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The long term impact of an end-of-life communication intervention among Veterans with COPD

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Abstract

Objective—The purpose of this study was to assess if an end-of-life communication intervention with patients with COPD led to higher long-term documentation of advance care planning discussions at the end-of-life.

Background—We previously demonstrated that providing clinicians a brief patient-specific feedback form about patients' preferences for end-of-life communication improved the occurrence and quality of clinician communication about end-of-life care.

Methods—The study was conducted at the Puget Sound VA Healthcare System. Among those individuals enrolled in the intervention study (2004–2007) who had died during the follow-up period (up to 2013), we assessed if patients in the intervention arm had more goals of care discussions and formal advance directives completed as compared to patients in the control arm. We conducted logistic models accounting for provider level clustering, adjusting for age, FEV_1, and race.

Results—Among the 376 patients in the parent study, 157 died, of which 76 were in the intervention arm and 81 in the control arm. The mean age was 72.5 (SD 9.1), 99% were male, with a mean FEV_1% predicted of 45 (SD 17.8). Over an average duration of 3.6 years (from the time of the first study appointment to death), 115 (73%) patients engaged in 451 unique end-of-life care discussions. The intervention was not associated with a higher percentage of patients with documented end-of-life conversations (I:C 75% vs 72%, p=0.63) or completion of advance care directives (26% vs 29%, p=0.55).

Conclusions—Despite initially improving the occurrence of end-of-life conversations, the intervention did not increase the documentation of subsequent conversations about end-of-life care, nor did it improve documentation of advance directives. Seventy-five percent of the patients

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in our cohort had documented follow-up conversations showing most have these conversations, but there is room for improvement and an unclear impact on goal-concordant care. Future research should focus on testing multi-faceted, longitudinal, system-level interventions to enhance conversations about goals of care that promote goal-concurrent care.

Keywords

End of Life Communication; Advance care planning; Chronic Obstructive Pulmonary Disease (COPD)

Background

Advance care planning (ACP) is a complex and dynamic process of communication in which a person who has decision-making capacity considers their goals and values with regard to future health or personal care to inform decisions that might need to be made should he/she become incapable of making his/her own decisions. (1) This process ideally occurs prior to acute medical events and involves discussions to help patients and surrogate decision makers prepare to make in-the moment decisions based on one's values and preferences for care. (2, 3) The ultimate goal of advance care planning is to align patients' preferences for treatment with the care they receive when they are unable to communicate those preferences. However, providers often avoid engaging in goals of care conversations during routine care resulting in care decisions being made during times of crisis (4) when patients are often unable to participate and families often "want everything done".(5, 6) Moreover, the process of advance care planning has been shown to occur infrequently among patients with COPD. (7, 8)

We previously reported that a one page patient-specific feedback form that contained preferences for advance care planning, provided to patients, patients' surrogates and their clinicians, improved the occurrence and quality of clinician communication about end-of-life care. (9) In this paper we report a follow up study examining those participants who died during the subsequent follow-up period to determine whether the intervention led to a higher number of end-of-life care conversations and completion of advance directives prior to death.

Additionally, we hypothesized that patient characteristics, including patient's perception of their general health status and disease-specific health status that may be predictive of engaging in subsequent goals of care discussions.

Methods

Design

Original Intervention Study—We conducted a clustered randomized trial to test an intervention to promote discussions about advance care planning and goals of care. (9) The trial examined short-term occurrence of and quality of communication about end-of-life care from the patient perspective. The unit of randomization was at the clinician level with patients clustered by clinician. As part of the intervention, we generated an individualized 1-page patient-specific feedback form that was distributed to clinicians who were randomized to the intervention and to their patients (Figure 1). The feedback form included patients' preferences regarding discussing advance care planning, patient-specific barriers and facilitators to communication about end-of-life care, patient preferences for cardiopulmonary resuscitation (CPR) and mechanical ventilation, and severity of their airflow limitation. We mailed the 1-page patient-specific feedback form to patients to review and share with their surrogate decision-maker(s). On the day of a scheduled clinic visit, study coordinators provided the patient-specific feedback form to clinicians and patients to use during the clinic visit. Patients were then surveyed at 2 weeks after the targeted clinic visits to administer outcome measures including the occurrence of and quality of end-of-life communication between themselves and the enrolled clinician. Information on whether the patient or clinician initiated the conversation during the clinic visit was not assessed. Patients in the intervention arm reported a nearly 3-fold higher rate of discussion about end-of-life care (unadjusted: 30% vs. 11%, $p<0.001$) and higher quality of communication (Cohen effect size: 0.21). (9)

