

EXECUTIVE SUMMARY

The national importance of CPR in the hospital. The procedure of cardiopulmonary resuscitation (CPR) was developed to sustain heart and lung function in patients with reversible causes of cardiac arrest, such as anesthesia. As CPR was used more widely, it became clear that, in patients with terminal illness, it could prolong but not prevent the dying process. An ethical and legal consensus developed that patients could refuse CPR, like other medical therapies, based on the principle of autonomy. Most Americans are hospitalized in the last months of their lives, and many die in hospitals. Studies finding that many hospitalized patients receive CPR against their wishes have bolstered national calls to improve CPR decision-making in the hospital.

Decision-making about CPR. In the hospital, a physician order is required to withhold CPR, so physician-patient CPR discussions are particularly important in this setting. Because patient preferences for care at the end of life vary, experts recommend that patients and physicians share decisions about CPR. In this model, physicians ask patients about their goals and values for the end of life, and use them to formulate a professional opinion about the suitability of CPR. Research demonstrates that patients are less likely to want CPR if their overall prognosis is poor. Thus, experts recommend that physicians address prognosis when discussing CPR. This proposal developed in response to research by the investigators and others showing that CPR discussions between physicians and hospitalized patients do not include these recommended elements.

Goal and rationale of the proposed research. The goal of this research is to understand patients' perspectives on how decisions should be made about CPR in the hospital. Hospitalist physicians, who only see patients in the hospital, now care for most hospitalized patients. Previous studies have found that patients prefer to discuss sensitive issues such as a cancer diagnosis with a physician they know and trust, as opposed to an unfamiliar hospital physician. Thus, encouraging hospitalists to discuss prognosis and end-of-life goals and values could improve decision-making about CPR, but might also offend and upset patients.

Summary of research methods. We propose to create two video simulations of CPR discussions, a test and a control, which we will use to elicit patients' perspectives about CPR decision-making. The test video will depict a hospitalist discussing prognosis and end-of-life goals and values with a seriously ill patient, and giving a recommendation about CPR. In the control video, the physician will provide detailed information about CPR and its risks and benefits, but will not discuss prognosis or end-of-life goals and values and will not provide a recommendation. Both videos will be shown to 20 hospitalized patients who have a serious illness such as cancer. Using the videos as triggers, we will interview patients about whether the discussions they viewed would be: 1) useful in their decision-making about CPR, and 2) upsetting or otherwise harmful to have with a physician they did not know.

Dissemination and future work. We request funding for a pilot study. Our findings will be disseminated to practicing hospitalists at the local and national level, and will lead to an NIH application for a larger, multicenter project. The ultimate goal of this research is to improve the care of seriously ill hospitalized patients at the bedside by training hospitalists to discuss CPR in a way that improves decision-making from the patient perspective and does not cause undue distress.

OBJECTIVES AND SPECIFIC AIMS

Improving CPR decision-making in the hospital is a national priority.¹ Patients with serious and life-limiting illness are frequently hospitalized,^{2,3} and past research raised concern that many received CPR that was not in accord with their wishes.⁴ Because CPR decisions are preference-sensitive, many experts advise a shared decision-making model in which physicians elicit patients' goals and values and use them to tailor a recommendation about CPR.⁵ Patients' understanding of their overall prognosis and likelihood of survival after CPR influences their decisions about CPR.^{6,7} This finding led to recommendations that physician-patient discussions of prognosis frame CPR decisions.⁵ Research by the investigators and others shows that physician-patient CPR discussions in the hospital do not follow these recommendations.⁸⁻¹¹

Encouraging hospitalist physicians to follow these recommendations could ensure that patients' decisions about CPR align more closely with their preferences. While patients respond positively to CPR discussions that do not address prognosis, goals, and values,¹²⁻¹⁸ they prefer to discuss sensitive issues such as a cancer diagnosis with a physician with whom they have a previous relationship.¹⁹ Discussing prognosis and end-of-life goals and values with an unfamiliar physician could upset patients, resulting in unintended harm.

