2016

Improving end of life care for the homeless

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http://hdl.handle.net/2144/19469

Boston University
BOSTON UNIVERSITY
SCHOOL OF MEDICINE

Thesis

IMPROVING END OF LIFE CARE FOR THE HOMELESS

by

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B.S. University of California, Davis, 2011

Submitted in partial fulfillment of the
requirements for the degree of
Master of Science
2016
ACKNOWLEDGMENTS

I appreciate having the opportunity to be a part of the inaugural class of Physician Assistant Students at Boston University and I would especially like to thank my thesis advisor, Dr. Susan White, for the help she has provided through every step of this process. I would also like to thank my family and friends for their unwavering love and support.
IMPROVING END OF LIFE CARE FOR THE HOMELESS

EMILY THOMAS

ABSTRACT

As the United States population continues to age, providing this ever-growing group of individuals with end of life care is becoming an increasingly important issue. Quality end of life care begins with understanding the distinct needs and desires of each individual, and the best way to ensure that their wishes are followed is through the completion of advance directives. Although many Americans understand the importance of completing advance directives, the most vulnerable members of our society, the homeless, are often not given the opportunity to document their end of life wishes.

In addition to dealing with the demands of everyday life on the street, homeless individuals are often disconnected from the healthcare system, and therefore they frequently miss out on the opportunity to partake in advance care planning. As this population ages, their end of life care is becoming ever more important. Studies have shown that homeless individuals are willing and able to fill out advance directives when they are given the opportunity, but in today’s busy healthcare system medical providers often do not have the time to assist each of their patients with completing an advance directive. Fortunately, nursing and medical students have proven that they can successfully assist homeless individuals in filling out advance directives, although the success of physician assistant students in providing this intervention has yet to be studied.

This thesis will propose a new educational intervention designed to teach physician assistant students about advance care planning as well as giving them the
opportunity to assist homeless individuals in completing advance directives. The curriculum will provide an innovative way of fulfilling educational standards set forth by the Accreditation Review Commission on Education for the Physician Assistant, and it can be adapted for physician assistant programs throughout the nation. As a result, physician assistant students will graduate with the confidence and skills necessary to provide advance care planning to all of their patients.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>TITLE</td>
<td>i</td>
</tr>
<tr>
<td>COPYRIGHT PAGE</td>
<td>ii</td>
</tr>
<tr>
<td>READER APPROVAL PAGE</td>
<td>iii</td>
</tr>
<tr>
<td>ACKNOWLEDGMENTS</td>
<td>iv</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>v</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>vii</td>
</tr>
<tr>
<td>LIST OF ABBREVIATIONS</td>
<td>ix</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>Background</td>
<td>1</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>2</td>
</tr>
<tr>
<td>Hypothesis</td>
<td>3</td>
</tr>
<tr>
<td>Objectives and specific aims</td>
<td>4</td>
</tr>
<tr>
<td>REVIEW OF THE LITERATURE</td>
<td>5</td>
</tr>
<tr>
<td>Overview</td>
<td>5</td>
</tr>
<tr>
<td>Existing research</td>
<td>11</td>
</tr>
<tr>
<td>METHODS</td>
<td>21</td>
</tr>
<tr>
<td>Study design</td>
<td>21</td>
</tr>
<tr>
<td>Study population and sampling</td>
<td>22</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Intervention</td>
<td>21</td>
</tr>
<tr>
<td>Study variables and measures</td>
<td>23</td>
</tr>
<tr>
<td>Recruitment</td>
<td>24</td>
</tr>
<tr>
<td>Data collection</td>
<td>24</td>
</tr>
<tr>
<td>Data analysis</td>
<td>24</td>
</tr>
<tr>
<td>Timeline and resources</td>
<td>24</td>
</tr>
<tr>
<td>Institutional Review Board</td>
<td>25</td>
</tr>
<tr>
<td>CONCLUSION</td>
<td>26</td>
</tr>
<tr>
<td>Discussion</td>
<td>26</td>
</tr>
<tr>
<td>Summary</td>
<td>27</td>
</tr>
<tr>
<td>Clinical and/or public health significance</td>
<td>28</td>
</tr>
<tr>
<td>APPENDIX</td>
<td>30</td>
</tr>
<tr>
<td>LIST OF JOURNAL ABBREVIATIONS</td>
<td>40</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>41</td>
</tr>
<tr>
<td>CURRICULUM VITAE</td>
<td>45</td>
</tr>
</tbody>
</table>
LIST OF ABBREVIATIONS

ARC-PA……Accreditation Review Commission on Education for the Physician Assistant
BHCHP……………………………… Boston Health Care for the Homeless Program
EOL……………………………………………………………………………End-of-life
HELP AD………………………… Honoring End of Life Preferences Advance Directive
NIH…………………………………………………………..National Institutes of Health
PA………………………………………………………………….Physician Assistant
SELPH AD…. Study of End of Life Preferences for Homeless Persons Advance Directive
INTRODUCTION

Background

In our society, end-of-life (EOL) care services have been developed with the assumption that individuals have a home, the support of their loved ones, and the resources available to pay for supplementary care.\(^1\)\(^-\)\(^3\) These assumptions exclude the most vulnerable members of our society: the homeless. As the United States’ population ages, so, too, does the homeless population, meaning that there will be an even greater need for EOL care services among this group of underserved individuals. Today there are an estimated 1.6 to 3.5 million homeless people living in the United States\(^4\) who have an average life expectancy of 64 years.\(^5\) It is estimated that more than 58,000 seniors will experience homelessness annually in the United States by 2020.\(^1\) Homeless individuals have some of the highest rates of mortality of any population in North America; despite this, many suffer through their last days without proper health care because of their inability to access the EOL care system.\(^1\) Successfully providing this underserved group of people with quality EOL care is a serious public health concern that needs to be addressed.