Current Study—We examined whether the communication intervention led to more conversations and advance care planning documentation in the medical record prior to death. We identified patients enrolled in the intervention study that died after their initial study visit (which occurred between 1/2004 and 11/2007) and before September 2013. We abstracted medical records including all in-patient and out-patient encounters documented by primary care clinicians, intensivists, pulmonary clinicians, palliative care clinicians and social workers. Data abstracted included: the occurrence and dates of end-of-life conversations, content of the conversation, for example discussion of mechanical ventilation, CPR, tube feeding or general end-of-life care, and completion of formal advance directives. We also collected documentation of the participants during the conversations (patients, clinicians, family members, friend, power of attorney). To ensure accuracy of the data abstracted, one of the investigators (LFR) reviewed content of 25% of the chart abstractions. Any discrepancies in the interpretation or documentation of the data was discussed and resolved among the study team members.

At baseline, we assessed patients' perception of their general health status, measured by a single item from the SF-36 (10) by asking patients to rate their health on a 5 point likert scale with 1 being excellent and 5 being poor. We assessed patients' perception of their disease-specific health status, measured by the St. George Respiratory Questionnaire (SGRQ) (11) total score. Patient demographics, co-morbidities and health status measures were also collected at enrollment in the original study.

Settings and subjects

The study was conducted at the VA Puget Sound Health Care System (clinicaltrials.gov NCT00106080). Subjects included patients with COPD as defined by the GOLD criteria (2003) (12) who participated in the End-of-Life Communication Trial and died after study completion (n=157). The study protocol was approved by the IRB at the VA Puget Sound Health Care System (#01378).

Analyses

We examined means (sd), and proportions of the cohort for demographic variables and health related variables. The outcome measures, end-of-life care discussions and completion of advance directives, are dichotomous variables. We conducted logistic models accounting for provider level clustering, adjusting for age, FEV_1, comorbidities, race, and patients' self-perceived general and disease-specific health status to identify patient predictors of documentation of subsequent end-of-life discussions. Statistical analyses were conducted in R version 3.2.2 9R Core Team, 2015.

Results

Among the 376 patients in the parent study, 157 died, of which 76 were in the intervention arm and 81 in the control arm. The mean age at death was 72.5 (9.1), 99% were male, 90% Caucasian, with a mean FEV_1% of 45 (17.8). The most common self-reported comorbidities were hypertension (65%), CVD (45%), pneumonia (43%) and depression (32%). There were no significant differences in the patients' baseline characteristics (Table 1).

End-of-life Discussions

Among the 157 patients that died, 115 (73%) patients had medical record documentation that they engaged in 451 unique end-of-life care discussions. These discussions occurred over an average duration of 3.6 years (SD 2.7) with a range from 9 months to 8.6 years. On average, there was documentation that patients engaged in 2.9 (SD 3.6) conversations (range 0–23). Patients assigned to the intervention averaged 3.1 (SD 4.0) documented conversations compared with patients in the control arm averaging 2.6 (SD 3.2) documented conversations (p=0.47 by Wilcoxon Rank Sum Test). Fifty-seven (75%) of the patients in the intervention group had documentation that they engaged in one or more end-of-life conversations as compared to 58 (72%) in the control group (p=0.63) (Figure 2). After adjusting for age, FEV_1, and race and accounting for provider level clustering, a logistic regression model found no significant difference (p=0.53) between the control and intervention arms on the odds of documentation of a patient engaging in one or more end-of-life conversations (intervention arm OR=1.30, 95% CI 0.58, 2.92).

Among the 451 end-of-life conversations, 234 discussions (52%) were specifically about hospice care and involved 75 patients. Overall, there were 38 referrals placed to hospice. We found no significant difference in the number of hospice referrals between patients in the intervention versus control arm (p=0.76). Among the 157 patients that died, 54 (34%) had an end-of-life discussion within 31 days of death. More than half of the conversations (n=241, 54%) occurred between a clinician and patient while 89 (20%) of the conversations took place among a clinician, patient and family member.