The objective of this research is to understand the perspectives of seriously ill hospitalized patients on the benefits and harms of discussing prognosis, end-of-life goals and values, and receiving a physician recommendation in the context of CPR decision-making. We request funding for a pilot project that will lead to NIH funding. The specific aims are:

Aim 1: Develop and produce two video simulation trigger tapes of CPR discussions between a hospitalist physician and a seriously ill patient. The test video will follow a *shared decision-making model*, in which the simulated physician frames the discussion in the simulated patient's prognosis, goals, and values and gives a recommendation about CPR.⁵ The control video, modeled after CPR discussions to which hospitalized patients have responded positively,¹³ will follow an *informed-decision making model*. The simulated physician in this video will present detailed information about the nature of CPR and its risks and benefits, but will not address prognosis or end-of-life goals and values or provide a recommendation.

Aim 2: Pilot the videos in semi-structured interviews with seriously ill hospitalized patients. We will recruit and present both videos to 20 seriously ill hospitalized patients in the context of 1-hour semi-structured interviews, which will be audio-recorded and analyzed qualitatively. The interview protocol will elicit patients' overall reactions to the videos as well as their opinions about the usefulness and potential harm of specific elements of the discussions: prognosis, end-of-life goals and values, specific details about CPR, and a physician recommendation.

We will assess the feasibility of the videos and our research design and modify them before submitting an application for NIH funding of a larger, multicenter study of patients from diverse cultural, geographic, and clinical backgrounds. We will ultimately incorporate these patient perspectives into an intervention to improve the care of individual patients at the bedside by promoting CPR discussions that aid patient decision-making and do not cause undue distress.

BACKGROUND AND SIGNIFICANCE

Improving CPR decision-making in the hospital is a national priority. Most Americans are hospitalized in the last months of their lives, and many die in hospitals.^{2,3} Research showing that many seriously ill hospitalized patients received CPR against their wishes bolstered national calls to improve hospital-based decision-making about CPR.^{1,4} In the hospital, CPR can only be withheld by a physician order, so physicians should discuss CPR with patients who are at risk for requiring it.^{5,20,21} Though rates vary widely by institution, physicians and patients frequently discuss CPR at many hospitals.^{22,23} However, research by the investigators and others indicates that CPR discussions may not promote patient autonomy.⁸⁻¹¹ Most CPR discussions are brief, and do not include information about the risks and benefits of the procedure. Furthermore, they infrequently include elements of preference-sensitive decision-making: discussion of patients' prognosis, goals and values, and a physician opinion about the use of CPR. These discussions often confuse patients, many of whom are unfamiliar with CPR.^{24,25} Patients often overestimate the likelihood of survival after CPR^{6,24} and feel that physicians do not understand their wishes.¹⁶

Experts recommend shared decision-making about CPR based on patients' prognosis, goals, and values. As with other medical therapies, patient autonomy should guide decisions about withdrawing and withholding life-sustaining therapies.⁵ Bioethicists and professional associations recommend that physicians and patients collaborate to form a plan for CPR, so that decisions are informed by patients' goals and values as well as their medical condition.^{5,20,21} In this shared decision-making model, the physician elicits the patient's goals and values and uses them to formulate a recommendation about CPR. The patient may then accept or reject the physician's recommendation. Patients are less likely to desire CPR if they understand that they have a poor overall prognosis or low likelihood of surviving CPR.^{6,7} Therefore, physicians should frame CPR discussions and recommendations with a discussion of the patient's prognosis.⁵