For most people, the joys of experiencing older age are accompanied by discussions of one’s plans and wishes for EOL care. This is not true, however, for homeless elders; living on the streets requires them to be concerned with more pressing issues, such as shelter, food, and safety.\(^6,7\) Unfortunately, not only is the homeless population missing out on opportunities to discuss their preferences for EOL care, they are also consistently left out of research focused on advancing this area of medicine.\(^8\) In its report, State-of-
the-Science on Improving End-of-Life Care, the National Institutes of Health (NIH) explained that minorities and patients with multiple comorbidities are underrepresented or even excluded from EOL research. Many homeless people are minorities, and they are often the sickest members of the population, suffering from eight to nine active medical problems on average. Therefore, due to the fact that the homeless are an underserved and medically complicated population, it is not surprising that little research has gone into studying this group of individuals and their preferences for EOL care. Involving the homeless population in research studies will be important for ensuring that all members of our society receive quality EOL care.

**Statement of the Problem**

In the same report, the NIH described its desires for future research in the area of EOL care; this included the goal of creating novel EOL interventions in a diverse group of patients with a variety of primary and comorbid conditions to improve the EOL experience for all patients. Who better to target for this intervention than the homeless population—an underserved group of individuals with many medical and social comorbidities. Multiple studies have explored alternative methods for delivering EOL care to the homeless, but there are still many challenges to providing care to this population which need to be addressed.

One specific area that the NIH indicated as needing improvement is more effective communication and documentation of EOL discussions in advanced care planning. There have been a few studies which have started to lay the foundation for understanding the unique EOL needs, desires, and wishes of the homeless population: some studies have
looked at homeless individuals’ experiences with death and dying\textsuperscript{12,13} and how these exposures have shaped their thoughts about death.\textsuperscript{12–14} Other studies have demonstrated that homeless individuals who receive counselor-guided assistance with completing advance directives have much higher completion rates than those who do not.\textsuperscript{15–17} For example, in one study, 50.2 percent of individuals who received one-on-one assistance completed an advance directive, which is much higher than the completion rate in the general population.\textsuperscript{15} Unfortunately, these studies have also reported that one-on-one counselor-guided assistance typically takes around 40-45 minutes per individual.\textsuperscript{15,16} In today’s busy healthcare system, few medical professionals have 40-45 minutes to dedicate to helping their patients complete an advance directive. However, research has shown that healthcare students can be successful in assisting homeless individuals with completing advance directives. One study demonstrated that nursing students could successfully assist homeless people with advance directive completion,\textsuperscript{18} while a different study concluded that medical students were capable of providing a similar intervention.\textsuperscript{15} Since advance directives are proven to be a valuable method for granting patients their EOL wishes,\textsuperscript{19,20} and research has demonstrated that healthcare students can successfully assist homeless individuals with completing advance directives,\textsuperscript{15–18} this study proposal will test to see if a new educational intervention can prepare physician assistant (PA) students to assist homeless individuals in completing advance directives.

**Hypothesis**

PA students will be successful in assisting elderly homeless individuals with filling out advance directives once the students have completed an educational intervention.
Objectives and specific aims

As described by the NIH in their State-of-the-Science report, there is much work to be done in improving EOL interventions in diverse patient populations. One of the areas the NIH specifically identified as requiring significant improvement is how to more effectively communicate and document EOL discussions. This study will seek to address these issues by implementing a program which will educate PA students at Boston University on how to successfully provide advance directive counseling to homeless individuals and how to accurately document their EOL wishes. There are two specific aims for this study:

- To analyze students’ knowledge of advance care planning in homeless individuals both prior to and after completing an educational intervention.
- To complete a qualitative analysis of students’ opinions of providing advance care counseling to the homeless.
REVIEW OF THE LITERATURE

Overview

Homelessness is a major public health concern in our society today. In the past thirty years, it has become one of the most important American social problems. Despite major efforts to end homelessness by organizations such as the National Alliance to End Homelessness and the National Coalition for the Homeless, this is a problem that expected to be with our society forever. Today, the prevalence of homelessness among adult Americans across their lifetime is an impressive 7.4 percent. There continues to be a large number of people who experience homelessness each night—one estimate found that number to be nearly 650,000 people. Unfortunately, as the high prevalence of homelessness in the United States continues to be a concern, so, too, is the issue of providing these individuals with health care, especially since this population suffers disproportionately from medical disease.

Years of exposure to the elements coupled with high rates of alcohol and drug addiction contribute to elevated rates of chronic medical conditions in homeless individuals. Among these include higher instances of reactive airway disease, chronic obstructive pulmonary disease, diabetes, hypertension and peripheral vascular disease. Other conditions, such as liver and renal disease can go undetected for long periods of time, only to present with end-organ damage many years later.

Communicable diseases are also incredibly common in the homeless population: the prevalence of tuberculosis is 30 times higher in the homeless than the national average. Due to high rates of drug abuse, other diseases, such as HIV, hepatitis B, and
hepatitis C are becoming more prevalent in this population; in some areas these diseases are even endemic.\textsuperscript{7} In fact, one study found that one out of every five Health Care for the Homeless patients had an infectious or communicable disease.\textsuperscript{7} The high rates of these conditions is largely due to the prevalence of illicit drug abuse in the homeless population. It has been found that the rates of drug and alcohol abuse among the homeless can be up to eight times as high as in the general population.\textsuperscript{7} A compilation of one year of data from the Department of Homeless Services in New York City found that drug overdose was the leading cause of death among single adults living in shelters, which accounted for one third of all deaths among this group of individuals.\textsuperscript{22}

The high rates of drug abuse and communicable diseases are, in part, due to mental illness, which a large proportion of the homeless population struggles with each day. One study found that the prevalence of mental illness in the homeless population to be as high as 80-95\%.\textsuperscript{7} The National Coalition for the Homeless reported that people with severe mental illness represent around twenty-six percent of all sheltered homeless persons in contrast to only six percent of the U.S. population.\textsuperscript{4} The issues of drug abuse, mental illness, and communicable diseases that the homeless population struggle with paint the picture for how important, and yet, how difficult, it is for these underserved individuals to receive consistent health care.