Completion of Advance Directives

Twenty (26%) patients completed advance directives in the intervention group as compared to 18 (29 %) in the control group (p =0.55) (Figure 3). After adjusting for age, FEV_1, and race and accounting for provider level clustering, a logistic regression model showed no significant difference (p=0.49) between the two groups on the odds of a patient completing an advance directive (OR 1.30, 95% CI (.614, 2.77)).

Predictors of Engaging in End-of-Life Discussions

We hypothesized that patients' perception of their health status may lead to further goals of care discussions. We examined the association of two patient characteristics at enrollment, self-rated perception of general health and disease-specific health status, with the occurrence of end-of-life discussions. We found neither general health status (SF-36 single summary item, how would you rate your current health) nor disease-specific health status (SGRQ-Total score) at study enrollment was associated with the odds of a patient having subsequent end-of-life discussions (general, OR 0.82, CI 0.55, 1.21), p=0.31); disease specific (OR 0.09, CI (0.01, 1.13), P=0.05) after adjusting for age, FEV_1 and race.

Discussion

We found that a one-time intervention that improved patients' reports of conversations about end-of-life care preferences at two weeks did not result in more frequent documentation of advance care planning over several years. Patient characteristics, including perception of general health and disease-specific health status, did not predict documentation of subsequent end-of-life discussions. Our data suggests there are opportunities to improve these discussions among patients with severe COPD. Among the 157 patients who subsequently died after the original intervention, 27% of these patients did not have documentation of any conversations about end-of-life care. Approximately one third of the these conversations were conducted within 1 month of death and among those patients that engaged in conversations about end-of-life care, there was large variability in the number of discussions for each patient.

Prior studies of patients with advanced cancers have shown significant variability in the proportion of patients who have discussions about end-of-life care. A study of patients diagnosed with advanced gynecologic cancer found that among 177 patients, 80% had documented end-of-life discussions and more than one half of the conversations took place less than 1 month before death.(13) However, in a prospective cohort study of 332 patients with several types of advanced malignancies, only 37% reported having conversations about end-of-life care. The median interval between the conversation and death was 33 days.(14) In a separate study using the same consortium data collection, Mack et al. found that 39% of patients reported having discussed their wishes for end-of-life care with their physicians.(15) Patients who were aware they were terminally ill and had engaged in end-of-life discussions were more likely to receive care consistent with their preferences. Our findings of 75% of patients with COPD having these discussions is comparable to the higher proportions seen in some prior studies. However, there is room for improvement since all patients diagnosed with advanced COPD should be offered the opportunity to engage in advance care planning and goals of care conversations and these conversations should take place earlier in the disease trajectory than it often does.(16)

Our relatively simple, patient-specific feedback form initially increased the quantity and quality of communication about end-of-life care with patients with COPD. Importantly, several studies demonstrate that employing advance care planning interventions result in ensuring patients receive the care they would elect if they were fully informed. (17–19) Many of these interventions use established guides to facilitate advanced care planning such as Respecting Choices® (20) or Five Wishes®. (21) Using a trained care planning mediator, social worker or nurse increases completion of advance directives and promotes interdisciplinary team communication about end-of-life care. (22, 23) (24, 25) Training non-physician health care professionals to initiate goals of care discussions may increase the frequency of conversations resulting in care provision aligning with patients' preferences. (17) Regardless of the health care professional designated to initiate goals of care discussions, these discussions are often challenging requiring communication skills training and practice. (26–28) Commitment to offering clinician communication skills training calls for leadership to recognize the value of goals of care conversations and the potential impact on patient care delivery and health care utilization.

