes inserted to provide nutrition if you are no longer able to eat, etc.) you wish to receive or refuse if you are no longer able to make decisions for yourself and your illness is likely to cause death within a short period of time.

**Durable Power of Attorney for Health Care-** A written document allowing you to appoint **another person** to make medical decisions for you if you lose the ability to communicate.

**Part A**

For the following items, please check the response that best corresponds to your answer unless otherwise specified.

1. Gender:  Male  Female
2. Age (fill in): \_\_\_\_\_
3. Are you currently:  Single  Married  Divorced  Widowed
4. Which of these groups best represents your race:  White  Black/African American  
 Hispanic/Latino  Asian  Other (please specify) \_\_\_\_\_
5. What is your religious preference:  Christian  Jewish  Muslim  
 Other (please specify) \_\_\_\_\_  
 No religious reference
6. How often do you attend worship services:  Regularly  Occasionally  
 Holidays only  None
7. What is the highest grade or year of school you completed?
  - Never attended school
  - Grades 1-8 (Elementary)
  - Grades 9-11 (Some high school)
  - Grade 12 or GED (High school graduate)
  - College 1-3 years (Some college or technical school)
  - College 4 years or more (College graduate)

**\*Please turn page over**

8. Are you currently:
- Employed full time
  - Employed part time
  - Unemployed
  - Unable to work
  - Retired
  - A student
  - A homemaker
  - Other (please specify) \_\_\_\_\_

9. What is/was your primary occupation? (fill in) \_\_\_\_\_

10. Is your household income from all sources:

- Less than \$25,000
- \$25,000-\$50,000
- \$50,000-\$75,000
- \$75,000-\$100,000
- \$100,000-\$150,000
- \$150,000-\$200,000
- More than \$200,000
- Don't know

**Part B**

The following items ask questions about end of life care for you or your loved ones. Please place a check next to the appropriate response. Some questions may require more than one answer.

11. Have you ever experience the death of a loved one?  Yes  No

12. Were you involved in the choices for healthcare for this individual during the end of their life?  
 Yes  No

13. Did this loved one have an Advance Care Plan?  Yes  No

If you answered **yes** to question #13, which type of document did your loved one have?

- Living Will  Durable Power of Attorney for Health Care  Both

14. How would you characterize your current heath?

- Excellent  Good  Fair  Poor

15. If you were to become seriously ill, is there a health care provider within your close contacts (family or friends) whom you would consult about your condition?

- Yes  No

16. How comfortable do you feel talking about death?

Very Comfortable     Comfortable     Apprehensive     Not Comfortable

17. Do you have a Last Will and Testament?     Yes     No

18. Do you have a Burial Plan or have you made arrangements with a Funeral Home?

Yes     No

19. Have you ever discussed, with another person, your wishes regarding the treatments you would want to receive at the end of your life?

Yes     No

If you answered **yes** to question #19, who have you discussed your wishes with? (check all that apply)

Spouse/Partner     Other Family Member     Attorney  
 Friend     Health Care Provider     Clergy member/Chaplain  
 Other (Please Specify) \_\_\_\_\_

If you answered **yes** to question #19, how helpful do you feel these conversations were?

Very Helpful     Somewhat Helpful     Not Helpful

20. Have you ever been presented with information about Advance Care Planning?

Yes     No

If you answered **yes** to question #20, who presented you with this information? (check all that apply)

Spouse/Partner     Other Family Member     Attorney  
 Friend     Health Care Provider     Clergy member/Chaplain  
 AARP     Hospice  
 Other (Please Specify) \_\_\_\_\_

21. Do you have an Advance Care Plan?     Yes     No

If you answered **yes** to question #21, which document(s) do you have? (check all that apply)

Living Will     Durable Power of Attorney for Health Care

If you answered **no** to question #21, which of the following most closely describes the reason you do not have an Advance Care Plan at this time? (Check all that apply)

- Never been presented with information/didn't know it was an option
- Document is unnecessary; my family will make decisions about my end of life care
- I am too young to think about/make these decisions at this time
- I would never complete this type of documentation
- Other (Please Specify) \_\_\_\_\_

22. If you have an Advance Care Plan, who has been influential in your completion of these documents? (Check all that apply or skip to #23 if you have not completed an Advance Care Plan)