Despite the medical and social conditions that threaten the health status of homeless people every day, the average age of the homeless population in America is on the rise.\textsuperscript{5,24} This will have implications not only in providing this population with basic health care needs, but more importantly, with EOL care. A recent study found that in
1990, only 11% of single homeless adults in the United States were age 50 and older, but today that number has increased to 50% of the homeless population. Another study looking at twenty-two years of data from New York City shelters has shown that peak age frequencies of shelter users in 1988 were between 28 and 33, but by 2010 they had risen to 46 to 51 years old. This is significant because research has found that homeless adults who are over age 50 tend to develop medical conditions that are typical of adults in the general population who are 15 to 20 years older. Experts consider homeless persons elderly at the age of 50—15 years younger than their housed counterparts. Therefore, providing EOL care to this growing population of aging homeless individuals will be incredibly important in the coming years.

EOL care is extremely important for all individuals, but the homeless have a difficult time accessing the services required for EOL care. The barriers to hospice and palliative care in the homeless include lack of knowledge, lack of monetary support, exclusion from hospice programs due to illicit drug use, and a system of EOL care that is built for housed individuals. These barriers have contributed to a system of EOL care that excludes the most vulnerable, unstable members of our society.

Many homeless individuals are not connected with the health care system for most of their lives. Because they have significantly less interaction with the health care community, there is a greatly reduced time period in which this population can obtain palliative care services. Unfortunately, due to the paucity of these interactions, homeless individuals are often unaware of the EOL services that are available to them. For example, a study of homeless people in Atlanta found that lack of hospice utilization
among patients was due to unawareness of hospice and palliative care as an option. The study went on to explain that these patients were often under the impression that hospice care was reserved only for patients with certain conditions, such as AIDS and cancer. The misunderstandings regarding the hospice care system expressed by these patients are consistent with other studies which found that minority populations are often not informed that hospice services are available to them. If many patients are not aware that these services exist, it will be impossible for them to obtain access; therefore, the first step in ensuring that homeless individuals receive EOL care will be increasing their awareness of the EOL services that are available to them. It is the responsibility of the health care providers to identify and implement successful practices to educate patients from traditionally underserved populations about hospice and palliative care services.

Another barrier to accessing EOL services in the homeless population is lack of available funds. Homeless people can rarely utilize hospice services because they do not have the means to afford inpatient hospice. Not only are homeless individuals unable to afford EOL care, many of them are not enrolled in Medicare or Medicaid, programs which, in many states, will help to cover the cost of EOL care. A study of chronically homeless adults found that almost three-quarters of those who qualified for Medicaid were not enrolled in the program. Without the financial resources to pay for EOL care, and lack of enrolment of homeless individuals in Medicare and Medicaid, it is not surprising that many homeless people are not receiving palliative and hospice care services.
Even when homeless individuals are aware of EOL services and fortunate enough to have access to these services, the EOL care system tends to exclude those who are illicit drug users. According to some estimates, this is up to one third of all homeless people. This concept has not been studied in-depth in the United States, but there have been a few Canadian studies which have addressed the issue. The Canadian studies have found that abuse of illicit drugs can be a barrier to EOL care for many individuals. EOL service providers are often worried about pain management in their patients—these providers are concerned that a history of illicit drug abuse will further complicate their ability to effectively manage the pain experienced by their patients. Many participants explained that EOL care service providers had zero-tolerance policies toward illicit drug use which automatically excluded this population. Homeless and unstably housed persons who abuse illicit drugs and/or alcohol already have complex EOL care needs, and these needs are further complicated by the challenges of trying to survive from day-to-day. Unfortunately, many EOL service providers enforce anti-drug policies which exclude homeless individuals from receiving EOL care.

Finally, another barrier to accessing EOL care for many homeless individuals, which has been well-documented in many studies, is the fact that the EOL care system is not built around the lifestyle of homeless individuals. Many studies have cited the fact that the hospice and palliative care organizations are set up based on the idea that people have supportive relationships and that they are stably housed. More specifically, many professionals and well-known organizations support the notion that a “good death”
occurs in the home. Unfortunately, this popularized way of experiencing death has failed to include some of the most vulnerable members of our society.

Despite the incredible number of barriers that homeless individuals face in receiving adequate EOL care, there is a single, simple intervention that can be used to ensure that these individuals have the opportunity to die with dignity and with their needs and desires being met at the end of their lives: advance directives.\(^\text{19}\) Respecting one’s choices at the end of their life is one of the most critical aspects to EOL care.\(^\text{8}\) Previous studies have shown that for homeless individuals, many of whom lack social supports, advance directives are often the only way for clinicians to direct the EOL care they provide for these individuals.\(^\text{16,17}\) Despite knowing this, completion rate of advance directives among the homeless population is lower than the general population,\(^\text{17}\) likely due to their longstanding lack of interaction with the health care system. The NIH has stated that research on improved communication and documentation of EOL wishes in underrepresented populations is one of its cornerstones for improving EOL care.\(^\text{8}\)

Therefore, many of the studies that have been done on EOL care in underserved populations involve research in this area.

**Existing research**

There has been some research which has attempted to understand what homeless individuals’ wants and desires are at the end of their lives. Many of these studies are the first of their kind, so they have attempted to gain a baseline knowledge surrounding the topic of EOL care in the homeless. In doing so, many of the researchers interviewed focus groups in hopes of understanding the unique desires of this group of individuals
regarding their EOL care. A few themes have emerged through the research that has been done in these focus groups.

The first requests made by homeless individuals regarding their EOL care were very basic, and, for most people, would be considered guaranteed rights when receiving care in the medical establishment. Many homeless individuals simply expressed that they hoped health care providers would listen to them at the end of their lives. Others expressed a desire to be treated with respect by health care providers. While these may seem like rights which should be granted to all people who receive EOL care, this population has long been discriminated against by the health care system, so it is understandable that these wishes were a common theme throughout the focus groups.

Discrimination by the health care system is a constant battle for the homeless population, and this issue has been well-documented in the literature. Many of the homeless individuals shared feelings of mistrust which were the result of poor interactions with the medical establishment in the past. Other participants were worried about being undertreated due to experiences of being discriminated against because of their housing status, race, HIV status, or addiction history. Some individuals stated that they expected to receive poor EOL care because of these past experiences, while others believed that EOL care was out of their control. This theme of discrimination by the health care establishment was woven into virtually every discussion of medical care involving homeless individuals.