Despite our findings that the communication intervention resulted in more patients engaging in end-of-life care discussions within the two week follow up period, we did not show any increase in advance directives or long-term documentation of more discussions. There may be several reasons for this discrepancy. First, it is possible that clinicians or patients may have engaged in subsequent goals of care discussions without these discussions being document in the medical record. Heyland and Houben (29, 30) found patients often express their preferences for end-of-life medical treatments with a loved one, but do not necessarily communicate their preferences with health care professionals nor do these discussions get documented in the medical record. Although documentation of care preferences on advance directive forms is considered only one aspect of advance care planning, some studies suggest completion of advance directives leads to more concordance of care (31), decreased likelihood of dying in the hospital (32) and less caregiver burden. (33) A second reason that our intervention may not have resulted in changes in long-term documentation of discussions about end-of-life care may be that a single intervention isn't adequate to change long-term clinician behavior. Further development and testing of multi-faceted, longitudinal, system-level interventions are needed to ensure advance care planning occurs over time and allows patients to receive care concordant with their preferences.

Our findings failed to support our hypothesis that patients' perception of their general health, or disease-specific health status, predicts engagement in future end-of-life conversations. This finding may be attributed to the fact that health status was assessed at enrollment, months to years prior to the documentation of conversations about end-of-life care. Using hypothetical scenarios, Turnbull and associates found physicians who were asked to assess patients' functional prognosis were 49% more likely to report they would initiate discussions about withdrawal of life support, while explicit description of patient values had no effect on physicians' intention to initiating these discussions.(34) These findings support the importance of health care professionals recognizing a decline in health status as a trigger to initiate goals of care discussions with their patients, and to ensure their current wishes are understood and documented.(35)

There are several limitations to this study. First, the sample was within one VA facility potentially limiting generalizability. Second, the subset of patients from our original cohort that subsequently died was small which may have prohibited our ability to detect differences. Third, the time period from baseline assessment of patients' perception of their health status to the time of subsequent follow up end-of-life conversations was on average 3.6 years. Assessment of health status more proximal to subsequent conversations may have predicted which patients were more likely to engage in advance care planning. Fourth, due to relatively limited evidence on current practice of advance care planning for patients with COPD, it is difficult to know if our finding that 75% had documentation of these discussions is better than other settings. Lastly, we were unable to assess whether the intervention had any effect on the receipt of goal-concordant care.

In summary, despite initially improved patient reported conversations about end-of-life care with their providers, we found no significant long-term effect of a communication intervention on subsequent documented advance care planning conversations, or completion of advance directives. Clinicians, patients and their families engaging in discussions about end-of-life care has been held out as a hope to align patient preferences for care and decrease unwanted services. Our results highlight the importance of clinicians engaging in ongoing goals of care discussions with patients and family, as their preferences and health status change over time. Our results also highlight the importance of larger sample sizes for studies examining long-term effects of goals of care communication interventions on patient- and family-centered outcomes.

