

Advance Care Planning in Patients with Heart Disease:

A Practice Improvement Initiative

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Abstract

Background & Purpose: Despite cardiovascular disease being the number one cause of death, Advance Care Planning (ACP) is infrequently used in this population. Health Care Proxy (HCP) is the essential first step in ACP. The purpose of this study is to examine the effect of a nurse practitioner-led promotion of ACP for hospitalized adult patients.

Method: A longitudinal case-control design was used in a convenience sample (n=120) of hospitalized patients with cardiovascular disease. A nurse practitioner educated and encouraged patients to identify and document a HCP. Patients admitted prior to initiating the intervention (n=60) was compared to those receiving the intervention (n=60) for HCP completion rate. A chi-square analysis was used to examine the effectiveness of the intervention.

Conclusions: There is significant relationship between NP intervention and new HCP completion (Chi-square = 86.769, df = 1, $p < 0.05$). Patients were more likely to complete HCP when there is an NP-led ACP intervention. Prevalence of HCP improved from 35% in controls to 90% in cases.

Implications for Practice: Findings suggest nurse practitioners are effective in identifying and leveraging opportunities to facilitate ACP communication. Health care professionals are urged to empower patients to take full advantage of their self-determination.

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The use of life-sustaining treatment modalities often cause ethical dilemmas when patients are unable to participate in their own health care decisions. Grounded in the ethical principle of autonomy, the Patient Self-Determination Act (PSDA) took effect on December 1, 1991 (Koch, 1992). The mechanism is the federal requirement that mandates any health care institution that receives Medicare or Medicaid funds to inform patients of state law governing self-determination. The Health Care Proxy Law, Article 29–C of the New York Public Health Law, enables competent adults to protect their health care wishes by appointing someone they trust - a health care agent - to make decisions on their behalf when they are unable to decide for themselves (www.health.ny.gov).

‘Health Care Proxy’ (HCP) is the term used for the health care agent in New York State. This is equivalent to the ‘Power of Attorney for Health Care’ in other states. Unless stated otherwise, a health care agent can make all decisions that the patient could make while competent. Implementation of the PSDA has been fraught with challenges since inception, and after two decades, only less than 25% of Americans have completed an advance directive (Johnson, Zhao, Newby, Granger, & Granger, 2012). Advance directives serve as a means of extending the autonomy of patients (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991). Documentation of advance directives may be in the form of HCP, living will, or Medical Orders for Life-Sustaining Treatment (MOLST). An essential first step in ACP is to identify the patient’s surrogate decision maker, which is the HCP. Therefore, the focus is on HCP for the purpose of this study.

Advance care planning (ACP) is the process through which a patient in consultation with health care providers, family members, and significant others, makes decisions about his or her future health care, in the event that should he or she become incapable of participating in medical treatment decisions. Its purpose is to inform and empower patients to plan current and future treatment, but it is a process that evolves over time (Hayes, 2014). ACP may best be considered a part of medical care similar to exercise, smoking cessation, dietary change, and cancer screening; i.e. activities that are good for individuals but which they may not want to do. Unlike these behaviors, however, ACP may not even be recognized as something that they ought to do (Fried & Drickamer, 2010). ACP improves end of life care, patient and family satisfaction, reduces stress, anxiety, and depression in surviving relatives (Detering, 2010).

Background and Significance

According to the US Census Bureau, the nation's 65-and-older population is projected to reach 83.7 million in the year 2050, almost double in size from the 2012 level of 43.1 million. More importantly, the 85-and-older population is projected to be 29.7 percent in 2050, up from 16.3 percent in 2012 (US Census Bureau, 2014). An important fact in relation to the health care of this population is that very few people have advance directives. A Pew Research Center survey found that only 29 percent of Americans have a living will. The Agency for Healthcare Research and Quality reported that fewer than half of severely or terminally ill patients had an advance directive in their medical record. The majority of Medicare-eligible individuals with chronic conditions such as end-stage cardiac disease, end-stage dementia, pulmonary disease, and stroke, who could benefit from ACP services, do not receive them (Hayes, 2014).