- Spouse/Partner       Other Family Member       Attorney
- Friend       Health Care Provider       Clergy member/Chaplain
- AARP       Hospice
- Other (Please Specify) \_\_\_\_\_

23. Which of the following would help you to know that your future health care wishes would be followed in the event that you were no longer able to communicate? (Check all that apply)

- Previous discussion about your values with regard to health care with **your physician**
- Previous discussion about your values with regard to health care with **your family**
- Putting your wishes for your health care into writing
- Appointing, in writing, a person who knows you well, to execute your health care wishes on your behalf

24. Who do you feel should be responsible for initiating discussions about end of life care? (check all that apply)

- You       Your health care provider       Your lawyer
- Other (please specify) \_\_\_\_\_

25. Would you feel comfortable with a **Health Care Provider** asking you to complete an Advance Care Plan?

- Yes       No

26. Would you feel comfortable with an **Attorney** asking you to complete an Advance Care Plan?

- Yes       No

Thank you again for completing this survey. If this survey has sparked an interest in learning more about Advance Care Planning, please contact Dr. Barbara Kopp Miller in the Center for Successful Aging at MCO, 419-383-4289 or you may call the Advance Care Planning Coalition hotline at 419-725-0523.

## Appendix B

IRB Number \_\_\_\_\_

Dear Participant,

As a student of the Medical College of Ohio Physician Assistant Program, I am conducting a research study to determine the attitudes of the residents of Lucas County with regard to Advance Care Planning. You were selected to participate in this study as part of a random sample of persons living in Lucas County. Information gathered in this survey is for research purposes only.

The following questionnaire will take approximately 10-15 minutes of your time to complete. Your participation in this study will provide valuable information about the public's attitudes with regard to Advance Care Planning and may help further educational efforts throughout the community.

Your participation in this study is voluntary and anonymous. Should you choose to complete the following survey, your responses will remain confidential. Please do not place your name anywhere on this survey. Participation is acknowledged by your return of the enclosed questionnaire and implies your consent. Please follow the instructions printed above each section of the survey. If you choose not to answer a particular question, please leave the answer space blank.

Please return the completed survey by (date to be determined) in the self-addressed, postage-paid envelope provided. If you would like to receive additional information about Advance Care Planning please contact Barbara Kopp Miller in the Center for Successful Aging at the Medical College of Ohio, (419) 383-4289 or you may call the Advance Care Planning Coalition hotline at (419) 725-0523. Questions concerning this survey or its contents can be directed to Theresa Jones at [thjones@mco.edu](mailto:thjones@mco.edu) or Barbara Kopp Miller at (419) 383-4289.

Thank you for your time and participation in this survey.

Sincerely,

Theresa M. Jones PA-S  
Co-Investigator

Barbara Kopp Miller, Ph.D.  
Principal Investigator and Research Advisor

## Appendix C

Dear Survey Participant,

Approximately two weeks ago you should have received in the mail a survey regarding Advance Care Planning. This card is sent to you as a reminder that if you would like to participate in this study, the completed survey must be returned in the self-addressed, postage-paid envelope provided by (date to be determined). Your contribution to this study will be greatly appreciated and will help us to understand the attitudes within the community regarding Advance Care Planning. If you have already completed and returned the survey, thank you for your time. Questions regarding this survey can be directed to Theresa Jones at [thjones@mco.edu](mailto:thjones@mco.edu) or Barbara Kopp Miller at (419) 383-4289.

Thank you, again, for your participation.