Discussing prognosis and end-of-life goals and values in the hospital could result in harm. Though most patients want to share decisions about CPR with physicians,^{15,16,24} our understanding of patient perspectives on CPR decision-making in the hospital is limited. Most hospitalized patients are cared for by hospitalist physicians who they meet for the first time at admission.²⁶ Research finding positive or neutral patient reactions to CPR and advance care planning in the hospital studied discussions that did not address prognosis or end-of-life goals and values.¹²⁻¹⁸ Research by Dr. Lo indicates that patients prefer to discuss sensitive topics, such as a cancer diagnosis, with a physician with whom they have an ongoing relationship, as opposed to a hospitalist physician whom they have just met.¹⁹ Encouraging hospitalist physicians to discuss prognosis and end-of-life goals and values could improve CPR decision-making. However, it could also result in unintended harm: patients could be upset or offended if a physician they do not know raises these sensitive topics. ***Thus, before we encourage physicians to incorporate prognosis, end-of-life goals and values, and physician recommendations into hospital-based CPR discussions, it is critical that we understand seriously ill hospitalized patients' perspectives on the benefits and harms of discussing these sensitive topics with unfamiliar physicians.***

PRELIMINARY DATA

Drs. Anderson and Lo and Ms. Cimino have worked together for the past year on studies of physician-patient and physician-family communication in the hospital. Their offices are located

in the same suite, which will facilitate collaboration on the proposed research. As described below, their past work and experience have prepared them to accomplish the aims of this proposal.

Conducting hospital-based research with seriously ill patient-subjects. The proposed research employs established recruitment procedures. For the Hospitalist Rapport Study,²⁷ Dr. Anderson recruited 39 seriously ill patients over 8 months from Moffitt-Long Hospital at the University of California, San Francisco (UCSF), the proposed study site (Table). Dr. Anderson's previous work also demonstrates that the proposed 1-hour time commitment is feasible and acceptable to patients. In the Hospitalist Rapport Study, patient participants spent 30 minutes completing questionnaires. In a similar study at a nearby hospital, Dr. Anderson and colleagues performed 1-hour semi-structured interviews with 20 seriously ill patients.²⁸ Ms. Cimino, who will perform patient recruitment and data collection for the proposed research, has developed skills in sensitively approaching and enrolling research subjects in her role as study coordinator for a multi-center study of physician-family communication in the ICU.

Table: Characteristics of seriously ill hospitalized patients enrolled into the Hospitalist Rapport Study ²⁷	
Characteristic	Patients (n=39)
Age , years, mean (SD)	59 (16)
Gender , % male	51%
Ethnicity , % Hispanic	3%
Race , %	
White	74%
Asian	10%
Black/African American	10%
Other	5%
Terminal diagnosis , %	
Cancer	54%
Chronic illness	13%
s/p Transplant	10%
End stage renal disease	8%
End stage liver disease	5%
HIV	5%
Other	5%

Collection and analysis of qualitative interview data and use of video-simulations as trigger tapes. Dr. Anderson has led qualitative studies of interviews with caregivers of hospice patients,²⁹ seriously ill hospitalized patients,²⁸ family members of ICU patients, as well as audio-recorded physician-patient communication.³⁰ She has received training in qualitative methods through coursework at the University of Pittsburgh and UCSF and mentorship by qualitative methods experts. Ms. Cimino has received training and experience in semi-structured interviews and qualitative analysis through previous research and her work with Dr. Anderson.^{27,28} Dr. Lo has mentored a number of investigators on qualitative research to investigate ethical issues.^{8,31-33} In addition, he has specific experience with the development and use of video simulations to address questions in ethics and physician-patient communication.³³⁻³⁵

Ethical aspects of CPR discussions in the hospital. The proposed research emerged from an analysis of audio-recorded CPR discussions between attending hospitalist physicians and medical inpatients conducted by Dr. Anderson and colleagues as part of the Hospitalist Rapport Study (manuscript under review, please see appendix).¹⁰ A number of patients who participated in this study had serious illness, and the participating physicians were experienced in hospital medicine and discussed CPR frequently. However, prognosis and larger life goals and values were not addressed in the audio-recorded CPR discussions, and no physicians gave a recommendation about the use of CPR. In addition, Dr. Anderson has studied and written about the ethical aspects of withdrawing and withholding life-sustaining therapies.³⁶ Dr. Lo has conducted extensive empirical and ethical work around life-sustaining therapies including CPR, as well as ethical and policy implications of systems of care.^{8,37-39} His expertise and qualifications make him an optimal mentor for this project.