The prevalence of chronic conditions increases with age, and it is estimated that 25% of older adults will lose decision-making capacity at the end of life (Silveira, 2010). Therefore,

ACP is essential to ensure that people receive care that reflects their values, goals, and informed preferences. About one in four Americans 65 and older dies in a hospital setting. One in three dies at home while the majority of Americans express a preference for dying at home (IOM, 2014). Frequent reports indicate that patients who wish to get nursing care at home at end of life, and their families find all the forces of American health care system against them – hospitals, nursing homes, home health agencies, insurance companies, and the shifting crosscurrents of public health care spending. A front-page report in The New York Times on 26th September 2014 with the title “A father’s last wish and a daughter’s anguish” is a typical example of this health disparity. In this case the patient wished to die at home, but home care was denied. Records showed that Medicare paid the nursing home \$682.48 per day, which would be about five times the cost of a day of home care (Bernstein, 2014).

The Affordable Care Act would allow patients access to a professional medical counselor who will provide them with any information they might need about preparing a living will, providing medical power of attorney, and end of life decisions (www.whitehouse.gov). Despite allegations of “death panel”, the issue of reimbursing physicians for advance care planning consultations is making a comeback, and such sessions may be covered for the 50 million Americans on Medicare as early as next year. Bypassing the political process, private insurers including Blue Cross Blue Shield have begun reimbursing doctors for these advance care planning conversations as interest in them rises along with the number of aging Americans (Belluck, 2014).

In a recently published consensus report (17th September 2014) from the Institute of Medicine – “Dying in America” – a committee of experts finds that improving the quality and availability of medical and social services for patients and their families could not only enhance

quality of life through the end of life, but may also contribute to a more sustainable care system. There is tremendous support for the proposed bill called the Personalize Your Care Act, federal legislation that would create a Medicare reimbursement for physician, NP, or PA time spent in advance care planning consultations (AAHPM, 2014).

Despite the compelling reasons for advance directives and their professional and public endorsement, they are infrequently used. In a study of elderly Americans who needed decision making near the end of life, Silveira (2010) revealed that patients who had prepared advance directives received care that was strongly associated with their preferences. These findings support the continued use of advance directives. There is reason to believe that most people would like to complete advance directives. Results of a survey conducted in Boston, MA revealed that 78% wanted a proxy decision maker, when only 8% had designated one in writing (Emanuel et al., 1991). This finding strongly suggested that completion of HCP requires practitioner initiative. Certain populations like cardiovascular and cancer patients provide a fertile ground for implementing this initiative.

Cardiovascular diseases (CVD) remain the number one cause of death in the United States. According to a 2013 update from American Heart Association, rates of death attributable to CVD have declined, but the burden of disease remains high. On the basis of 2009 data, the overall rate of death attributable to CVD accounted for 32.3% deaths, or 1 of every 3 deaths in the United States (Go et al., 2013). Although a tremendous amount of work is done on CVD, very little is known about AD completion in patients with CVD.

Cancer is the second most common cause of death after CVD (Askoxyllakis et al., 2010). Two recent studies conducted in New York State were reviewed to compare the prevalence of HCP in cardiac versus cancer populations. In a retrospective study of 1,333 oncology ICU

admissions, 47.6% patients had HCP, where as the prevalence of use of HCP was only 19% in a study of 512 patients hospitalized in cardiac care units in two community hospitals (Halpern, Pastores, Chou, Chawla, & Thaler, 2011; Kumar et al., 2010). This difference is significant since heart failure has a poorer prognosis than many cancers. Kumar et al (2010) suggest that AD may be more important for care of heart failure patients than for cancer patients in whom a terminal phase is identified. Cardiology practitioners should learn from the communication models in oncology to address the current deficiency in ACP.

There is reason to say, “All roads lead to heart failure” (Klein, 2011, p. 5). Given the progressive nature of heart failure, and its high mortality rate, practice guidelines from major cardiovascular societies include sections on end-of-life considerations, which advocate ongoing patient and family education regarding prognosis for quality of life and survival. Despite these guidelines, data on end-of-life issues in heart failure is sparse. It was found that ambulatory patients with heart failure tended to substantially overestimate their life expectancy compared with model-based predictions for survival (Allen et al., 2008). As differences in perceived survival could affect decision-making regarding advanced therapies and end-of-life planning, it is important to find opportunities for ACP discussions.

