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# The Effectiveness of Video and Other Electronic Media on DNR/DNI Decisions within Advance Care Planning

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The Effectiveness of Video and Other Electronic Media on DNR/DNI Decisions within Advance

Care Planning

By

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Of the Requirements for the Degree

Of Masters of Science

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**Abstract:**

Advance Care Planning is used to ensure patients' wishes and preferences for treatment are in line with their medical situation. Its use has increased over the past years, but it has been implemented in a piece wise and unorganized fashion. Changes in provider billing capabilities and a recent consensus definition and implementation strategies of Advance Care Planning have created an opportunity to research and explore best use practices. A key feature of Advance Care Planning is creating autonomy for patients' decisions. Autonomy is especially important for the use of cardiopulmonary resuscitation (CPR) in the event of a medical crisis.

Research has shown that using videos to describe disease states or medical procedures has a positive effect on patient knowledge and has a demonstrable effect on patient care preferences. A literature review of recent studies using videos to depict and describe CPR has shown similar results. The future of using videos to aid in advance care planning will need to be incorporated with provider facilitated discussions and the use of out-of-clinic multimedia and internet based learning tools. Standardized charting and electronic medical record management will also need to be utilized to adapt to changing patient needs and ensure patient preferences are respected as patients transition from primary care to acute care settings. In addition, large scale studies using standardized video tools in diverse populations will aid in developing best practices.

**Introduction:**

End-of-life care decisions often occur during times of serious illness or medical crisis, and therefore, decisions need to be made by the patient and family members or care givers in times of great stress. To address these realities, care providers have been implementing Advance Care Planning (ACP) for years. ACP is understandably a complex topic, incorporating numerous medical scenarios with patient wishes and provider ability. The consensus definition of ACP as only recently been established by a multidisciplinary Delphi panel in 2016:

A process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care... to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness... this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her decisions.<sup>1</sup>

This lack of definition has led to years of inefficient use and suboptimal implementation, but there is ample opportunity to develop effective strategies to improve patient care and utilization of medical resources.

Within ACP there are various documents and definitions related to end-of-life planning. A Living Will or Advance Directive is a legal document, not a medical order, and it provides information about which treatments a patient prefers. It may also designate a legal representative often called a, “surrogate” or “medical proxy” who can provide general guidance, but since it is not an official medical order, in emergency or critical situations providers are not obligated to follow those instructions. Often, an Advance Directive establishes a Power of Attorney, generally a spouse, child, or close friend. If the patient is incapacitated and unable to make his or her own medical decisions, this person will have legal authority to make medical decisions on their behalf. Medical treatments can be officially documented as medical orders in a Physician

Orders for Life-Sustaining Treatment (POLST) form, a document generally reserved for patients with terminal illness or nearing the end-of-life. It does not name a surrogate, medical proxy, or establish a Power of Attorney, but it does document specific treatments to be used or not used. POLST is often used in conjunction with an Advanced Directive to guide treatment by providers if a patient is unable to make decisions. Unfortunately, POLST forms can vary state to state, illustrating one for the major challenges of ACP: portability, getting the patient's wishes documented and transferred to providers for any care the patient may need.<sup>2</sup>

A major part of ACP is a medical order for DNR/DNI status. A DNR or "Do Not Resuscitate" order means that no cardiopulmonary resuscitation (CPR) will be performed if a patient has a cardiac arrest. CPR is standardized set of procedures to preserve oxygenation and the perfusion tissues need to survive, including chest compressions, medications to improve blood pressure or contractibility of the heart, or devices to give electrical shocks to the heart to induce a proper heart rhythm. A DNI or "Do Not Intubate" order means that CPR will be performed, but no breathing tube will be placed to ensure oxygen delivery to the lungs.<sup>3</sup> CPR can be physically and emotionally traumatic to patients, family members, and care providers, and it is important that patients are aware of the risks, benefits, and possible complications of CPR to make informed choices for their care.

Another goal of ACP is to improve patient autonomy: understanding medical procedures, complications, and treatments for whatever situation patients are in, to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illnesses.<sup>1</sup> One major advancement in improving patient autonomy is that ACP discussions are now billable services. Effective January 1, 2016, physicians and non-physician practitioners can bill ACP services to Medicare as part of an Annual Wellness Visits, Evaluation

and Management, Transition Care Management, Chronic Care Management, or separately as a Part B service. ACP is also now billable to private insurance companies, but specific coverage varies among companies.<sup>2,4</sup> This new policy creates financial incentives for providers to have ACP discussions with patients on an on-going basis. It is meant to be a continual discussion, not a one-time decision, so that patients' understanding can adjust to their changing medical conditions, needs for treatment, expectations, and life goals.<sup>2</sup> ACP discussions throughout the continuum of care helps support patients at any stage of health or illness by involving the patient, providers, and patient-trusted individuals in the decision-making process. Furthermore, this demonstrates that policy makers are paying attention to the benefits of ACP and value-aligned care.

