

Special Article - Palliative Care

Intersection of Homelessness, End of Life, Substance Use and Mental Illness: Challenges for Homeless Veterans and Providers

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Received: January 15, 2017; Accepted: February 13, 2017; Published: February 15, 2017

Abstract

Homeless Veterans at the end of life and the providers who serve them face a many challenges. In addition to the simultaneous demands presented by being both homeless and end of life, many Veterans also struggle with substance use and/or psychiatric disorders. Navigating the intersection of these challenges is complex, but unpacking the competing issues and identifying areas of overlap is critical to serving this vulnerable population. Using a three phase sequential mixed methods design the authors 1) surveyed homeless and end of life programs affiliated with the Department of Veterans Affairs (VA); 2) conducted interviews and focus groups with 136 Veterans with unstable housing and multidisciplinary VA and community staff in five cities in the United States (US); and 3) held a forum with national stakeholders to identify specific educational and policy recommendations to improve care. This paper reports on one of the most significant barriers to care to emerge from these data: the complexity of pain management in this population. Recommendations to address this complex interaction of care are discussed.

Keywords: Homeless veterans; Homeless and end of life; Pain management; End of life; Substance use

Abbreviations

HV: Homeless Veteran; EOL: End of Life; VA: Department of Veteran Affairs; US: United States; PTSD: Post Traumatic Stress Disorder; TBI: Traumatic Brain Injury; HSR&D: Health Services Research and Development; FG: Focus Group; IRB: Institutional Review Board; HVI: Homeless Veteran Interview; KII: Key Informant Interview; FGP: Focus Group Participant; NPDF: National Program Development Forum; VASH: Veteran Affairs Supportive Housing

Introduction

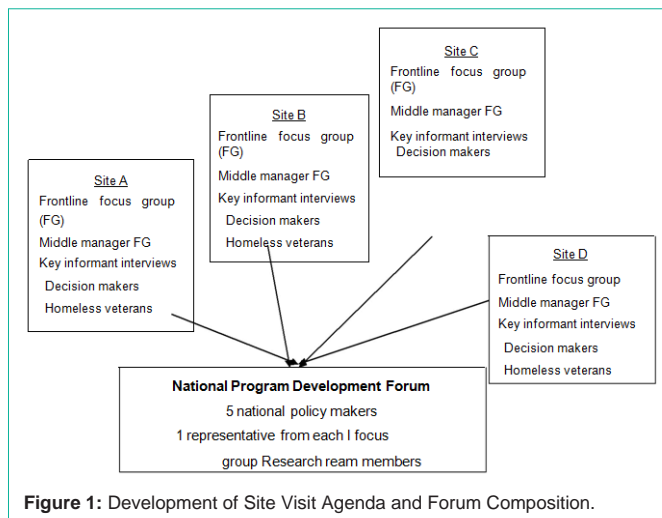
More than 500,000 people are homeless on a given night, according to 2014 data from the United States Department of Housing and Urban Development. Of these, almost 70% are in residential programs, and over 30% are living on the streets [1]. For many in this population, managing the difficulties presented by unstable housing are often compounded by the added burdens of chronic physical, mental, and substance problems [2,3]. In a recent survey of homeless adults conducted by the lead author, approximately 43% described a serious/chronic physical health problem, 53% a serious mental health problem, and 49% a substance use disorder [4]. Adults experiencing homelessness are estimated to have mortality rates 3-5 times higher than the general population [5,6]. Even with this higher level of mortality, there is very little data on the end of life needs for homeless adults in general, with even less data available on homeless Veterans specifically.

Kushel and Miaskowski [7] were among the first researchers to identify the medical complexities of homeless individuals who need End of Life (EOL) care. Most respite facilities, which are designed to

provide temporary shelter and care for people with medical problems who are without housing, have neither the staff nor knowledge to care for homeless individuals at the EOL. McNeil and Guirguis-Younger [8] conducted a qualitative study of EOL challenges faced by Canadian homeless individuals with substance use issues. Major themes included competing priorities with drug/alcohol withdrawal and treatment, significant discrimination, and lack of trust in health care providers.

Although homeless Veterans make up approximately 15% of the homeless population [9], this subpopulation has only relatively recently attracted attention from researchers [8,10,11]. There are many VA services for homeless Veterans as well as for Veterans in need of palliative or EOL care; there are no specific programs for those homeless Veterans and in need of palliative care or EOL care. Providing EOL care is difficult even without the added challenges of homelessness and/or substance use. In addition, little is known whether Veteran status and associated stressors such as chronic mental illness, Post-Traumatic Stress Disorder (PTSD), and Traumatic Brain Injury (TBI) have an impact on EOL care. The results of a survey of VA programs (available in the published manuscript) completed by the authors, indicated that EOL needs for housing was a significant barrier for this sub-population of homeless Veterans [12].