Culturally, Americans strive to control nearly every aspect of their lives. But many Americans abandon control of life’s final passage. End-of-life care is a matter of personal values, economics, public policy, and a looming public health crisis (Morhaim & Pollack, 2013). The development and spread of specialty-level palliative care programs in hospitals over the recent years has been impressive, outstripping the capacity of many teams to meet the demand for their services (Weissman & Meier, 2011). A number of hospital systems are now replacing the term “Do Not Resuscitate” with “Allow Natural Death” which makes more sense. “Americans hate to

talk about death, but advance care planning is about how we live before we die” (Mason, 2013, p. 11). Therefore it is highly important to ensure communication between patients and their loved ones, and to facilitate completion of HCP.

Review of Literature

This review of literature was undertaken with an intention to explore the current state of science surrounding the promotion of advance care planning with special interest on health care proxy (HCP) in cardiovascular patients. The literature reveals patient education is lacking in the current practice of just fulfilling the requirements of PSDA by offering advance directives at time of admission. In an academic medical center, adult patients admitted to the cardiac intensive care unit were studied by Johnson et al (2012) to explore their understanding of advance directives. The study findings indicate that simply asking, “Do you have an advance directive?” and offering the opportunity to complete a directive does not provide an accurate reflection of a patient’s understanding of advance directives. This study points to a need for restructuring the current implementation of the PSDA. Clinicians must move forward from simply checking a box to providing a meaningful discussion with each patient and the patient’s family.

Finding appropriate time to discuss preferences, prognosis, and medical options with patients and their families is a formidable challenge. Formal discussions about prognosis and decision-making are often deferred until more emergent and less favorable occasions, when thoughtful decision-making may be impaired. For instance, at the time of presentation for hospital admission, patients are frequently uncomfortable and often require urgent, intensive evaluation and management. Hasty questions such as, “Do you want us to do everything?” can yield inaccurate and conflicting answers. Studies also indicate that physicians tend to engage their patients in discussions about preferences for care only late in the course of illness; and

infrequently use ACP communication during clinic visits after the heart failure hospitalization (Ahluwalia et al., 2013; Fried & Drickamer, 2010).

For those who come to the acute care setting without HCP, the actual hospitalization period may be a better time for more in-depth discussions on health care decision-making. Once the clinical course has become apparent during hospitalization, clinicians can take advantage of the substantial time they have with the patient and family to further address complex medical decisions before discharge. Hospitalization may afford better access to multidisciplinary teams, palliative care, and other resources than can be marshaled into the outpatient setting. All of these considerations underscore the importance of a proactive, anticipatory, and iterative approach to soliciting patients' preferences both routinely and at the occurrence of milestones that herald a worsening prognosis (Allen et al., 2012).

ACP is a continual process, and not merely a document or isolated event. It consists of explaining trajectory of the illness, eliciting preferences, and encouraging documentation of advance directives (Ahluwalia, Levin, Lorenz, & Gordon, 2013). It is described as a two-step process as per Dr. Patricia Bomba, a nationally recognized palliative care, and end-of-life expert. Community Conversations on Compassionate Care (CCCC) and Medical Orders for Life-Sustaining Treatment (MOLST) are the two steps. The first step in the CCCC is identification and completion of HCP (Bomba, 2011).

As implied by Johnson et al (2012), when advance directives are discussed with a patient, conveying the importance of choosing the "right" person to be the HCP is crucial. The person selected - who is given the responsibility of health care power of attorney - must not only be aware of the patient's wishes but also be someone who is willing and able to advocate for the patient and to convey the patient's wishes, whether or not the person agrees with those wishes.

At times, a patient's next of kin or the person who might be the most logical choice for being the patient's HCP is not able to carry out the patient's wishes because of religious or cultural beliefs. These factors should be mentioned and the responses considered when choosing a suitable health care decision-maker.

Ahluwalia et al (2012) points out that there is a need for future research and quality improvement efforts to focus on identifying and leveraging opportunities for facilitating ACP communication. Nurse practitioners are considered to be in a key position to educate, advocate, and assist in the completion of advance directives (Hinders, 2012). Yet, no known study has tested an NP-led intervention for promoting advance directives in acute care settings. However, Lawrence (2009) examined completion rates of advance directives among long-term institutionalized older adults in Arizona, Georgia, and Massachusetts. A significantly greater proportion of advance directives have been completed by individuals enrolled in an NP-led long-term healthcare model when compared to individuals living in long-term care settings with traditional healthcare model.