A systematic review by Brinkman-Stoppelenberg et. al, investigated the effects of ACP on end-of-life care. Their investigation of experimental and observational studies published in 2000-2012 found an overall positive benefit: use of ACP increased the likelihood that patients' wishes were known and respected at end of life. ACP also positively impacted quality of end-of-life care for patients by decreasing life-sustaining treatments and hospitalizations, and it increased the use of hospice and palliative care services. Caregivers and family members also benefited by ACP, suffering less regret during bereavement. The utilization of DNR orders reduced the use of cardiopulmonary support measures, other invasive medical procedure, and hospitalizations, and increase utilization of hospice care. However, only two studies investigated found an association between DNR orders and quality of care: one had an increased quality of life, while the other was associated with a lower quality of care, making it difficult to discern any meaningful conclusions.<sup>5</sup>

While providers now have a financial incentive to implement ACP into the care of their patients, strategies and tools for ACP utilization vary. Although Brinkman-Stoppelenberg et. al demonstrated the effectiveness of ACP, a systematic review of randomized control trials (RCT) involving ACP discussions with patients, families, and healthcare providers by Weathers et. al, found that there is a lack of RCTs in general and specifically, no high-quality studies on the effects of ACP interventions in older populations.<sup>6</sup> Providers can help facilitate ACP discussions using decision aids such as websites, pamphlets, and videos. Jain et. al, found that decision aids in general can increase patient knowledge of treatment options and outcomes, and can also increase participation and autonomy in decision making. Videos specifically, “may assist with ACP because they can dynamically depict diminishing health states and the nature of different treatment options, and may help individuals to become more informed and confident about their preferences for care at end of life.”<sup>7</sup> The conclusions of these investigators demonstrate the effectiveness of ACP, but implementation and development of best practices need more evaluation and study.

One aspect of ACP to focus on involves CPR education and determination of DNR/DNI status. Epstein et. al, performed a survey on two groups of gastrointestinal cancer patients after receiving information about CPR. One group viewed a video depicting CPR, the other listened to a verbal description of CPR. They found several consistent themes between the two groups:

- ACP should be done early in life.
- Participants were apprehensive about ACP, but wanted to discuss it.
- There were gaps in ACP knowledge.
- CPR information was helpful and appropriate.
- Physicians should be involved in ACP.



- Participants had additional medical questions about critical illness.<sup>8</sup>

This study did not produce any data comparing the knowledge gained about CPR, the utilization of ACP or DNR/DNI status, or the care that participants ultimately received, but it demonstrated the importance and appropriateness of CPR education as an initiator of ACP discussions.

Due to the technology and skills available today, the ability to produce and present videos depicting care options during ACP discussions has never been more possible, but there is a definite need to determine best practices and proper implementation to improve the care provided to patients in terminal or critical situations. The purpose of this paper is to evaluate and analyze the effectiveness of CPR videos in ACP discussions, patient understanding and autonomy, and the utilization of DNR/DNI status.

### **Background:**

Healthcare providers, patients, and family members agree that shared decision making and communication is vital for quality care in serious illness. Decreased patient autonomy because of poor communication, however, often results in care inconsistent with patients' needs or preferences. Utilizing interventions for ACP, either self-directed or facilitated by professionals, are important in increasing communication and shared decision making between patient and provider. Austin et. al, building on the research of Brinkman-Stoppelenberg et. al and Jain et. al, studied and analyzed communication tools, including print, video, or web-based decision tools designed to be used by patients or caregivers without the immediate support of clinicians. The tools they evaluated met the International Patient Decision Aid Standards Collaboration definition: "...tools that present treatment options in a balanced and evidence-based manner."<sup>9</sup> They determined that video or online tools effectively increased patient

understanding of treatment choices and ACP goals for a variety of medical conditions including cancer, cystic fibrosis, and dementia, and increased adoption of comfort care in terminal illnesses. Therefore, patients demonstrated more autonomy by having greater understanding, satisfaction, and ease of decision making.<sup>9</sup>