Another topic that was brought up during many of the interviews with homeless individuals was spirituality. Many individuals were unsure of how advance care planning
would fit into their belief system. Some thought that planning for the end of life was interfering with God’s will,\textsuperscript{12} and that talking about death prematurely would bring it closer.\textsuperscript{32} For others, their spirituality and faith in God made them feel that they would never be alone, even at the time of death.\textsuperscript{14} Some individuals even explained that they did not believe that EOL planning was necessary, as death was in the hands of God.\textsuperscript{32} A strong religious faith is common among many people,\textsuperscript{27} therefore, this is definitely a topic that needs to be incorporated into effective EOL care for those of all faiths. This is extremely important because studies have demonstrated that patients feel that they are receiving better care when the provider asks about their spirituality.\textsuperscript{13}

Despite many individuals’ strong religious beliefs, many homeless people feel that EOL care planning is extremely important for giving them a voice—some even felt that advance care planning was even more important in their population than in the housed population.\textsuperscript{13,32} Many individuals explicitly stated their desire for written documentation of their EOL desires, as they felt that having their wishes in writing was the only way to ensure that they would be followed at the end of their lives.\textsuperscript{12,14,17} For some, these desires were due to the belief that they would be alone at the end of their lives, so documenting their written wishes was the only way to ensure proper EOL care,\textsuperscript{32} while others explained that they had often thought about what they wanted for their EOL care, but never had the opportunity to discuss and document these desires.\textsuperscript{15} The knowledge that many homeless individuals are interested in completing advance directives is extremely valuable; now the research must focus on how to best engage this population in completing advance directives so that their wishes can be followed.
It is important to realize that homeless individuals are interested and willing to discuss EOL planning, but there are many fears surrounding the end of life which are unique to this population and need to be addressed when discussing their EOL care. First, it is important to remember how brutal life, and death, on the streets can be. Many homeless individuals have had early experiences with death, face death on the streets each day, and have even had their own close encounters with death. Therefore, it is not uncommon for these individuals fear death, and think about it often. Other fears, which appear to be unique to the homeless population, include their fear of dying anonymously, the fear of unethical disposal of their body, and a fear that they will die alone and unnoticed. These worries, which are unique to the homeless population, most definitely need to be addressed when discussing EOL care with this population.

An area of much debate in the literature in regards to EOL care in the homeless population was whether or not this group of people will be able to name a surrogate decision maker when making plans for their EOL care, given that so many homeless individuals are isolated and lack social supports. A study by Song et. al found that, for the individuals who were able to name a surrogate decision maker, many of them did not wish to name a family member. These individuals cited either feelings of abandonment by their families or shamefulness regarding their housing situation as reasons why they preferred to have someone else as a proxy other than a family member. Similarly, other studies reported that homeless individuals usually do not have strong family ties, which they speculated could lead to difficulties when naming a health care proxy. However, when other studies actually looked at advanced directives completed by
homeless individuals, they all found that a majority of the participants named a family member as their health care proxy.\textsuperscript{15,16,33} Despite the assumptions made in much of the literature regarding a homeless person’s inability to name a surrogate decision maker, studies which have examined this topic directly have found that homeless individuals are often willing and able to name a family member to make health care decisions for them.

Another issue that was discussed frequently in the literature was the desire to name a physician or case manager as a surrogate decision maker.\textsuperscript{14,32–34} Unfortunately, this often puts physicians or other healthcare providers in a difficult position. A study that compared homeless persons’ care preferences in various EOL scenarios to the preferences of healthcare providers highlighted this issue: it found that homeless individuals were much more likely to choose invasive care measures than the clinicians.\textsuperscript{33} Other studies have also found that people of lower socioeconomic status and lower education levels are more likely to prefer more invasive EOL treatments.\textsuperscript{33,35,36} These studies highlight the fact that physicians who are designated as the proxies for homeless individuals may be less likely to provide the care that these patients desire, and this research shows just how essential it is for clinicians to discuss EOL care preferences with their homeless patients.

Another important issue which has been the subject of various studies is understanding the barriers to completing advance directives. Castillo et. al did a comprehensive review of twenty studies which looked at advance directive laws throughout the country.\textsuperscript{37} Many issues were discovered based on this review. First, they noted that every state has its own laws on advance directives and the laws can be highly
variable from state to state. In addition, most advance directives are written above the 12th grade reading level; considering the average elder American reads at the 5th grade level, this inhibits many people from being able to complete advance directives. In addition, many states have regulations on who an individual can name as their health care agent—most states do not allow people who are directly involved in the patient’s care to serve as the agent. For those who are unable to name an alternate proxy, the fate of their EOL care is often left up to the court.

When medical care is in the hands of the courts, it is often a challenging and convoluted process. For example, the decision to end life-sustaining treatment for a patient cannot be made by a court-appointed guardian or a surrogate decision maker unless there is a living will. Unfortunately, this interferes with a person’s right to die with dignity. As the current literature shows, not only is the language of advance directives a barrier for many patients, those individuals who are unable to fill out an advance directive or name a proxy often have additional barriers imposed by the court system which further inhibit their ability to access EOL care.

Despite the many barriers homeless individuals face in expressing their desires for EOL care, recent studies have found that when these individuals are given the opportunity to engage in advance care planning, the majority are willing and able to effectively participate in this activity. After performing research on homeless individuals’ desires for EOL care, Song et. al designed a special advance directive form which specifically targeted the needs and desires of the homeless population at the end of their life. The researchers used this form, entitled Honoring End of Life Preferences Advance
Directive (HELP AD) (see Appendix 1), in their study where they compared the completion rates of advance directives in two groups of homeless individuals: one group received self-guided materials while the other group received self-guided materials in addition to one-on-one assistance from trained counselors. What they found was that the group who had one-on-one assistance in completing the HELP AD had a completion rate of 59 percent, while the self-guided group had a completion rate of 30 percent.