Opportunities exist for nurse practitioners to change structure and process related to improving completion and availability of advance directives (House & Lach 2014). Advance directive documents like HCP are free, legal and readily available. Morhaim & Pollack (2013) suggest that completion of advance directives will very likely reduce health care costs. Enormous funds are consumed for life-sustaining treatments at end-of-life. By respecting the wishes of individual patients, reducing needless or unwanted end-of-life care expenses would allow those funds to be diverted to other pressing public health needs such as prevention. Increasing the rate of completion of HCP is a key step, and specific policy strategies can be identified to accomplish this objective.

Conceptual Framework

The proposed model of ACP is based on a conceptual framework of Shuler Nurse Practitioner Model and Self-Determination Theory. The nurse practitioner (NP) utilizes a unique blend of both nursing and medical knowledge and skills when caring for and interacting with patients. The Shuler Nurse Practitioner Model assumes that the NP and the patient are partners in health care, that patients have the right to accept or reject health care, being patient health educator is one of the most important roles performed by the NP, and the family can be the greatest single influence on the health behaviors of the patients since health beliefs, practices, values and attitudes are often determined and monitored by this unit (Peterson & Bredow, 2013). These components provide a framework for a holistic paradigm for NP practice. This holistic approach should include collaboration with patient and family to facilitate ACP decisions.

The Shuler Nurse Practitioner Model focuses on an open system that consists of an organized set of dynamically and rhythmically interrelated parts and processes. These interrelated parts and processes should include the patient, family, advance care planning process, and patient's autonomy (see Figure I). The NP synthesizes the information gathered from the patient by diagnosing and identifying problems and continually adjusts conditions of the interaction so that the patient remains as an active participant (Shuler & Davis, 1993). Most importantly, the patient is constantly included in the health care planning process that fosters the appointment of a substitute decision maker. Documenting a HCP is the essential basic step in the process of advance care planning.

Since patients' autonomy is an essential aspect of Shuler Nurse Practitioner Model, a second theory that informed this study is that of self-determination. Self-Determination Theory (SDT) is an empirically derived theory of human motivation and personality in social contexts

that differentiates motivation in terms of being autonomous and controlled (Deci & Ryan, 2008). According to SDT, developing a sense of autonomy and competence are critical to the process of internalization and integration, through which a person comes to self-regulate and sustain behaviors conducive to health and well-being. Thus, treatment environments that afford autonomy and support confidence are likely to enhance adherence and health outcome (Ryan, Patrick, Deci, & Williams, 2008). Patients are often unaware of the loss of self-determination. The restoration of self-determination requires awareness and deliberate intension (Schiffbauer, 2013). Explaining the trajectory of illness, eliciting preferences, and encouraging documentation would be the steps in the process of advance care planning driven by the NP to enhance patient's self-determination. In brief, this project uses the Shuler's Practice Model to facilitate the patient's autonomy.

Method

A longitudinal case-control study was designed to determine if advance care planning discussions with patients (intervention) by NP is associated with an increase in completion rate of health care proxy (outcome). Patients receiving only standard practice protocol were controls, and patients who received the NP's intervention that supplement the standard practice protocol were cases. The standard practice protocol alone was provided for the control group. A retrospective chart review was undertaken to determine the number of patients who completed a new HCP during the hospitalization of this period. The cases received the NP intervention in addition to the standard practice protocol to encourage documentation of HCP. The number of patients who completed a HCP following the NP intervention was determined by retrospective chart review. The outcome of interest was new HCP completion rate. Prevalence of HCP was another interesting finding from the samples. Demographic variables for descriptive statistics

included age, gender, ethnicity, religion, education, living situation, admitting diagnosis, and comorbidities.

Setting.

The setting used for the project was a northeastern, sub-urban, tertiary care, academic medical center. The study was conducted in the cardiac intermediate care unit (Cardiac ICR). Patient population primarily consisted of patients with diagnoses of heart failure (HF), arrhythmias, and acute coronary syndrome (ACS).

Sample.

Inclusion criteria consist of all cognitively intact, adult patients with heart diseases either admitted or transferred to cardiac ICR. A convenience sample of first 60 patients admitted to Cardiac ICR from August 1, 2014 through September 30, 2014 was considered as the control group. The NP-led advance care planning intervention (NP intervention) was initiated on October 1, 2014. The group of first 60 patients admitted to cardiac ICR from October 1, 2014 through November 30, 2014 was cases. Patients who have HCP at time of admission, and patients with cognitive impairment (as evidenced on the EMR) were excluded from the intervention. All patients continued to receive the standard practice protocol.