Theresa Jones PA-S  
Co-Investigator

Barbara Kopp Miller, Ph. D.  
Research Advisor

Table 1. Sources of advance care planning information as cited by respondents

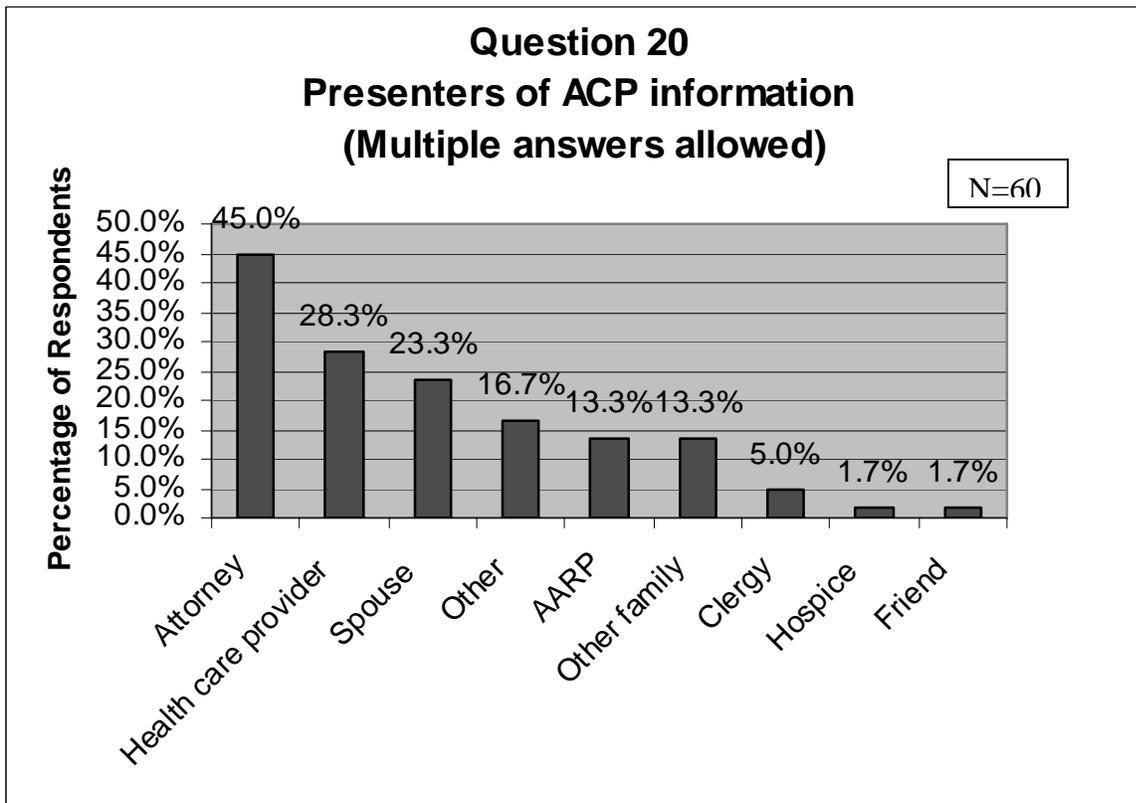


Table 2. Persons influential in respondents' completion of advance care planning documentation