The importance and effectiveness of ACP is demonstrated in two RCT's which facilitated discussions about ACP. The first was an Australian study of elderly inpatients, by Detering et al, which used a trained facilitator (nurse or allied health worker) to discuss ACP via the Respecting Patient Choice Model, a collaborative model with the patient, family, physician, and facilitator discussing healthcare values, identifying surrogates, and documenting preference for life sustaining treatments and CPR. ACP was delivered to 81% of the intervention group compared to 0.6% of the control group ( $p < 0.001$ ). The ACP form was only completed by 70%, or 108 patients, of the intervention group. Of those 108, 82% made decision regarding CPR; 53 of those making a CPR decision chose to refuse it.<sup>10</sup>

There was a 6-month follow-up in which data was collected on patients who, 29 from the intervention group and 27 from the control, to determine if their wishes were known and/or followed. For the intervention group, the patient wishes were known and followed at death for 86% compared to 8% of the control,  $p < 0.001$ . The control group had a significantly higher rate of having their wishes unknown at death compared to the intervention group, 63% v. 10%, respectively. Also, the family of the intervention group was more satisfied with quality of death from their own perspective compare to the control, 83% v. 48%, respectively ( $p = 0.02$ ), from the perceived perspective of patient, 86% v. 37% ( $p < 0.001$ ).<sup>10</sup>

The second study was performed at Bridgeport Hospital and Yale University School of Medicine, an intervention group received a scripted description detailing information about CPR,

mechanical ventilation, and Advanced Directives from a physician upon admission to the hospital. Both control and intervention groups had similar rates of having an Advance Directive completed prior to admission, but 12.7% of the intervention group compared to 0.8% of the control completed an Advance Directive after the intervention ( $p < 0.001$ ). Patients' documented DNR/DNI status was also similar between groups prior to admission. After receiving the intervention, 92% clarified their DNR/DNI status, and by discharge 87.3% of the undocumented intervention group had their DNR/DNI status documented compared to 6.0% of the undocumented control group.<sup>11</sup>

Additional studies have shown that the general population lacks knowledge or misunderstands CPR. Results from a survey of inpatients performed by Wee et. al, indicated that many patients lacked an accurate understanding of the components and measures used in CPR and resuscitation. 80.4% of patients correctly identified the goals of CPR, but 64.7% were unaware of the complications of CPR, and the majority overestimated the success rate of CPR.<sup>12</sup> Sharma et. al, found that 58% of medical inpatient participants had an acceptable amount of understanding of all elements of CPR, but 91% overestimated its success.<sup>13</sup> Another study of medical inpatients by Levinson et. al, found similar results and concluded that although participants had some understanding of terms related to CPR, patients did not understand the possible outcomes of CPR, and there was minimal understanding of how, when, and why CPR is performed.<sup>14</sup>

Many patients fail to understand that CPR can be a potentially traumatic event for the those surviving a cardiac arrest. Chest compression can break ribs and cause internal injuries to lungs and liver, or air can improperly get into the stomach, causing distention, vomiting, and aspiration of stomach contents potentially leading to pneumonia.<sup>15</sup> Researchers have determined

that the prominent sources of misinformation were television and print media. Popular medical-based TV shows like *Grey's Anatomy* and *House* portray CPR outcomes more positively than what occurs in reality; the immediate survival rate in the shows was nearly twice that of actual survival rates.<sup>16</sup> Retrospective studies found the survivability rate for people receiving CPR after a cardiac arrest in an in-hospital setting was 21%,<sup>17</sup> and people receiving CPR in an out-of-hospital setting showed an overall one-month survival rate of 36.8%, with 21.8% having favorable neurological outcomes.<sup>18</sup>

In a 2004 study, Thorevska et. al, studied hospital patient understanding of CPR in the context of Advance Directives, finding results similar to and mirroring some of the conclusions from previously mentioned studies.<sup>8,11,12</sup> Patients with living wills had a poor understanding of the significance of their Advanced Directive and the details of life-sustaining therapies. They were successfully able to identify some details of CPR, but only 19% understood the complications or prognosis if CPR was performed, and only 37% had accurate documentation of their DNR/DNI status. For those without living wills, a significant number of patients were found to have end-of-life wishes and were open to the idea of creating Advance Directives, but most patients did not include their physician in creating them.<sup>19</sup>

Not only is there a demonstrable need to improve education of CPR and DNR/DNI status in patient ACP, but studies have also shown the preferences for care and DNR/DNI status can change for patients depending on their medical situation. An analysis of preferences for resuscitation and intubation in patients with DNR/DNI orders by Jesus et. al, determined that 60% of patients had conflicts between DNR/DNI documentation and preferences when patients were presented with hypothetical scenarios of critical conditions.<sup>20</sup> In a study of older adults admitted to an acute medical service in New Zealand, Sharma et. al noted changes for CPR

preferences in different hypothetical medical scenarios. Overall, 58% of participants wished to have CPR with their current health status, but this declined depending on the scenario: 46% for a critical illness, 17% for a functional impairment, and 13% for a terminal illness or dementia.<sup>13</sup>