RESEARCH DESIGN

Study design: The design is a qualitative analysis of semi-structured interviews. Because this is a pilot study, our primary goals are to assess feasibility and collect preliminary data. We will create two high quality video-simulations to elicit patients' perspectives on discussing prognosis and end-of-life goals and values and receiving a recommendation about CPR from a hospitalist physician. In 1-hour interviews, 20 seriously ill hospitalized patients will view and comment on a test video, which includes these elements, and a control video, which does not.

Our design has several strengths. First, we chose qualitative methodology so as to appreciate the breadth and depth of patients' perspectives on CPR decision-making and to explore the meanings behind their reactions to discussing end-of-life issues with an unfamiliar physician.⁴⁰ Second, by using video-simulations we will approximate patients' reactions to CPR discussions in clinical practice. However, because patients will not be evaluating a discussion they had with a physician caring for them, they may be more likely give genuine responses. Third, we will elicit the perspectives of patients who would be faced with these discussions and decisions in clinical practice, and who might change their decisions about CPR based on a discussion of their prognosis.⁷ Finally, the results of this proposal will lead directly to a multicenter study, which will form the basis of an intervention to improve CPR discussions at the bedside.

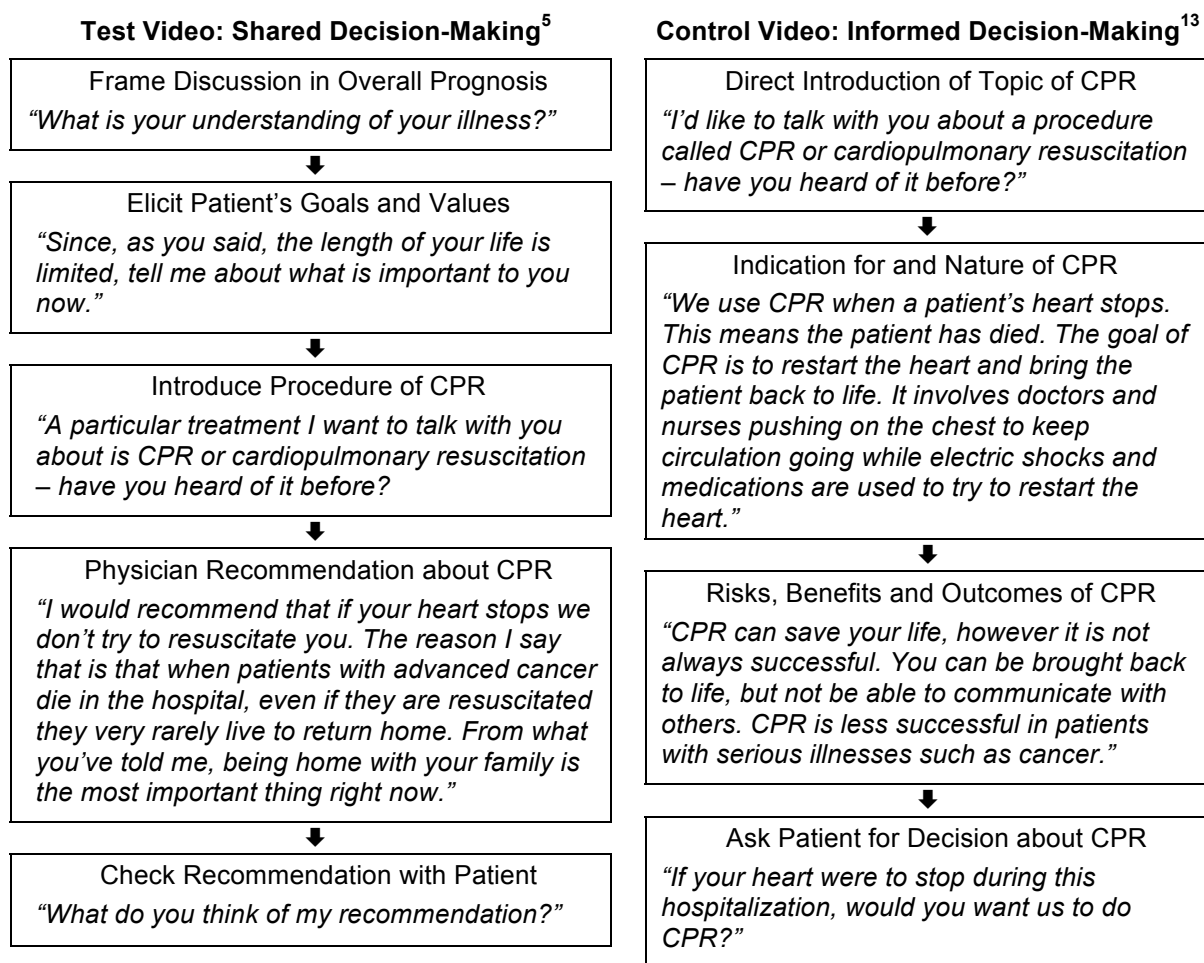
Study setting: Patients will be recruited from the inpatient medical service at UCSF's Moffitt-Long Hospital, an academic tertiary care referral center and community hospital for the surrounding neighborhoods. Approximately 4000 adult patients are admitted to the medical service each year, and are cared for by hospitalist physicians.