Another study looked at completion rates in a group of homeless individuals who received one-on-one assistance in completing a similar form, entitled the Study of End of Life Preferences for Homeless Persons Advance Directive (SELPH AD), versus those who were only provided with self-guided assistance; this study also found that completion rates among those who received one-on-one assistance were higher: 37.9% in the counselor-guided group versus 12.8% in the self-guided group.

In a third study of homeless individuals, 50.2% of the participants volunteered to complete an advance directive. Of those who were willing to participate, all were able to successfully complete an advance directive with one-on-one assistance from medical students and doctors who had been trained as counselors. These recent studies exemplify the success that homeless individuals can have when they receive one-on-one assistance with completing advance directives. All of these studies used an advance directive form which complied information from previous trials regarding homeless individuals’ unique desires for EOL care. These studies are extremely useful, considering the importance of advance directives in this disenfranchised population and their history of lower completion rates.
of advance directives. Certainly the information gained in these studies can be used to further improve completion rates of advance directives among homeless individuals.

One other study looked at the completion rates of advance directives in homeless individuals who received assistance from nursing students. The students’ education prior to assisting the homeless included attending a workshop which addressed demographic and health related-issues unique to the homeless population. The students were also taught about the importance advance directives and their use in the healthcare field. They were then given the opportunity to assist homeless individuals with completing an advance directive form, which was adapted from the HELP AD designed by Song and colleagues. What the researchers found was that not only were the students effective in helping homeless individuals complete advance directives, they also gained skills which would be helpful to them in their nursing careers. This study demonstrated the success that students in the medical field can have when assisting homeless individuals in the completion of advance directives. It is clear that this intervention was beneficial to both the students and the homeless persons involved. This research provides the framework for future studies involving healthcare students in assisting homeless individuals with the completion of advance directives.

Unfortunately, not much is known about the educational curriculum provided to healthcare students regarding advance care planning, but most studies have found that generally, students who enter the workforce are not equipped with the skills necessary to take on the challenging task of discussing EOL care with their patients. According to one study, most medical programs generally do not teach their students about how to discuss
advance care planning. Another study explained that many medical students are not adequately equipped with the communication and management skills necessary to provide quality EOL care. Even medical residents have stated that the quality of their EOL education is much lower as compared with the rest of their medical education.

Unfortunately, information regarding EOL education in PA programs is scarce in the literature. However, it is known that since 2010 the Accreditation Review Commission on Education for the Physician Assistant (ARC-PA) has required Standard B1.06: all PA programs must incorporate education on palliative care and EOL care into their curriculum. In addition, Standard B2.06 set by the ARC-PA requires all programs to prepare students to work with patients from diverse populations. Finally, Standard B2.16 ensures that all programs incorporate the principles of medical ethics into their curriculum. Despite these standards, it is likely that many PA students are not prepared to effectively discuss EOL care options with their patients when they graduate.

This literature review has explored the importance of EOL care in the homeless population and it has addressed many of the barriers that these individuals face in receiving quality EOL care. Throughout their lives homeless individuals struggle with unstable housing as well as higher rates of communicable diseases, mental illness, and illicit drug abuse. They are often disconnected from the healthcare system, and when they do receive care, they frequently experience discrimination by healthcare providers. The culmination of these experiences makes providing EOL care to this population an extremely difficult task. As stated in an article in the Canadian Medical Association Journal, “there is no population more challenging to assist in dying than the homeless.”

10
Unfortunately, even though providing homeless individuals with EOL care is an incredibly challenging task, it is also a highly underdeveloped area of medicine and an understudied area of research.

As the average age of the homeless population continues to rise, providing these individuals with quality EOL care is an increasingly important public health issue. Recent studies have addressed problems related to EOL care that are unique to this population, including lack of awareness of EOL services, lower completion rates of advance directives, and a hospice system that excludes this group of individuals because of their living situation. Other researchers have successfully studied the unique EOL needs of this population and through these studies, they have designed the HELP AD, an advance directive which is catered to incorporate the unique wishes and desires of homeless individuals. Since the development of the HELP AD, studies have compared the completion rates of advance directives among homeless individuals who received one-on-one assistance with those who did not. These studies have all found that homeless individuals who received one-on-one assistance had significantly higher completion rates. Most importantly, the individuals who completed advance directives felt that this activity gave them a voice and a sense of autonomy in an area of their health care where they had previously felt powerless. Although research has shown that nursing and medical students can be successful in assisting homeless individuals with advance care planning, there have been no studies which have investigated PA students’ proficiency in this area.
METHODS

Study design
This study will be a curricular evaluation which will seek to compare PA students’ knowledge of advance care planning in a homeless population both before and after an educational intervention. The study will include a qualitative analysis of students’ reactions to providing advance care counseling for the homeless.

Study population and sampling
Subjects will be recruited from a single class of students in the Boston University Physician Assistant Program and will include all members of the class enrolled in their didactic year of training. The Boston University PA class size typically ranges from twenty-five to thirty-five students.

Intervention
Learning objectives for this intervention will be created with the help of faculty at the Boston University PA Program in order to incorporate standards set forth by the ARC-PA. Two lectures, each two hours in length, will be developed. Both lectures and the mock interview session will be directed by the study author. Students will be asked to complete a pre- and post-Workshop written exam, as well as a questionnaire which will allow the students to evaluate the educational intervention.

This curricular intervention will be implemented during the Clinical Practicum II Course in the Spring semester of the didactic year. The intervention will begin with all of the students completing a pre-Workshop exam consisting of ten multiple choice questions which will be used to assess the students’ baseline knowledge. The study author will then
present the first two-hour lecture. At the end of this session, the learner will be knowledgeable in the following areas:

A. The use of advance directives in the medical setting
B. Types of EOL care
C. Indications for EOL care
D. Barriers to EOL care for the homeless
E. Unique wishes and desires for EOL care in the homeless.