Acknowledgments

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Abbreviations

COPD	Chronic Obstructive Pulmonary Disease
ACP	Advance Care Planning

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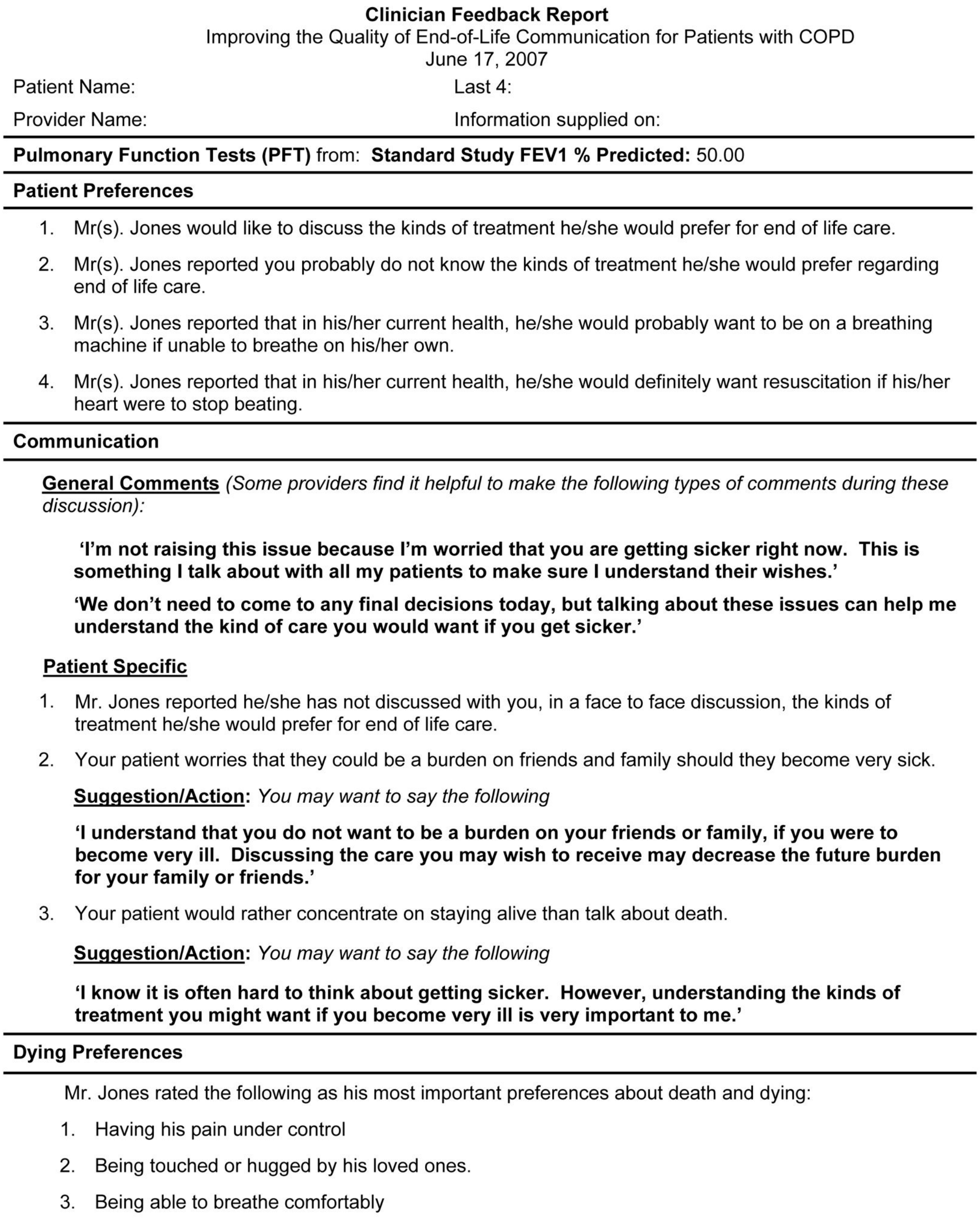

Clinician Feedback Report

Improving the Quality of End-of-Life Communication for Patients with COPD

June 17, 2007

Patient Name: Last 4:

Provider Name: Information supplied on:

Pulmonary Function Tests (PFT) from: **Standard Study FEV1 % Predicted:** 50.00

Patient Preferences

1. Mr(s). Jones would like to discuss the kinds of treatment he/she would prefer for end of life care.
2. Mr(s). Jones reported you probably do not know the kinds of treatment he/she would prefer regarding end of life care.
3. Mr(s). Jones reported that in his/her current health, he/she would probably want to be on a breathing machine if unable to breathe on his/her own.
4. Mr(s). Jones reported that in his/her current health, he/she would definitely want resuscitation if his/her heart were to stop beating.

Communication

General Comments *(Some providers find it helpful to make the following types of comments during these discussion):*

'I'm not raising this issue because I'm worried that you are getting sicker right now. This is something I talk about with all my patients to make sure I understand their wishes.'

'We don't need to come to any final decisions today, but talking about these issues can help me understand the kind of care you would want if you get sicker.'

Patient Specific

1. Mr. Jones reported he/she has not discussed with you, in a face to face discussion, the kinds of treatment he/she would prefer for end of life care.
2. Your patient worries that they could be a burden on friends and family should they become very sick.

   Suggestion/Action: *You may want to say the following*

   'I understand that you do not want to be a burden on your friends or family, if you were to become very ill. Discussing the care you may wish to receive may decrease the future burden for your family or friends.'
3. Your patient would rather concentrate on staying alive than talk about death.

   Suggestion/Action: *You may want to say the following*

   'I know it is often hard to think about getting sicker. However, understanding the kinds of treatment you might want if you become very ill is very important to me.'

Dying Preferences

Mr. Jones rated the following as his most important preferences about death and dying:

1. Having his pain under control
2. Being touched or hugged by his loved ones.
3. Being able to breathe comfortably

Figure 1.