The pilot study conducted by the authors [12], led to the development of the parent research study [13-15]. The purpose of this parent study was to develop a deep and broad understanding of the barriers to and facilitators of excellent EOL care for veterans without homes and define the key structural, clinical and policy elements required to improve care. In 2012, the VA Health Services Research

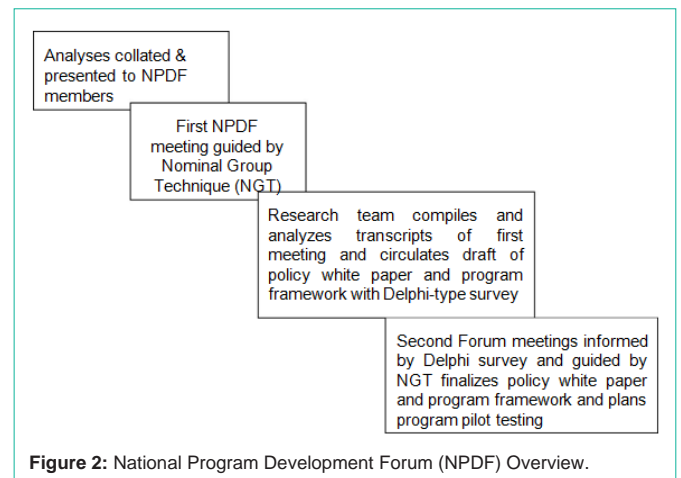


and Development (HSR&D) funded this three-year research project. The results from this study, described in detail in other presentations or manuscripts [13-17], included five barriers to quality EOL care. The authors then completed a secondary data analysis on one of these barriers, the challenge of symptom management, to further explore this theme. In this paper, the authors discuss the results of this secondary data analysis regarding the intersection of homelessness, EOL needs, substance use, and mental illness for Veterans and the providers who serve them. Recommendations to address these issues are discussed.

Materials and Methods

The HSR and D funded study [13] was structured according to a three phase sequential mixed methods design in which the authors: (1) surveyed homeless and EOL programs affiliated with the VA [12]; (2) conducted interviews and focus groups with 136 Veterans with unstable housing and multidisciplinary VA and community staff during site visits to five U.S. cities [13,14]; and (3) convened a forum with national stakeholders, including representation from each Focus Group (FG) and national leaders in homeless and palliative care, to identify specific educational and policy recommendations to improve care (Figure 1). Institutional Review Boards (IRB) at the Central VA, the University of Colorado, and the local site VA Research and Development committees approved this study.

The research team conducted 2-3 day site visits at five geographically dispersed sites that had both a large volume of homeless Veterans and a strong VA program in palliative care and/or homeless care. Two members of the research team conducted individual key informant interviews at the pilot site and each of the other four sites with homeless Veterans (n=29) who had significant chronic illnesses, and with community and VA leadership (n=21). Separate focus groups with frontline and program management multidisciplinary staff from VA and community palliative care and homeless care programs were conducted, audio-recorded and transcribed verbatim. Following the site visits, a National Program and Policy Development Forum with representation from each focus group and national stakeholders and policy makers was convened (Figure 1).



The forum met in person for an 8-hour session in July 2015, followed by two half-day tele-video conferences in November and December 2015 (Figure 2). Forum participants included physicians, nurse practitioners, social workers, nurses, peer support (Veterans with a history of unstable housing who work for homeless care programs) and staff from VA Decedent Affairs. Approximately two thirds were from homeless programs and one third from palliative care programs. Five policy makers from within and outside VA were identified by VA leadership in homeless care and in EOL care to participate in this Forum. Approximately two thirds of Forum participants were from homeless programs and one third from palliative care programs.

Analysis

A Social Constructivist (SC) theoretical framework guided the data analysis for the parent study and this secondary data analysis [18]. Interview transcripts, focus group transcripts, ethnographic field notes, and team debriefing notes comprised the data for analysis. Analysis occurred in an iterative and team-based process involving established qualitative content methods, and reflexive team analysis [19,20,21]. Led by two senior qualitative researchers, the analytic team consisted of multiple disciplines and multiple interpretive perspectives (sociology, nursing, medicine, social work, mental health, palliative care, and geriatrics) from both VA and non-VA systems, which provided depth of interpretation achieved through iterative individual data review and group meetings.

Data analysis commenced immediately following data collection, and continued for 15 months after the site visits. Focus group and interview transcripts were read multiple times by five members of the study team to achieve immersion, and code categories were then developed using a line by line approach to in vivo coding using participant language [22].