A two-year longitudinal study investigating life-sustaining treatment preferences in older adults followed 88 elderly patients before hospitalization, during recovery, and after hospitalization. Preferences for nine different hypothetical medical situations, and what interventions they would want, were documented via the Life-Support Preferences Questionnaire (LSPQ). Statistical analysis of the three surveyed time periods showed a decreased desire for CPR immediately following hospitalization, but returning to near pre-hospitalization levels after one year, while people not wanting CPR during pre-hospitalization survey stayed consistent throughout study. Researchers called this the “hospitalization dip.”<sup>21</sup>

Videos, like other tools discussed above, have been studied to determine their effectiveness in a variety of contexts and medical situations. A 2014 study by Toraya evaluated the use of a 12-minute video describing Advance Directive forms and the importance of Advance Directive discussions with a pre- and post-viewing survey. She found that the video increased understanding and the intent to fill out an Advance Directive form. Pre-video results: 44.4% had completed Advance Directive forms, 66.7% had discussed Advance Directive wishes with family, and 28.9% had discussed with primary care provider. Post-Video results: 78.6% planned to complete an Advance Directive, and 97.6% felt they had enough information to start discussing Advance Directives with family and/or healthcare providers.<sup>22</sup>

A two-year study implemented in Hilo, HI by Volandes et. al investigated the effects of an education program, Video Images of Disease for Ethical Outcomes (VIDEO), which provided videos for patients via a mobile app and website. Providers were trained in using the VIDEO

program, but were not required to use it, with the goal of facilitating discussions, understanding and utilization of ACP via these videos. After implementation, hospital documentation of ACP for inpatients in the late stages of disease increased from 3.2% to 39.9% ( $p < 0.001$ ). Primary care patients in Hilo had higher ACP documentation compared to the general population of Hawaii, 37.0% v. 25.6%, respectively. From 2012 to 2014, hospice admissions also grew at faster rates: for Hilo, 50.7%, rest of Hawaii, 34.5%, and nationally, 18.7% ( $p < 0.01$ ).<sup>23</sup>

Volandes et. al also studied how video-support tools affected ACP utilization in two different populations of dementia patients in geriatric primary care clinics in Boston and rural Louisiana. The studies assessed and compared dementia knowledge, health literacy, and preferences of care after randomized groups received verbal descriptions of dementia or verbal descriptions followed by video depictions of dementia. Care preference were defined as:

- Prolonged, utilizing CPR, hospitalization or ICU admission.
- Limited, utilizing hospitalization, IV fluids and antibiotic medications, but no CPR or ICU admission.
- Comfort, utilizing oxygen, pain medication, and hospitalization for administration of pain medications only.

In Boston, the video group had a higher mean knowledge score (0-5) versus the verbal group, 4.5 v. 3.8 ( $p < 0.001$ ) and more stable responses at a 6-week post survey. Preferences of care were also different between the verbal and video groups, Prolonged was 14% v. 4%, Limited was 19% v. 9%, and Comfort was 64% v. 86%, respectively ( $p = 0.003$ ). Participants in rural Louisiana had similar results for preferences of care. Between the verbal and video groups Prolonged was 16% v. 0%, Limited was 12% v. 9%, and Comfort was 72% v. 91%, respectively ( $p = 0.047$ ). In both studies, participants with higher health literacy chose comfort care.<sup>24,25</sup>

A separate study in Boston by Deep et. al examined the effects video decision aids have on dementia patients by analyzing results of a survey given before and after watching a video depicting a person with dementia. Participants were surveyed for preferences of care as described previously and then the rationale of their choice. After viewing the video, no participant chose a more aggressive treatment, switching to either Limited or Comfort care. The most common rationales for choosing Comfort were to reduce suffering, decrease the burden to families, or because they didn't believe they would have an adequate quality of life.<sup>26</sup>

Three studies for advanced or poor-prognosis cancer patients researched the effects on patient preferences of care and knowledge. In a 2012 study by Volandes et. al, participants were given verbal description of three levels of care: life-prolonging (including CPR and intubation), basic care (hospitalization without CPR), or comfort care (symptom relief), then watched a 6-minute video depicting the three levels of care. Survey results found no statistically significant changes in preference of care, but mean knowledge scores on a scale of 0-6, improved by 1.6, SD 0.95, ( $p < 0.001$ ) after viewing the video. However, when specifically asked about CPR or intubation in pre- and post-video viewing questionnaires, 61% v. 71% did not want CPR ( $p = 0.03$ ), and 67% v. 79% did not want ventilation ( $p = 0.008$ ), respectively.<sup>27</sup>