Example of clinician pamphlet

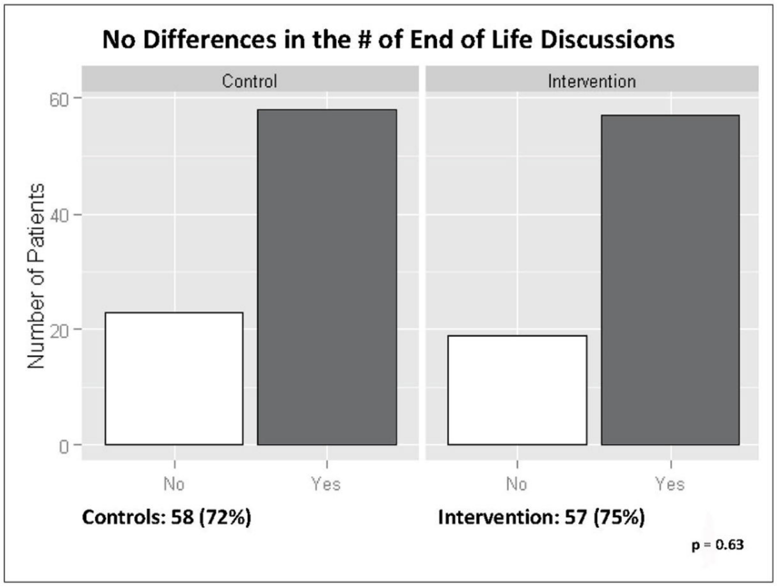

Figure 2.
Number of End of Life Care Discussions

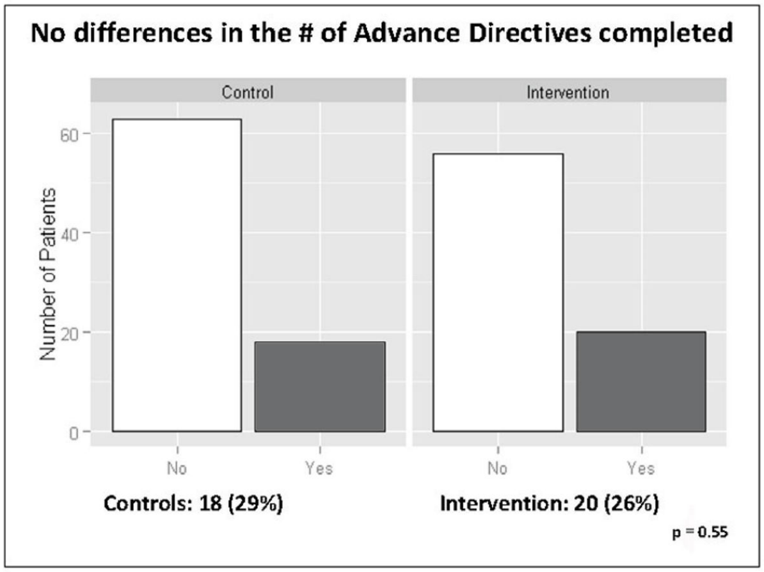

Figure 3.

Number of Advance Directives completed

Table 1

Patient Characteristics

Patient characteristics	Intervention (n=76)	Control (n=81)	P-Value
Age at baseline: μ (sd)	71.9 (9.7)	73.2(9.3)	0.3883
Male	98.7%	98.8%	0.99
Smoking Status			
Never smoked	1.4%	1.4%	0.25
Past smoker	76.1%	64.9%	…
Current Smoker	22.5%	33.8%	…
FEV1ofPredPost: μ (sd)	43.2 (17.0)	46.8 (18.4)	0.21
Self-Reported Caucasian	68.4%	67.9%	0.99
Comorbid Conditions			
Hypertension	69.0%	60.8%	0.39
Stroke	15.5%	13.5%	0.92
Depression	32.4%	31.1%	0.99
PTSD	22.5%	17.6%	0.59
Diabetes	23.9%	21.6%	0.89
Pneumonia	38.0%	48.6%	0.26
CVD (excluding hypertension)	42.3%	48.6%	0.54
Cardiac revascularization	18.6%	22.2%	0.74