Standard Practice.

During the admission process, the registered professional nurse (RN) initiates the standard practice protocol. The adult nursing history form in the EMR has a section for advance directives (See Figure II). If patients come with HCP, it is documented in the EMR. For those without HCP, establishment of a HCP is offered. If patient is interested, chaplaincy, patient/guest relations, or social work consult would be initiated for completion of HCP.

NP Intervention.

The ACP intervention by the NP was a supplement to the standard practice protocol. The NP met with the patient to discuss advance care planning. This discussion included “the 3E’s” - Explaining trajectory of patient’s medical condition, Eliciting healthcare preferences, and Encouraging documentation of HCP. The HCP form provided by the New York State Department of Health (see Appendix) was handed out to the patient during the ACP discussion. This hand out includes description about the HCP, answers to frequently asked questions, and instructions to complete the form. The dependent variable is the completion of HCP form by the patient.

Data Analysis.

The collected data was entered into SPSS for analysis. Chi-square statistics was used to analyze the significance of association between NP intervention and HCP completion rate. Cross tabulations of demographic variables were done to identify other factors influencing the HCP completion rate. An alpha level of 0.05 was used as a significance criterion for the statistical analysis.

Results

It was hypothesized that NP intervention would have an effect on new HCP completion rate. The results supported the hypothesis. The relationship between NP intervention and new HCP completion was significant (Chi-square = 86.769, df = 1, $p < 0.05$). Patients were more likely to complete HCP when there is an NP-led advance care planning intervention.

As per chart review 21 patients (35%) of controls and 34 patients (56.66%) of cases had existing HCP at time of admission to the unit. At time of discharge the number remained the same in controls, whereas following the NP intervention, HCP completion rate increased to 90%

(See Graph I). It was also found that 10 charts from controls were missing data on HCP, while HCP documentation was complete in cases (See Table I). Among the total sample (n=120), there were 72 males and 48 females. Only 5 patients were from ethnic minority, while 115 were Caucasian. The age ranged from 33 to 94. Notably 55 patients (45.83%) had HCP, and fifteen patients (12.5%) had living will at time of admission. Nine patients requested Do Not Resuscitate (DNR). The study shows that HCP is the most commonly used advance directive (See Graph II). Acute Coronary Syndrome (ACS), Heart Failure (HF), and Arrhythmia were the most common diagnoses on admission. Interestingly, majority of the patients with ACS did not have a HCP at time of admission, whereas the opposite was true in patients with other admission diagnoses (See Graph III).

Limitations

The convenience sample (n=120) was limited to cardiac intermediate care unit. Since it is a specialty floor, the HCP prevalence cannot be generalized. Although the findings suggest that the intervention has a significant effect, the chi-square is unable to show how strong the relationship is.

Implications for Practice

This study proves that Nurse Practitioners are effective in identifying and leveraging opportunities to facilitate Advance Care Planning communication. Further opportunities exist for nurse practitioners to change the structure and process related to improving completion and availability of advance directives. Health care professionals are urged to empower patients to take full advantage of their self-determination. The following quality improvement measures are recommended:

1. Provide education for practitioners on ACP and its importance in day-to-day practice to support patients' autonomy.
2. Consider forming an NP position with the role of 'advance directive specialist' in collaboration with ethics committee.
3. Add NP to the list of consults in advance directive section of adult nursing history on EMR to provide ACP and promote completion of advance directives.
4. Incorporate advance care planning in the progress note templates for practitioners on EMR in order to promote completion of advance directives.
5. Once implemented, conduct a large-scale study including all in-patients to evaluate the effect of ACP.

Through the application of Shuler Nurse Practitioner Model, and Self-Determination Theory, this project is expected to introduce a new practice model to achieve 100% compliance with completion of Health Care Proxy. The goal is not only to minimize pain and suffering, but also to avoid futility by supporting patients' wishes in their health care. Health care professionals are urged to find the best, positive, and most effective ways to empower patients to take full advantage of their self-determination. The hope is that having an advance directive on file becomes as routine as getting a driver's license.