Video Development and Production: We will develop two 10-minute videos of simulated CPR discussions between a seriously ill patient and a hospitalist physician to assess patients' perceptions of the utility and acceptability of discussing prognosis and end-of-life goals and values and receiving a recommendation from a hospitalist physician (Figure). Professional actors and production will be used to ensure high video quality.

Test video: The test video will simulate a physician-patient discussion based on a *shared decision-making model*.⁵ It will begin with discussion of the patient's overall prognosis, followed by elicitation of the patient's end-of-life values and goals. The physician will introduce CPR as a procedure, but will not provide extensive detail about what happens during CPR. This video will conclude with the physician giving a recommendation for CPR based on the patient's prognosis, goals, and values. After stating and describing the reasoning behind the recommendation, the physician will elicit the patient's opinion about it.

Control video: The control video will simulate an *informed decision-making model*, based on a script to which hospitalized patients have responded positively.¹³ This video will provide detailed information about the nature of CPR as a procedure, and its indication, risks, benefits and outcomes. In this video, the simulated physician will not elicit the patient's goals and values and will not give a recommendation. At the end of the discussion, the physician will ask the patient to state their preference for CPR. The physician will not discuss the patient's specific prognosis, but will note that patients with serious illnesses have a lower likelihood of survival after CPR.

Figure: Preliminary Plan for Videos to Elicit Patients' Perspectives on CPR Decision-Making, including Selected Example Physician Script



CPR = Cardiopulmonary resuscitation

Ensuring authentic content: The first step in video development will be an extensive review of the literature around CPR decision-making and discussions to ensure that each video is consistent with best practices in shared and informed decision-making models, respectively. We will review published journal articles, books, and electronic media (e.g. *Grave Words*⁴¹) for content and examples of CPR discussions using various decision-making models. Second, to ensure that the video is realistic, we will base the video scenario and scripts on actual discussions between seriously ill patients and hospitalist physicians audio-recorded by Dr. Anderson for the Hospitalist Rapport Study.²⁷ Next, for feedback about the videos' compliance with recommendations and authenticity, we will distribute a draft script to experts in bioethics, physician-patient communication, and hospital medicine, including those providing letters of support for this application: Drs. Wachter, Auerbach, and Arnold, in addition to other national experts. Finally, we will pilot test our scripts with five seriously ill hospitalized patients, who will be recruited as research subjects.