Two days later students will take part in the second two-hour session. For this session there will be two learning objectives:

A. Administer the HELP AD
B. Feel comfortable assisting a homeless individual with filling out the HELP AD.

During the first hour of the lecture, students will each receive a copy of the HELP AD. The study author will go through the form step-by-step with the entire class. Next, the study author will demonstrate a role play by interacting with one of the students. The students will then break off into pairs and each will have the opportunity to play the part of both the homeless individual and the part of the student counselor. Finally, in the last half of the session, the class will walk across the street to BHCHP for a short tour of the facility in order to familiarize them with where they will be working—students will also have the opportunity to mingle with the homeless individuals who are at the site. Upon returning to campus, the students will be asked to complete the post-Workshop test in
order to ensure that the learning objectives have been addressed and that the students’ skills are sufficient to counsel homeless individuals in completing the HELP AD.

The final day of the study will take place during one of BHCHP’s health fairs. A booth will be set up by the BHCHP staff. Homeless individuals who are interested in completing an advance directive will have the opportunity to work one-on-one with a Boston University PA Student. After the health fair has concluded, students will give their feedback of the curricular intervention and of their experiences with assisting the homeless population.

**Study variables and measures**

All students will be asked to take a ten question multiple choice exam both before the first lecture and after the second lecture. Students will take the same exam on both occasions. The following topics will be addressed in this exam:

- Use of advance directives in the healthcare setting
- Legal issues regarding advance directives
- Naming a health care proxy
- Understanding the HELP AD
- Qualifications for palliative care
- Qualifications for hospice care
- Demographics of the homeless population
- Barriers to EOL care in the homeless
- Religion and advance directives
- Feelings associated with completing an advance directive
Students will also complete a qualitative questionnaire in which they will evaluate both of the lectures, the interview practice session, the visit to BHCHP, their interactions with the homeless population, and the likelihood of the application of this intervention in their future practice. All of these items will be assessed on a Likert scale of 1-5.

**Recruitment**

All students enrolled in the didactic year of training at the Boston University PA Program would be recruited for the study. All students will receive the same curriculum but participation in the study will be voluntary.

**Data collection**

Data will be collected using a self-administered, ten question, proctored written exam as well as a self-administered Likert scale questionnaire.

**Data analysis**

Data from the pre- and post-Workshop exams will be analyzed using the paired t-Test to assess students’ understanding of advance care planning in homeless individuals both prior to and after completing an educational intervention. The Likert scale questionnaire will be analyzed for mean item scores with standard deviation to assess students’ evaluation of the program and to guide changes to the program in the future.

**Timeline and resources**

| Summer 2016 | • IRB submission and approval  
|            | • Development of curriculum for first lecture |
| Fall 2016  | • Development of curriculum for second lecture  
|           | • Development of pre/post-Workshop exams  
|           | • Development of Likert scale program evaluation |
Spring 2017

- 4 hours lecture
- BHCHP health fair
- Pre/post-Workshop exams
- Post-Workshop Likert scale evaluation
- Study completion

Summer 2017

- Data analysis
- Manuscript to be submitted for peer-review

Project oversight, data collection, and data entry will all be completed by the primary investigator. Data analysis will be completed with the help of a statistician. Program directors at the Boston University PA Program and the primary investigator will work together to develop curriculum for the two lectures. Coordination of the health fair will be completed by staff at BHCHP.

**Institutional Review Board**

The study will be submitted for review to the Boston University Medical Campus IRB for exemption for educational studies under 45 CFR 46. 101 (b) criteria. If the board does not approve the educational status, a full IRB protocol will be submitted for expedited review.

Budget line items:

**Administrative Support**

- Clerical (Wages)
- Data entry
- Statistical consulting

**Supplies and Expenses**

- Use of HELP AD Form
CONCLUSION

Discussion

The ARC-PA has outlined accreditation standards which require every PA program to educate their students on EOL care, medical ethics, and working with diverse patient populations. Unfortunately, there has been very little research to address the topic of educating PA students on EOL care, and no studies exist which focus on how to best teach PA students about the EOL care needs of the homeless. This study is unique, as it incorporates these three accreditation standards into a single educational curriculum. Importantly, the study provides PA students with the opportunity to familiarize themselves with the topic of EOL care through their face-to-face interactions with homeless individuals.

Although this is a unique study which will ultimately improve a PA’s ability to provide high quality EOL care to the homeless population, there are some limitations to the study which need to be pointed out. First, the sample size of the PA students participating in the study is relatively small: each PA class at Boston University is only made up of 20-30 students. In addition, all students in the study will be recruited from the same PA school which is located in a major metropolitan city. Finally, although the students will have the opportunity to interact one-on-one with homeless individuals, the time allotted for these interactions is relatively short and may need to be lengthened to ensure that the students are comfortable with discussing advance care planning with this population.
In addition to the study limitations addressed above, one major obstacle that may be encountered during this study is that the homeless individuals who attend BHCHP’s health fair may not be interested in discussing their EOL care needs with PA students. If this becomes a barrier to completing the study, more work may be needed to educate the homeless individuals on the importance of advance care planning.

This educational intervention can be easily incorporated into PA curriculums throughout the nation. PAs everywhere work with patients from underserved populations and all PAs are required to have the skills necessary to discuss advance care planning with their patients. This intervention gives PA students the tools needed to perform these tasks. Although not every PA program is located near a well-established organization for the homeless, such as BHCHP, most PA programs are located near a homeless shelter or community program that assists the homeless where this educational intervention can be implemented.

**Summary**

Advance care planning has been shown to be an incredibly important for all individuals to ensure they are able to die with dignity and with the knowledge that their final wishes are met. With an ever-growing number of Americans reaching advanced age, this is more important now than ever before. This issue of advance care planning has been recognized by the NIH—this organization called for improvements in the communication and documentation of EOL wishes, specifically in diverse and underserved populations. In response, many studies have focused on improving advance care planning in homeless individuals, a group who is often disconnected from, and discriminated by, the healthcare
system. Many homeless individuals are dying before their EOL wishes have been addressed. Despite these obstacles, recent studies have found that when homeless individuals are provided with one-on-one assistance in completing advance directives they can successfully document their EOL wishes. Moreover, researchers have found that medical and nursing students can be successful with providing this service, although there have not been any studies which have focused on PA students.