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Figure I – Conceptual Framework

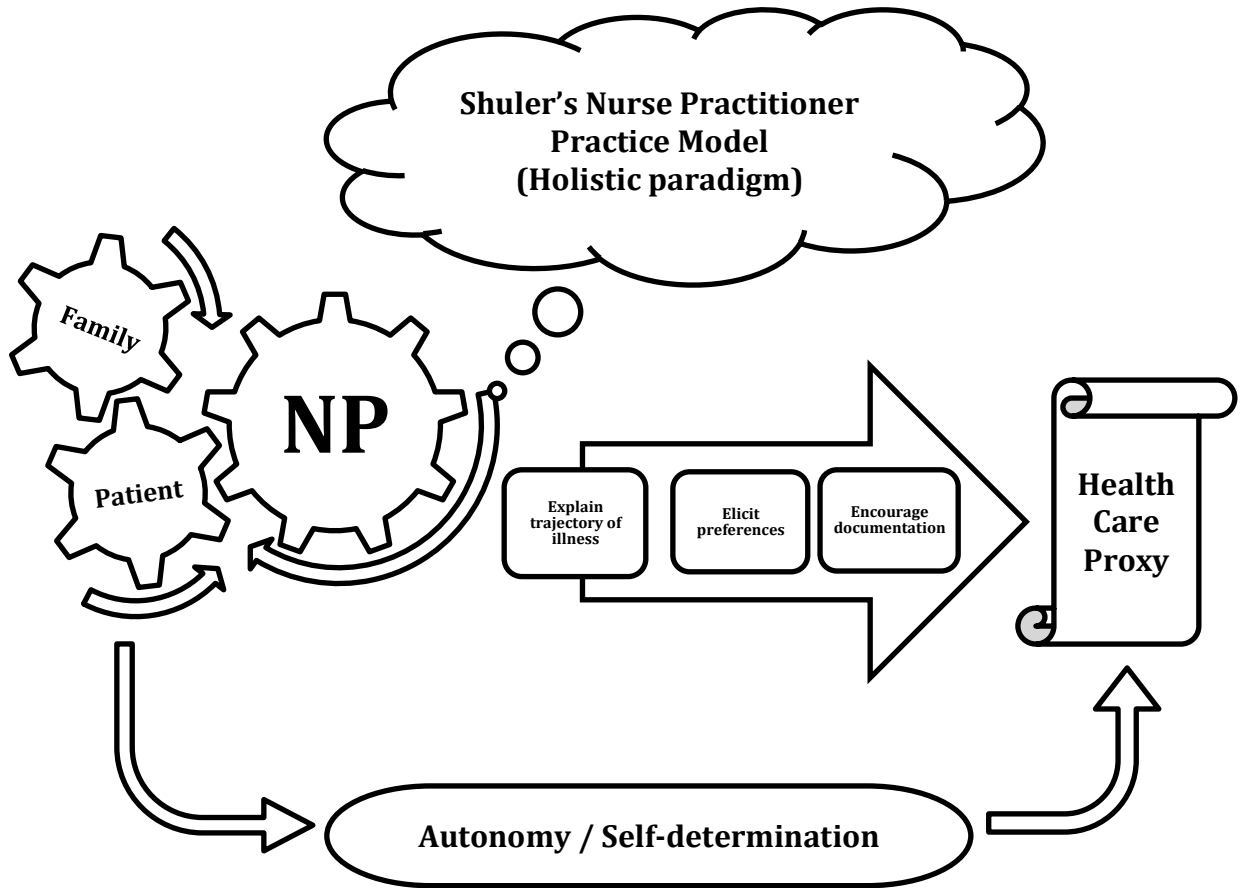
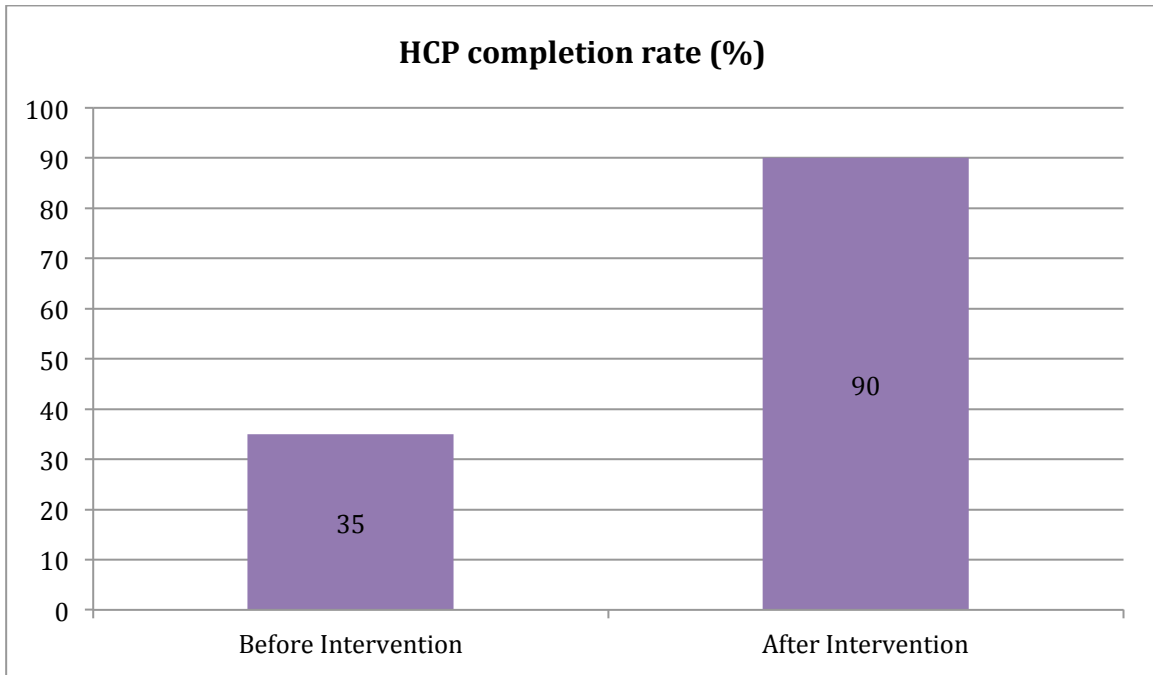