A study of similar patients by El-Jawahri et al in 2009 did find statistically significant results for preferences of care. Participants who heard verbal descriptions compared to those who watched a video chose life-prolonging care, 29.5% v. 0%, basic care, 51.9% v. 4.4%, and comfort care, 22.2% v. 91.3%, respectively ( $p < 0.0001$ ). Video watching participants were also found to be more confident with their choices and more likely to prefer no CPR when specifically asked.<sup>28</sup>

Another study by Volandes et. al in 2012, compared two groups, verbal and video. The verbal group was given a verbal description of CPR and the likelihood of successful resuscitation. The video group was given the same verbal description of CPR and likelihood of success, followed by a 3-minute video depicting CPR. Video viewers were more likely to prefer no CPR and be more knowledgeable of CPR. 48% v. 20% wanted CPR, and 51% v. 79% did not want CPR, for the verbal and video groups, respectively (unadjusted OR 3.5, 95%CI, 1.7-7.2;  $p < 0.001$ ). Compared to the verbal group, the video group had higher levels of knowledge on a scale of 0-4 with 4 being highest,  $3.3 \pm 1.0$  v.  $2.6 \pm 1.3$  ( $p < 0.001$ ). Also, the mean increase of knowledge from baseline was greater for the video group, 1.3 (95% CI, 1.0-1.6), compared to the verbal one, 0.6 (95% CI, 0.3-0.8).<sup>29</sup>

Several studies have attempted to track changes to ACP documentation in conjunction with changes in preferences and knowledge. Epstein et. al, studied CPR knowledge, CPR preferences, and ACP documentation in pancreas and hepatobiliary cancer patients. Knowledge was tested before as a baseline, and then after the intervention of verbal descriptions of CPR versus a video depiction. Following the intervention, medical records were analyzed every month to track changes of ACP documentation. At one month, there were nearly statistically different changes in ACP documentation or discussion (40% v. 15%; OR=3.6 95% CI: 0.9-18.0,  $p = 0.07$ ) for verbal and video groups, respectively. Knowledge increased for both groups, but there was no statistically significant difference between them. For CPR preferences, only the video group showed significant differences after intervention, 24% no longer wanted CPR and 0% became interested in CPR ( $\chi^2 = 5.1$ ,  $p = 0.023$ ).<sup>30</sup>

In 2016, El-Jawahri et. al studied video decision-support tools effect on care preferences, knowledge, and ACP discussion documentation. Intervention participants received verbal and



video descriptions for CPR and intubation and goals of care (life-prolonging care, limited care, and comfort care) plus an ACP checklist. Control subjects received only the verbal description. Comparing the verbal description versus the video intervention, people were more likely to forgo CPR 35% v. 68% ( $p < 0.001$ ), intubation 48% v. 77% ( $p < 0.001$ ), decrease preference for prolonged care 41% v. 22% ( $p < 0.001$ ), increased preference for comfort care 30% v. 51% ( $p < 0.001$ ), and had higher mean knowledge 3.0 v. 4.1 ( $p < 0.001$ ), respectively. Both groups had an increase in documented ACP discussions with providers, but the video-intervention group was greater at one month 6% v. 40% ( $p < 0.001$ ), and three months 15% v. 61% ( $p < 0.001$ ).<sup>31</sup>

A similar designed study of patients of skilled nursing facilities by Volandes et. al, evaluated care preferences and ACP documentation. Intervention participants received a verbal and video descriptions for goals of care options, life-prolonging care, limited care, or comfort care. Control subjects received only the verbal description. Medical charts were reviewed after goals of care descriptions to determine ACP documentation. Care preferences for verbal versus video were as follows: life-prolonging 33% v. 12%, limited 8% v. 8%, comfort, 57% v. 80%, and uncertain, 2% v. 0%. Participants who viewed the video were associated with greater likelihood of opting for comfort (unadjusted rate ratio, 1.4; 95% CI, 1.1–1.9,  $p = 0.02$ ). Among subjects in the verbal group who chose comfort, 29% had a DNR order (j statistic 0.18; 95% CI–0.02 to 0.37). 33% of subjects (not statistically significant) in the video group choosing comfort had a DNR order (j statistic 0.06; 95% CI–0.09 to 0.22).<sup>32</sup>

A 2015 study by El-Jawahri et. al, introduced physician interaction to the study of patients viewing videos depicting CPR and intubation. Baseline questionnaires on DNR/DNI status preferences were obtained from patients with advanced illnesses. The intervention group watched a 3-minute video depicting CPR and mechanical ventilation and completed a post-video

care-preference questionnaire and knowledge assessment. Researchers reported patients' preferences to their physician, and asked the physician to confirm the code status with the patient. The control group were given a care preference questionnaire and knowledge assessment. Admitting physicians for control patients were encouraged to discuss CPR and intubation preferences by the researchers, but were not specifically told the patients' preferences.<sup>33</sup>