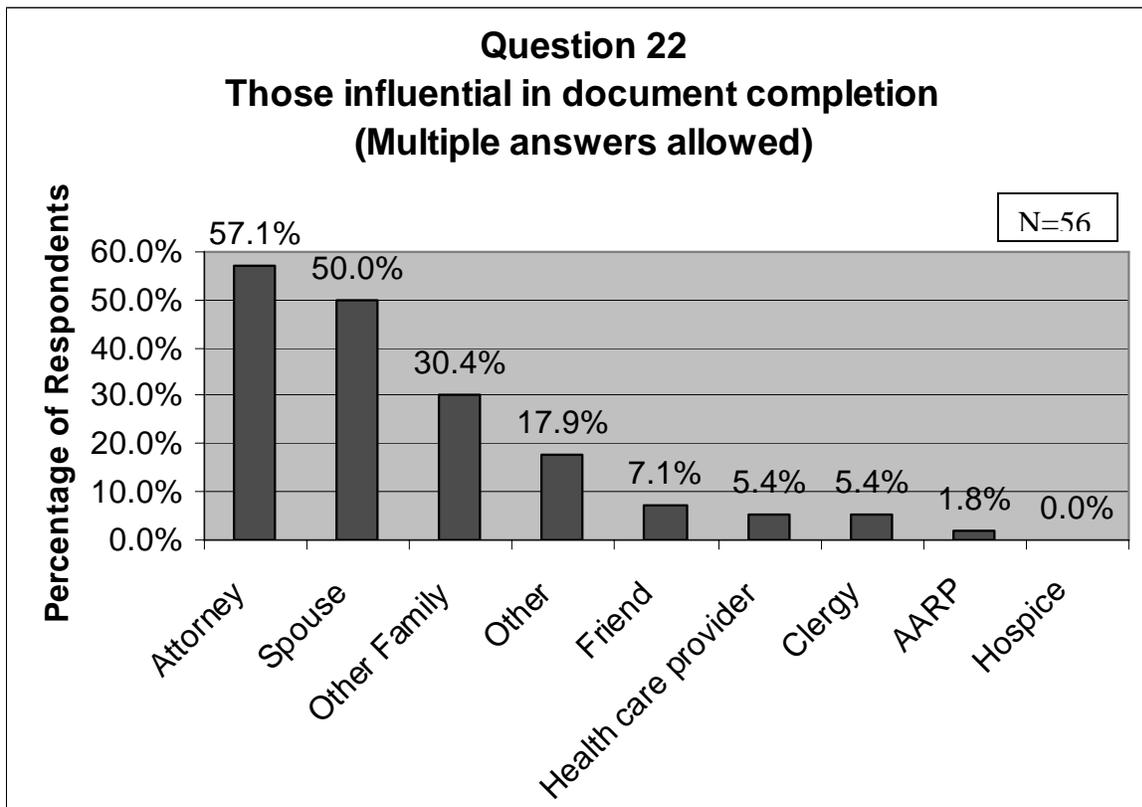


Table 3. Persons whom respondents had chosen to discuss their future health care desires with