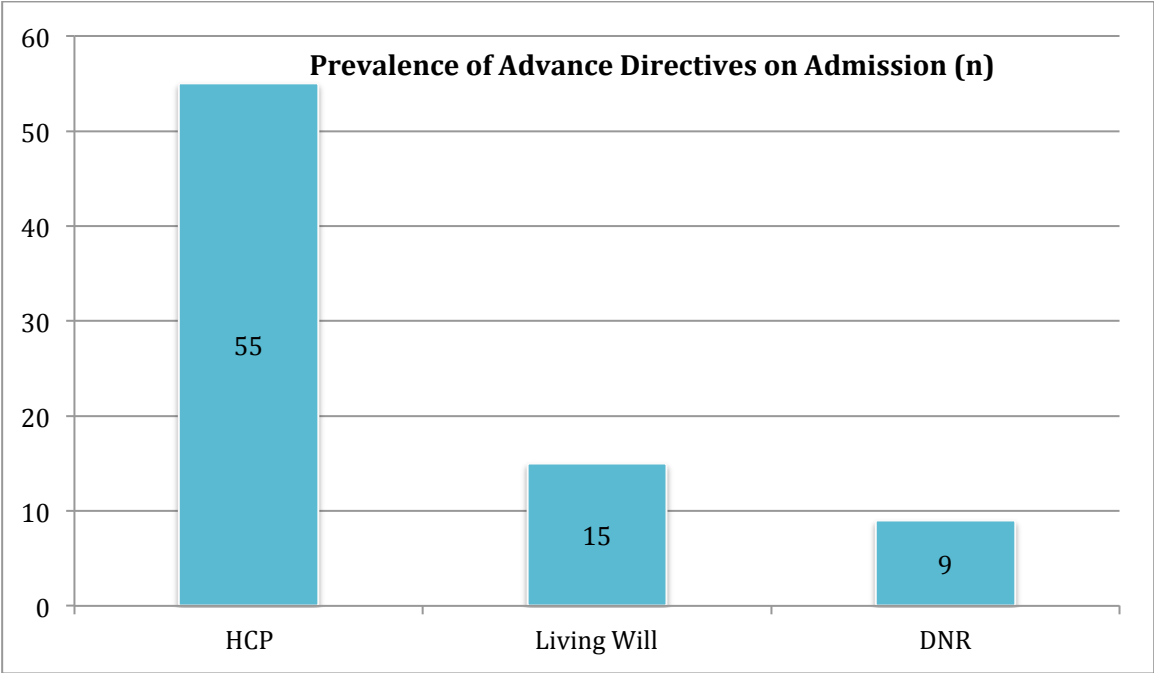
Table I – Findings from retrospective chart review

n = 120	CONTROLS	CASES
N	60	60
HCP on Admission	21	34
No HCP on Admission	29	26
Missing data on HCP	10	0
NP intervention	0	26
HCP completed	0	20