Researchers found the intervention group had higher mean knowledge scores after viewing the video compared to the control participants ( $4.11 \pm 1.13$  v.  $2.45 \pm 1.00$ ,  $p < 0.0001$ ) and was more likely to not want CPR 64% v. 32%, ( $p < 0.0001$ ) and intubation (72% v. 43%,  $p < 0.0001$ ) versus the control group. There was no statistically significant difference of DNR orders at admission, but at discharge, orders were significantly higher for the intervention versus control group, DNR (57% v. 19%,  $p < 0.0001$ ) and DNI (81% v. 43%,  $p < 0.0001$ ), respectively. Discussions with medical providers about CPR and intubation were not statistically different at admission, but increased for the intervention versus control groups by discharge 81% v. 43%, ( $p < 0.0001$ ). Readmission follow up within one year found the intervention group compared to the control were more likely to have DNR orders (49 % v. 13 %,  $p < 0.0001$ ) and DNI orders (53 % v. 13 %,  $p < 0.0001$ ), respectively.<sup>33</sup>

## **Methods:**

For this literature review and analysis of randomized control trials, the following databases were searched from May 15, 2017 to June 30, 2017: PubMed (2007-2017), CINAHL (2009-2017), Johanna Briggs Institute EBP database (2007-2017), Ovid Table of Contents and Abstracts (2007-2017). The following terms were searched in those databases: CPR,

cardiopulmonary resuscitation, video, DVD, media, advanced care planning, POLST, outcomes, adverse effects, in-hospital, and understanding.

### **Discussion:**

Adoption of an agreed-upon definition of ACP is key for implementation and analyzing best practices for ACP and patient autonomy. Before the Delphi panel meeting in 2016, no unifying definition of ACP existed across the medical, legal, or policy literature, and even ACP experts disagreed on not only a formal definition, but also the purpose, goals and key components of ACP. Once having an agreed definition, the panel developed strategy frameworks to optimally support adult ACP:

- Bring together patients, trusted individuals and healthcare providers to make informed choices on treatment.
- Determine the amount of understanding a patient wants to have about condition or care.
- Establish goals of care based on current condition, provider ability, local healthcare laws, and patient understanding.
- Revisit ACP regularly to adjust to changing health conditions and prognosis.
- Identify a trusted person to make medical decisions on patient's behalf.
- Record and document patient goals and choices after each discussion in a way that is easily accessible and updateable.<sup>1</sup>

Patient education for ACP is key for autonomy, but is limited by poor communication between providers and patients. Fortunately there are a variety of tools, including, but not limited to, healthcare-provider facilitated discussions, pamphlets, books, websites, and videos, which are effective in increasing patient knowledge and confidence in decision making.<sup>9</sup> Analysis of

current literature demonstrated the effectiveness of video in ACP discussions, but the studies overall were limited and left ample opportunities for future research, which could help address the five key ACP strategies determined by the Delphi panel.

Viewing of education videos describing disease states has shown to affect utilization of ACP. The video depiction of dementia studies did not investigate outcomes in terms of actual changes to ACP documentation, or actual discussions with care providers about their specific ACP wishes, but they did demonstrate that video is an appropriate tool that can increase health literacy and understanding for dementia patients and had effects on preferences of care and utilization of CPR in ACP.<sup>24-26</sup> It can be deduced that viewing videos depicting other disease states or medical procedures such as CPR will increase patient knowledge and autonomy.

There is a general lack of accurate CPR knowledge and overestimations of its success,<sup>12-15,19</sup> which results in decreased patient autonomy and effective decision making. Studies of video-education tools for specific medical interventions including CPR, in a variety of different patient populations, has also influenced ACP utilization, knowledge, and DNR/DNI status. Watching CPR videos increases knowledge and understanding,<sup>27-31,33</sup> and changes preferences of care for poor prognosis conditions. These videos also increased the adoption DNR/DNI status and the choice for comfort care.<sup>27-33</sup> Selecting less aggressive treatment options such as, comfort care, palliative medicine, or hospice, increases patient satisfaction at death, decreases negative psychological effects of bereavement for families, and are the most cost effective.<sup>34,35</sup>