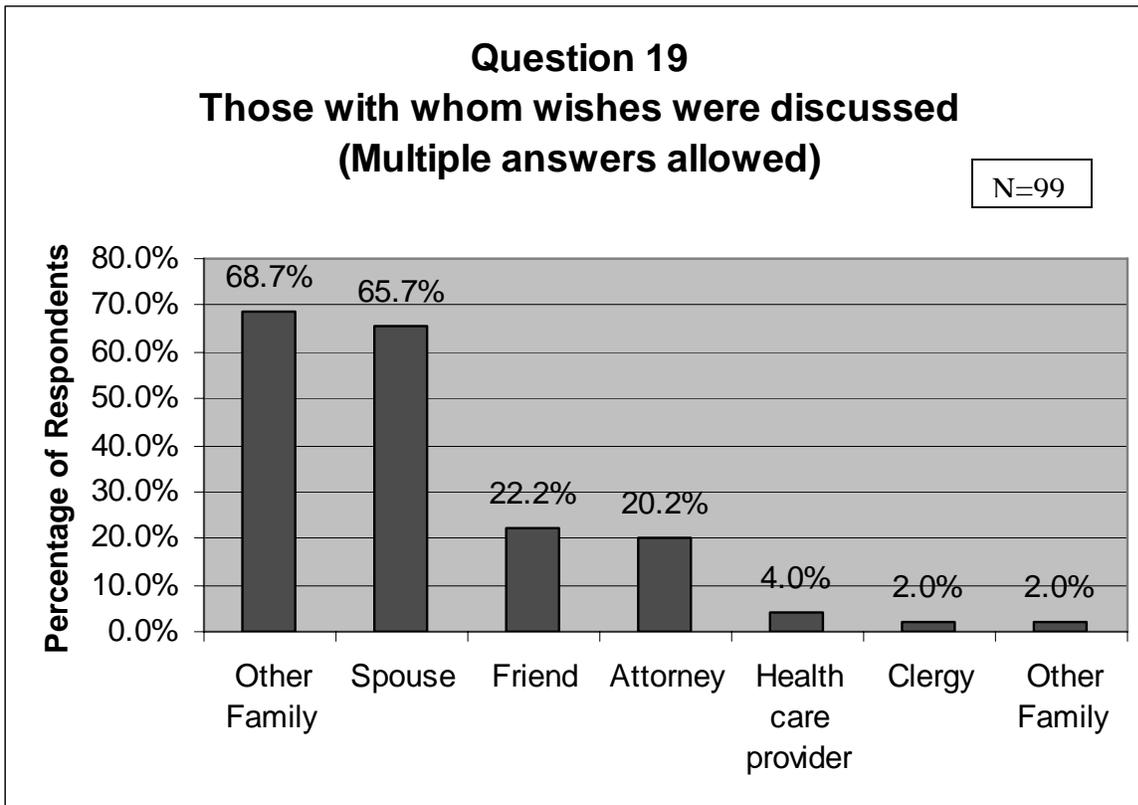
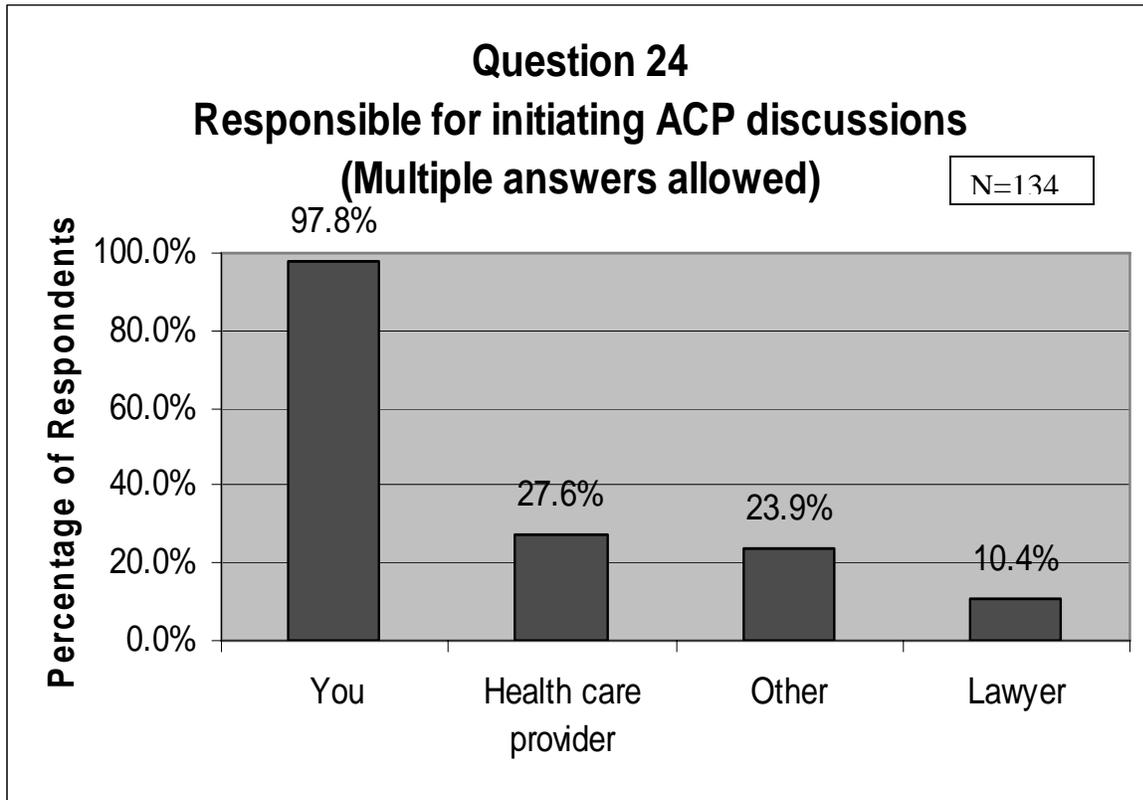


Table 4. Persons whom respondents feel are responsible for initiating ACP discussions



## Abstract

**Objective:** Residents of Lucas County, Ohio were surveyed to determine their attitudes toward advance care planning (ACP). Sources of information and the role of health care providers (HCP) were also explored.

**Methods:** One thousand participants were randomly selected from Lucas County, Ohio. Surveys, specific to this study, were distributed by mail.

**Results:** Fourteen percent of surveys were returned. Overall, 44.8% of respondents had received ACP information, 41.1% had completed ACP and 41.7% had a positive attitude toward ACP. Attorneys were the primary influence in document completion and primary source of information. HCP were a source of information but were not influential in completion. Over 70% would feel comfortable with either HCP or attorneys discussing ACP.

**Conclusion:** Overall, respondents had a positive attitude towards ACP. Both attorneys and HCP were an important part of this process. Future public education should be focused on increasing the percentage of persons who receive information.