Ensuring quality production: Christian Burke, a Media Architect in the UCSF Office of Educational Technology will provide pre-production consultation including storyboarding of the video (free of charge to UCSF faculty). Mr. Burke has extensive experience in video development for educational and other purposes. Special focus will be given to the videos' intended audience (seriously ill patients participating in a research study), and goal (to elicit patients' responses to ethical aspects of CPR discussions). Professional actors from the UCSF Standardized Patient Program will play the roles of the simulated physician and patient. The actors will be trained in conjunction with Bernard Miller, Program Manager at the UCSF Clinical Skills Center. The videos will be shot at the Clinical Skills Center, which provides a simulated hospital room that is optimized for audio- and video-recording. Digital audio- and video-recording and post-production will be done professionally by Tony Mills at Spark Productions, a San Francisco Bay Area production company that has worked extensively with large and small corporations as well as on UCSF faculty projects. We have budgeted sufficient time to allow for re-shooting and re-editing portions of the videos. The final product will be two digital videos that will be presented to patients on a laptop computer.

We will take several measures to ensure that the videos are similar in all aspects aside from the different decision-making models presented, including length, likability and trustworthiness of the simulated patient and physician, and response of the simulated patient to the physician. In creating the script and directors notes, we will specify verbal and nonverbal physician actions to build rapport in both videos. During actor training, production, and post-production, we will elicit feedback from the simulated patient trainer as well as from laypersons about differences between the doctor and patient in the two videos. Both videos will state that the likelihood of surviving CPR is lower in patients with serious illness. However, only the physician in the test video will address the fact that the simulated patient has a serious diagnosis.

Participants

Eligibility criteria: Patients will be included if they: 1) are admitted to the medical service at Moffitt-Long Hospital, and 2) their attending hospitalist physician reports that they have a terminal illness, or "Would not be surprised by the patient's death or ICU admission within 1-year."⁴² We will exclude patients who would not be able to discuss CPR with their inpatient physician or participate in the informed consent and interview process because: 1) they have acute or chronic altered mental status or confusion, 2) their English fluency is not sufficient to communicate without a translator, or 3) they are unable to communicate verbally for another reason (e.g., speech disorder, tracheotomy).

Recruitment: Potential patients will be identified on a daily basis via their attending physician and approached in their hospital room for screening and informed consent. These eligibility criteria and recruitment strategy were used to recruit 5 seriously ill patients per month into the Hospitalist Rapport Study.²⁷ Thus, we expect to recruit our goal of 20 patients within 6 months. Patients will be blinded to the enrollment criteria that their physician felt they were seriously ill so as not to inadvertently disclose their prognosis. Patients will be told that the purpose of the study is to understand their perspectives about and improve discussions of CPR in the hospital.

Data Collection and Measures

Semi-Structured Interview: A semi-structured interview protocol will be developed to elicit patients' perspectives on discussing CPR in the hospital, using the videos as prompts. Each

patient will view and comment on both videos. The order in which they are shown will be alternated so that 10 patients see the shared decision-making video first and 10 see the informed decision-making video first. Once a patient has enrolled in the study, Ms. Cimino will find a time when he/she can spend an hour viewing and responding to the videos. In our previous experience, a 1-hour interview is feasible and acceptable to patients so long as we are flexible about when it is conducted.^{27,28} The interview will begin by ascertaining the patient's prior experience with discussion of advance care planning and CPR in particular in the inpatient and outpatient settings. Next, both videos will be played through in their entirety, and patients will be asked to comment on differences they noted between the videos. Patients will be asked how they would feel about having a similar discussion with a doctor who they had just met in the hospital, and what they would decide about CPR if they were the patient in the video. In addition, control questions will be asked about the likability and trustworthiness of each of the simulated physicians. The interviewer will then play back segments of each video to elicit patients' reactions to the discussion of prognosis, end-of-life goals and values, detailed information about CPR, and the physician recommendation. For each of these segments, patients will be asked: 1) how useful a similar discussion would be to their decision-making about CPR, and 2) whether the discussion would offend or upset them. Interviews will be digitally audio-recorded and transcribed for analysis.