CPR video tools are only one part of implementing ACP more effectively so that patient wishes for treatment are documented and fulfilled. Creating a trusting relationship and improving interactions between the patients and healthcare providers will help. Evidence shows that healthcare-provider prompting increases ACP documentation; patients want to talk about it,

but are reticent to initiate conversations.<sup>8</sup> If prompted or engaged by medical professionals, patients are receptive to conversations about DNR/DNI, ACP, and CPR. These interventions have a significant positive effect on the adoption and utilization of ACP, increasing autonomy and informed consent for CPR and mechanical ventilation.<sup>10,11</sup>

While translating preferences to actual documentation is a key of ACP, the research of CPR video tools showed mixed results. Three did not evaluate changes to documentation or evaluation of appropriate care based on preferences.<sup>27-29</sup> One study did not find statistically significant changes to documentation after its intervention,<sup>30</sup> while another showed an increase in documented ACP discussions at one and three months post intervention.<sup>31</sup> El-Jawahri et. al.'s 2015 study found that increased levels of discussions and DNR/DNI documentation at hospital discharge were maintained at readmission within a year. Their study had a unique design where physicians were prompted by researchers to confirm the patient's DNR/DNI status after the patient watched the CPR video, which could show that conversations led by physicians or healthcare providers play a pivotal role in increasing and facilitating DNR/DNI status discussions and documentation.<sup>33</sup> Furthermore, The Respecting Choice Model, using facilitated discussions, was effective in maintaining patient wishes at the time of death.<sup>10</sup>

The most promising study was the trial implementation of the VIDEO Program in Hilo, HI. This study combined video-education support tools and facilitation by healthcare provider over two years. It did not directly study changes in patient knowledge, but did show significant increases in ACP documentation for both inpatient and primary care patients, and a higher rate of hospice admissions compared to the overall population of Hawaii and the United States.<sup>23</sup> Although not investigated in the study, the Hilo Study demonstrated an ability to overcome some of the challenges to ACP documentation as demonstrated in other studies. Almost 1/3 of study

participants at a skilled nursing facility who chose comfort care in both the verbal and video groups, had their DNR status appropriately documented.<sup>32</sup> One of Volandes et. al's studies found that only 5% of people who were DNR/DNI had actual documentation of their status.<sup>27</sup>

There were some common themes regarding the limitations of the studies analyzed. The majority of the studies were not blind, and few had follow-up tracking of any permanent changes in care preference or knowledge. The style, quality, and length of videos depicting CPR also varied among the studies, ranging from 3 to 12 minutes using human actors or mannequins to depict CPR, intubation, and/or care preferences. Most of the research was limited by sample size and duration as well. Due to the duration limitation, the fulfillment of wishes or care preferences, and/or the following of DNR/DNI orders was not evaluated in any of the studies investigating the effectiveness of videos in ACP or DNR/DNI status. Longer-duration studies need to be a key part of future studies of this topic, especially because the preferences of care change over time and in different medical situations.<sup>20,21</sup> Another limitation of the studies was the lack of demographic diversity. Patients' religious, spiritual, and cultural beliefs have major influences on how end-of-life care is approached and implemented. Future researchers should be cognizant of this effect as population demographics continue to change.

Moving forward, it would be beneficial to create a study using the same video format for a variety of different patient populations. Videos are effective at supplementing verbal discussions of medical procedures, and they help people outside the medical field gain knowledge and autonomy by visualizing procedures that may be difficult to imagine using words.<sup>28</sup> However, there is a need for standardized guidelines for effective tools. The Agency for Healthcare Research and Quality "described a multitude of published ACP tools that are diverse in quality and rarely supported by evidence of effectiveness or patient benefit...

Healthcare organizations may be more successful at improving shared decision making if they demand tools with evidence of effectiveness.”<sup>9</sup> Angel Volandes, MD, MPH, was the lead investigator or co-author in 13 of the randomized control trials using videos for ACP education analyzed for this paper. He is a major influence in this field of study and the implementation of the VIDEO Program in Hilo, HI was extremely effective. Adapting his tools in a consistent format for study would allow better analysis and comparisons of data among different populations.

The Hilo, HI study was the beginning of evaluating the effectiveness of video-tool use in the primary care setting. Volandes recognizes the need for longer studies introducing CPR and other video tools into primary care settings to determine if ACP or DNR/DNI documentation changes over time, and if care wishes are fulfilled at the time of need.<sup>32</sup> Now that providers can bill for ACP conversations in a primary care setting, CPR educational videos could be a helpful tool to facilitate ACP conversations and DNR/DNI status. Due to technology availability, video viewing is not limited to being in a provider’s office. Through mobile phone apps and websites, patients could view these after prompting by a provider, which could facilitate future conversations and documentation opportunities. Health systems, nonprofit organizations, and government health departments could also create social media campaigns to share information via Facebook, Instagram, or Twitter. The ability to disseminate information to today’s technologically savvy culture is constantly increasing.