The proposed project will seek to fulfill accreditation standards set forth by the ARC-PA by educating PA students on how to provide advance care planning to homeless individuals. Not only will the students learn about the importance of advance directives, they will also be taught how to counsel homeless individuals in completing a HELP AD. This project will advance the education of PA students in providing care to a diverse, underserved population, as well as developing an educational curriculum for PA programs which can be used throughout the nation.

**Clinical and/or public health significance**

Throughout their careers PAs will have the responsibility of discussing EOL care with patients from a variety of socioeconomic, religious, and cultural backgrounds. The ARC-PA has recognized this is as an important skill set which all students must become proficient in prior to graduation. However, the best way to provide students with this set of skills has yet to be studied. As a result, this curriculum has been created to educate PA students on the importance of advance care planning along with giving them the opportunity to provide advance directive counseling to homeless individuals. This curriculum can then be adopted by PA programs across the nation. The hope is that PA
students who have completed this intervention will graduate with the confidence to provide advance care counseling to all of their patients, ensuring that each and every one of them can approach the end of their life with the dignity they deserve.
APPENDIX

HONORING END OF LIFE PREFERENCES (HELP)

Health Care Directive

Identification
Name: ____________________ Date of Birth: ________________________
Religion: ______________________________ email ___________________
Things which would help emergency and health care staff to identify me (e.g. scars, birthmarks, photo, other identification:
_____________________________________________________________________
_____________________________________________________________________
____________________________________________________________ 

I _________________________________, understand that this document allows me to do ONE OR BOTH of the following:

Part I: Name another person (called the health care agent) to make health care decisions for me if I am unable to decide or to speak for myself. [My health care agent must make health care decisions for me based on the instructions I provide, if any, the wishes I have made known to him or her, or must act in my best interest if I have not made my health care wishes known.] AND/OR

Part II. Give health care and post death instructions to guide others in making decisions for me. [These instructions may be used by health care providers, others assisting with my health care and my family, in the event I cannot make decisions for myself.]

Part I. Appointment of Health Care Agent:

The person I want to make health care decisions for me is:

_______________________________________________________________________

Relationship to me: _____________________________________________________

Telephone: ______________________________________________________________

Address:

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________
Optional appointment of another health care agent:
Name: ____________________________________________

Relationship: __________________________________________

Phone: ____________________________________________
Address:
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
I want my health care agent to do the following if I am unable to decide or to speak for myself:
If I am unable to decide or speak for myself, my agent has the power to (check):
   a. Consent to, refuse, or withdraw any health care treatment, service, or procedure _____
   b. Stop or not start medical intervention which is keeping or might keep me alive ___
   c. Choose my health care providers _____
   d. Choose where I live when I need health care and what personal security measures are needed to keep me safe _____
   e. Obtain copies of my medical records and allow others to see them _____
   f. Decide whether or not to donate organs, tissues, and eyes, when I die. _____
   g. Decide what will happen with my body when I die _________

List any additional powers or limits for my health care agent:
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

If a health care professional is appointed, describe the reasons for selecting that person:
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

People who should NOT be contacted in case of serious injury or death:
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
II: Health Care and After Death care instructions

If I have appointed an agent, I want him/her to follow the instructions which reflect my preference below.

People/agencies who should be notified in case of serious illness, injury or death (in addition to decision-maker(s) listed above):
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
These are instructions for my health care when I am unable to decide or speak for myself.

These instructions must be followed (so long as they address my needs).

THESE ARE MY BELIEFS AND VALUES ABOUT MY HEALTH CARE
(I know I can change these choices or leave any of them blank)

I want you to know these things about me to help you make decisions about my health care: __________________________________________________________

My goals for my health care: __________________________________________________________

My fears about my health care: __________________________________________________________

My spiritual or religious beliefs and traditions: __________________________________________________________

My beliefs about when life would be no longer worth living: __________________________________________________________

My thoughts about how my medical condition might affect my family: _______________________

THIS IS WHAT I WANT AND DO NOT WANT FOR MY HEALTH CARE
(I know I can change these choices or leave any of them blank)

Many medical treatments may be used to try to improve my medical condition or to prolong my life. Examples include artificial breathing by a machine connected to a tube in the lungs, artificial feeding or fluids through tubes, attempts to start a stopped heart,
surgeries, dialysis, antibiotics, and blood transfusions. Most medical treatments can be tried for a while and then stopped if they do not help.

(Note: You can discuss general feelings, specific treatments, or leave any of them blank)

If I had a reasonable chance of recovery, and were temporarily unable to decide or speak for myself, I would want:

________________________________________________________________________

If I were dying and unable to decide or speak for myself, I would want: ________________

________________________________________________________________________

If I were permanently unconscious and unable to decide or speak for myself, I would want:

________________________________________________________________________

________________________________________________________________________

If I were completely dependent on others for my care and unable to decide or speak for myself, I would want:

________________________________________________________________________

________________________________________________________________________

In all circumstances, my doctors will try to keep me comfortable and reduce my pain. This is how I feel about pain relief if it would affect my alertness or if it could shorten my life:

________________________________________________________________________

________________________________________________________________________

There are other things that I want or do not want for my health care, if possible.

Who I would like to be my doctor:

________________________________________________________________________

________________________________________________________________________

Where I would like to live to receive health care:

________________________________________________________________________

________________________________________________________________________

Where I would like to die and other wishes I have about dying: ________________

________________________________________________________________________
My wishes about donating parts of my body when I die: ________________________________

My wishes about what happens to my body when I die (cremation, burial): ______________

Any other things: __________________________________________________________________

PART III: MAKING THE DOCUMENT LEGAL

This document must be signed by me. It also must either be verified by a notary public (Option 1) or witnessed by two witnesses (Option 2) to be made legal. It must be dated when it is verified or witnesses.

I am thinking clearly, I agree with everything that is written in this document, and I have made this document willingly.

My signature: _______________________________________________________________________

Date signed: _______________________________________________________________________

Date of birth: _______________________________________________________________________

Address: __________________________________________________________________________

If I cannot sign my name, I can ask someone to sign this document for me.