Brief written questionnaire: At the conclusion of the semi-structured interview, participants will complete a brief 10-minute paper survey, to describe the study sample. Information obtained will include demographics, perception of prognosis,⁴³ preferences for end-of-life-care,⁴⁴ previous discussions and decisions about CPR, preferred role in decision-making,⁴⁵ and advance directive completion. Clinical information will be obtained from physicians during screening.

Feasibility: Assessing feasibility is a primary goal of the project. We will track the number of patients who are referred, eligible, screened, consent, and complete data collection. At the conclusion of the interview, we will ask patients about the experience of participating in the study, and for feedback about the quality and authenticity of the videos.

Data Analysis

Qualitative Analysis of Semi-Structured Interviews: Interview transcripts will be analyzed qualitatively to describe themes within participants' responses to semi-structured interview questions. Specifically, we will describe how each element in the videos – prognosis, goals and values, detailed information about CPR, and receiving a physician recommendation – might: 1) benefit them or help them to make decisions about CPR, and 2) offend them or cause distress or harm. We will use a grounded theory approach⁴⁶⁻⁴⁸ with concurrent analysis and data collection. First, Dr. Anderson and Ms. Cimino will independently perform line-by-line open coding on 5 transcripts. They will create a comprehensive list to track and organize codes, and will review the list and data exemplars with Dr. Lo to select salient themes for further analysis. The interview guide will be modified to gather additional information about salient themes in future interviews. Open coding and modification of the code list will continue until recurrent themes are identified and new themes do not emerge. Though we may not reach thematic saturation after 20 interviews, this number should provide variation in patients' perspectives and allow planning for future, larger studies. After we have identified salient themes in all of the transcripts, we will apply additional passes of coding to describe aspects and variations of each theme and relationships among them.

Feasibility: Data on referral, screening, and recruitment will be reviewed on a weekly basis to identify barriers and facilitating factors. The protocol will be modified iteratively over the course of the data collection period to find an optimal protocol. Patient responses about the experience of participating in the study and the videos will be reviewed on a weekly basis as well. Changes to the protocol will be made to improve the patient experience. Possible modifications to the videos will be cataloged and discussed by the research team. We have allowed for re-shooting and re-editing portions of the videos during the protocol, and will also plan modifications of the videos before use in the larger, multicenter study.

PLANS FOR DISSEMINATION AND FUTURE WORK

Dr. Anderson is a hospitalist and palliative care physician and researcher. Her career goal is to improve the quality of care for seriously ill patients by improving decision-making between physicians, patients, and families in the hospital. She has received career development awards from the National Palliative Care Research Center and the UCSF Clinical and Translational Science Institute, and is site-PI for an NIH-funded multicenter study of physician-family communication in the ICU. The proposed research grew from her previous work demonstrating that CPR discussions between hospitalists and patients do not include elements felt to be important for decision-making: discussion of prognosis, goals and values, and a physician recommendation. The next step in her research is to translate ethical recommendations into practice by creating an intervention to train hospitalist physicians to discuss CPR.

The research described here will provide important patient perspectives on discussion of prognosis, goals and values, and a physician recommendation when discussing CPR in the hospital. It is critical that we obtain patient perspectives before implementing changes to how physicians discuss code status. We will disseminate our findings to practicing hospitalists via location presentations, submission to the Society of Hospital Medicine Annual Meeting, and publication in a peer-reviewed journal. This project will result in an NIH application to fund a larger, multicenter study of culturally diverse patients from academic and community hospitals in geographically distinct locations. The results of the larger study will inform the development of an intervention to train hospitalists to discuss CPR based on ethicists' and researchers' recommendations as well as patients' perspectives.

STUDY TIMELINE

Activity	2010	Funding Year 2011 by Month												2012
		Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	
IRB approval	X													
Video development		X	X	X										
Patient interviews					X	X	X	X	X	X				
Assess feasibility					X	X	X	X	X	X				
Analysis of interviews					X	X	X	X	X	X	X	X		
Local presentations												X		
Abstract preparation												X		
Manuscript preparation												X	X	
Funding for larger study														X

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