ACP is a dynamic process and it changes with health status and illnesses, both actual and hypothetical. It can therefore be difficult to ascertain a patient’s true wishes for end-of-life care and DNR/DNI status. The findings of Sharma et.al, Jesus et. al, and Ditto et. al reinforced the belief that proper utilization of ACP requires continual conversations and evaluations of needs,

wishes, and expectations as patient medical conditions change, with subsequently appropriate updating of medical records and Advanced Directives.<sup>13,20,21</sup> This elicits concerns that decisions made at a primary care visit may change when a patient's health condition changes, and their wishes will not be followed. Combined with the fact that physician and advanced providers themselves need education training on appropriate and ethical uses of CPR as health conditions change,<sup>36</sup> there needs to be consistent documentation practices that are accessible, adaptable, and portable. The lack of correlation between documented DNR/DNI status and patient preferences for goals of care<sup>29,32</sup> demonstrates the need for providing effective portability of ACP and allowing opportunities for patients and families to effectively discuss and document preferences, especially for patients in vulnerable conditions. Fortunately, a documentation system already exists, POLST, which could be adapted for use in the primary care setting.

The POLST form is a portable order set determined through collaborative discussions between patients, providers, and families to establish and document wishes and end-of-life care preferences for seriously ill patients. The use of CPR and deciding DNR/DNI status are an important part of the form.<sup>37</sup> Pope concluded that combining CPR video-decision tools and POLST forms can be an effective way to limit futile, unnecessary, or unwanted CPR.<sup>38</sup> Adapting the POLST form for primary care ACP discussions, in conjunction with video-decision tools depicting CPR, could have dramatic effects on patient autonomy and care. Incorporating these forms into patient Electronic Medical Records (EMR) is a sensible solution to ensure portability and adaptability. This portion of the EMR could be referenced during any medical situation including, but not limited to, Primary care appointments, Emergency Department or urgent care visits, hospitalizations, surgery consultation, or ICU admissions. Major changes to patients'



health status may require more in-depth discussions on treatment preference, but this is feasible for well-trained providers.

Application of this approach to ACP would require training for all staff within a health-system and substantial changes to its culture, but a benefit of having larger health systems incorporating multiple hospitals and clinics under a single organizational structure is the ability to disseminate information efficiently to all members of the organization. This has been demonstrated with the success Gundersen Health System's approach to ACP called *Respecting Choices*. In over ten years, the percentage of patients having completed an Advance Directive went from 2% to 96%. The community of La Crosse, WI embraced this approach after years of consistent messaging and advocacy by healthcare professionals.<sup>39</sup>

Inspired by the *Respecting Choices* model, Reidy et. al attempted "building a systematic, population-based ACP initiative focused on health system-wide deployment of an Internet-based tool as an adjunct to a facilitator-based model" with moderate success in two subspecialty clinics, lung cancer and heart failure. Over 18 months, they incorporated clinician ACP training and accommodated ACP discussions into current workflow designs. An internet based ACP tool was promoted at clinic visits, on social media and electronic platforms, and employee wellness forums to facilitate and encourage ACP discussions inside and outside the clinic. After the trial period, researchers concluded that "changing culture and systems to promote ACP requires a comprehensive vision with simultaneous, interconnected strategies targeting patient education, clinician training, EMR documentation, and community awareness."<sup>40</sup>

**Conclusion:**

The goal for establishing ACP for all patients, but especially those with terminal or vulnerable health conditions, is to increase patients' understanding and autonomy in their end-of-life care, as well as to make documented decisions portable and consistent across all healthcare settings. The ability for providers to bill for ACP discussions may be a catalyst for dramatic changes in ACP documentation and implementation. Incorporating the use of videos in depicting disease states and medical procedures like CPR will be an integral part of successful implementation of ACP due to its demonstrable effects on patient knowledge and care preferences. Furthermore, combining aspects from initiatives like the VIDEO program and *Respecting Choices*, with the creation of a POLST form applicable to all patients, not only those suffering from serious or terminal illnesses, can greatly influence patient autonomy and decision making regarding CPR and DNR/DNI choices within ACP. Consistent and regular ACP discussions between providers and patients, the easier these major decisions can be established and adapted before, during, and after times of crisis. The hope is to respect patients' decisions regarding their end-of-life care, especially after they have had an opportunity to explore options with their healthcare provider and gain better understanding of practical applications of CPR protocols and procedures regarding their DNR/DNI status.

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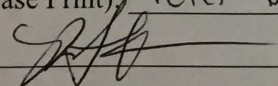
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