Signature of the person who I asked to sign this document for me: _________________________

Printed name of the person who I asked to sign this document for me: ______________________

OPTION 1: NOTARY PUBLIC

In my presence on ____________________ (date), ___________________________________________
_________(name) acknowledged his/her signature on this document or acknowledge that he/she authorized the person signing this document so sign on his/her behalf. I am not named as a health care agent or alternate health care agent in this document.

____________________________________
Signature of Notary
Notary Stamp

OPTION 2: WITNESSED SIGNATURE

Printed name: ____________________________________________
Signature: ________________________________________________
Witnesses’ Signatures (2):
__________________________________________________________

Things to consider before completing HELP Form (pages 1-3)
It may be helpful to keep this form with HELP form when filed/stored

Illness-related Concerns:
Current illnesses/health challenges that concern me:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Symptoms of greatest concern:
A. Physical distress:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Psychological distress:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

b1. Things I worry about related to death:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
b2. Concerns I have about being recognized in case of emergency or death:

__________________________________________________________________

b3. Relationships that cause me concern or worry: ________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

b4. Possible actions that would relieve any of the above concerns: __________

__________________________________________________________________

Level of Independence concerns:
Worries or concerns I have about my ability to think, communicate, or act:
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

Continuity of Self:
Roles or relationships which are important to me:
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

Person(s) I want to make medical decisions in case I am unable to make them (primary decision makers)
Note: list contact information on page 1 of this HELP form:
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

Maintenance of Pride:
I am most proud of these things:
__________________________________________________________________
__________________________________________________________________
I would want to be remembered as a person who:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

People who care for me could do the following to respect my dignity:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Autonomy/ control:
Describe of options for expressing/recording EOL wishes:

I would like this information about care at the end of my life information stored as:
(check format(s)):
   a. Web-based format _______
   b. Paper-based format_______
      a. If paper, where stored?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

b. I prefer no record of this discussion

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Finding Spiritual Comfort
After death, what should happen to my body (Record contact information on page 2 of HELP form):
   a. Burial (where)________________________________________________________

   b. Cremation and ashes put where________________________________________

   c. A memorial service (where/ by whom)___________________________________

   d. Other ______________________________________________________________
My concerns related to religion of spirituality are:

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

a. Who should be notified for assistance with these needs (name, address, phone or other contact information):

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

b. Who could be helpful in making arrangements/ notifying others (name, address, phone or other contact information):

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

If medical treatment failed to restore consciousness, and I would remain seriously ill or disabled, I would want (check on line):

a. all medical measures taken for survival____
b. limited medical measures for comfort (e.g. medications, treatment of other symptoms that make you uncomfortable) _____
c. no treatment _____
d. I would want these directives followed even if I were pregnant? Yes ___ No___
e. I would want nutrition/hydration (food and fluids) to be considered a medical treatment which could be discontinued as part of an end of life care plan? Yes____ No_____ 

Wishes regarding organ donation:
When I die:
I want to be an organ donor______
I do NOT want to be an organ donor______

Wishes regarding care of my body when I die:

a. burial or cremation site (place, contact, address, phone)

__________________________________________________________________
b. a memorial service at (place, contact, address, phone)

Other values that should influence my care in the event of serious injury or death:

Additional concerns:
Are there any questions not asked or concerns that we haven’t considered that are important for end of life care planning for you?
**LIST OF JOURNAL ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Name</th>
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<tr>
<td>Am J Public Health</td>
<td>American Journal of Public Health</td>
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<tr>
<td>Ann Intern Med</td>
<td>Annals of Internal Medicine</td>
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<td>BMC Palliat Care</td>
<td>BMC Palliative Care</td>
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<td>BMC Public Health</td>
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<td>Can Med Assoc J</td>
<td>Canadian Medical Association Journal</td>
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<td>Chest</td>
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<td>Health Aff Proj Hope</td>
<td>Health Affairs</td>
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<tr>
<td>HEC Forum</td>
<td>HEC forum: An Interdisciplinary Journal on Hospitals' Ethical and Legal Issues</td>
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<tr>
<td>JAMA</td>
<td>The Journal of the American Medical Association</td>
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<tr>
<td>J Gen Intern Med</td>
<td>Journal of General Internal Medicine</td>
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<tr>
<td>J Health Care Poor Underserved</td>
<td>Journal of Health Care for the Poor and Underserved</td>
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<tr>
<td>J Hosp Med</td>
<td>Journal of Hospital Medicine</td>
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<td>J Pain Symptom Manage</td>
<td>Journal of Pain and Symptom Management</td>
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<td>J Palliat Med</td>
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REFERENCES


CURRICULUM VITAE

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Education
• Boston University Physician Assistant Program, Boston, Massachusetts
  M.S. Physician Assistant Studies, expected August 2016

• University of California, Davis, Davis, California
  Bachelor of Sciences in Exercise Biology, 2011

Professional Society Memberships
• American Academy of Physician Assistants, 2014

Licenses and Certifications
• Advanced Cardiac Life Support, April 2015
• Basic Life Support, April 2015

Volunteer Experience and Community Service
• Boston Health Care for the Homeless Program Women’s Health Fair, October
  2014
• Boston Run to Remember, May 2014
• Volunteer Bicycle Mechanic, Good Karma Bikes, February-July 2013
• Point Arena Preschool Beautification Day, April 2012
• Second Harvest Food Bank Thanksgiving Dinner, November 2012
• Point Arena High School Volunteer Varsity Volleyball Coach, September-
  November 2011
• Santa Rosa Boys & Girls Club Health Fair, February 2012
• Ukiah Health Fair, October 2011
• University of California, Davis Endoscopy Clinic Volunteer, January-March 2010

Employment Experience
• Health Services Specialist/Referral Coordinator
  Planned Parenthood Mar Monte
  2012-2014
• AmeriCorps Health Educator
  Redwood Coast Medical Services
  2011-2012
• Physical Therapy Intern
Physical Edge Physical Therapy 2011
• Head 8th Grade Volleyball Coach
  Harper Junior High School 2010
  Team Member
  Jamba Juice Corporation 2009-2010