Graph I – Intervention increased HCP completion rate by 55%



Graph II – Prevalence of advance directives on admission



Graph III – Prevalence of HCP according to admission diagnosis

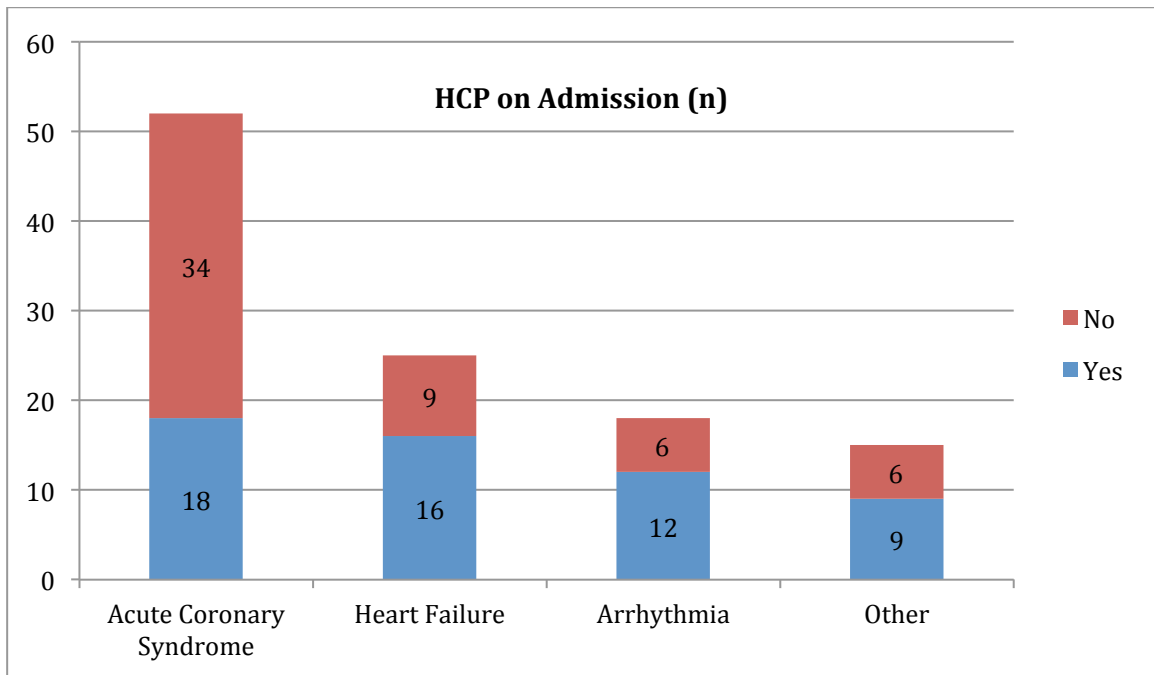


Figure II – Standard practice template in electronic medical record

Adult Nursing History Form

General Info

✓ Cultural Assess

Contact Inform

➤ Advance Directiv

Immunization

Valuables & Be

Health History

* Anesth/Transf

✓ Nutrition

Functional

Sexuality

✓ Social Habits

* Tobacco Use His

✓ Psychosocial

✓ Education Neec

Discharge Neec

Suicide Risk Scro

Advance Directive

Advance Directive

Yes, Copy Placed in Chart
 Yes, Current and in Eclipsys
 Yes, Currently Not with Patient
 Yes, But Requesting a Change in Proxy
 In Eclipsys, Unable to Verify
 Unable to Assess
 No

Family/Significant Other Advised to bring in Document.

Check Eclipsys For Current Advance Directive

Documenting "Unable to Assess", "In Eclipsys, Unable To Verify" or "Yes, Currently Not with Patient" Automatically Enters a Consult Order to Social Work.

Advance Directive Type

Health Care Proxy
 Living Will
 Psychiatric Advance Directive
 Other:

Name of Health Care Agent

Relationship to Patient

Advance Directive - Need Assistance

Yes
 No, Patient Refused

Advance Directive - Department to Assist

Chaplaincy
 Patient/Guest Relations
 Social Work

Organ Donor

Yes
 No

Consult Order will be Sent to the Selected Department Automatically

An Oral or Written Advanced Directive can be given by the patient without the assistance of the three departments listed above