Coding schemas were developed for each group of stakeholder perspectives and each site as a case; then within and cross case theme analysis was performed. The study team met regularly to confer about new findings, discuss emergent themes, and assess the preliminary results of the analysis process [22]. Developing analyses were presented to professional and academic forums related to either homeless and or hospice/palliative care service delivery to test the

Table 1: Focus Group Participants and Interviewees at Site Visits (N=136).

| Front Line Staff Focus Group Participants (N=51) | | Middle Manager Focus Group Participants (N=37) | |
|---|----|--|----|
| Role | N | Role | N |
| Social worker | 13 | Nurse manager, Palliative Care Unit | 5 |
| Nurse | 12 | VA Homeless Point of Contact | 7 |
| Chaplain | 6 | Nurse Manager, Community Living Center | 2 |
| Physicians (includes primary care, palliative care, psychiatry) | 7 | Homeless shelter administrator | 10 |
| Nurse Practitioner/Physician Assistant | 8 | Hospice administrator | 3 |
| Decedent Affairs administrator | 1 | Hospice nurse manager | 2 |
| Veteran Service organizations representatives | 2 | Veteran Service organizations representatives | 7 |
| Peer support | 2 | VA Cemetery Administrator | 1 |
| Key Informants (N=19) | | Veterans with Unstable Housing (N=29) | |
| Role | N | Male | 27 |
| Medical Center Director | 3 | Female | 2 |
| Service Director | 4 | White, Non-Hispanic | 21 |
| Shelter Director | 1 | African American | 8 |
| Veterans Integrated Service Network Service Director | 1 | Housing Status at Interview | |
| Other VA Administrator | 10 | Stable Independent | 8 |
| | | Shelter | 9 |
| | | Other Temporary | 4 |
| | | Assisted Living, Domiciliary or Nursing Home | 8 |

potential transferability of our contextual interpretations.

From the parent analyses, one of the major themes identified was that of the complexity of pain management in the context of substance use in Veteran homeless populations. This secondary analysis focused on the data gathered specifically about Veterans and providers coping with the intersection of unstable housing, substance abuse, mental illness, and EOL care needs. Additional in-depth analyses of these data were conducted. A similar social constructivist theoretical framework and methodology described above guided a secondary analysis of this theme. A re-review of all Veteran, focus groups, key informant, and forum transcripts from the lens of complexity of pain management/substance use/mental illness/TBI/PTSD/end of life care, was conducted. Developing analyses were presented to professional forums related to either homeless and or hospice/palliative care service delivery to test the potential transferability of our contextual interpretations (Figure 2) [13,15,16,17].

Results and Discussion

One hundred thirty-six individuals participated in this study (Table 1). Forty-eight individuals participated in key informant interviews across the five study sites. Interviewees included 19 administrators in leadership positions and 29 chronically ill Veterans without stable housing, at least 12 of whom were identified by the interviewer as being likely to die within a year. Eighty-eight multi-disciplinary staff participated in one of 10 focus groups across the five study sites. The professional positions of participating VA staff and demographic characteristics of participating Veterans are presented in Table 1. These major themes were refined in the secondary data analysis and are illuminated here through substantive participant language:

1) Complexity of Substance use and pain management in context of possible diversion of medications.

In reviewing the data from key informants, the complexity of providing and receiving medication for pain management, especially addicting medication like an opiate, was immense and overwhelming for providers and for Veterans. Key issues such as worry about the possibility of diversion of opiates in those with substance issues from providers, and the unwillingness of providers to give opiates to those with an active substance abuse disorder were discussed at length.

“There are usually issues of substance dependence. If you’re trying to relieve their pain with pain medication there is concerns about diversion of the medications...And then compliance is an issue, you know, I mean just being able to be compliant with their regimen because if they don’t have stable housing and you’re trying to house them and where do they store this medication? It can be stolen from them and then it is out on the streets somewhere, you know, and pain medications it’s gold, basically”. (Key Informant Interview (KI), Site C).

“I think ...enough physicians and providers and nurses who have some comfort level with symptom management at the end of life, which is great. However I think a caveat to that is that the prevalence of opiate use disorders and dependence is so high in our population that symptom management can be a lot more challenging to cope with when there is just this very dramatic level of tolerance in general across the population. So we’re often needing to use much more potent opioids and try to treat in a different way than you might be used to doing in a different setting. And that’s a huge challenge”. (KI, Site B).

“Well it’s a dance, it’s a balance act, you know, somebody who has chronic substance abuse and has chronic pain that we know about we want to treat their pain, you know, we’re very passionate about treating their pain but how do we do that while balancing their, you know, possible drug diversion or misuse of the medications. That can be really difficult and they can also, it can be very difficult for the nurses because they feel very conflicted at times”. (Focus Group (FG), Site B).

So this “balancing act” of trying to provide pain relief is complicated by the lack of knowledge in how to provide this in individuals with a current substance misuse issue or a previous substance use history. There were challenges identified about the risks of homeless Veterans with opioids on their person and the risks that pose to vulnerable individuals. There was clear frustration with the lack of knowledge on how to address this issue and the desire to provide high quality end of life care.

2) Homeless Veterans feeling the stigma of having a substance use issue.

Many homeless Veterans who had a co-morbid substance use disorder with a significant physical issue, whether cancer or other life-threatening illness, described that care was different because of their substance use, whether current or past. In these cases, the homeless Veterans expressed much frustration with the current health system that does not seem to understand how to treat them in this context.

“It’s gonna get worse...And when it started to get worse and more painful, [my provider] didn’t want to up...my meds and I’m like, ‘Dude, you know this is a progressive disease, you know it’s getting worse for me’...His problem is I have long hair and he thinks I’m out...selling the...damn things. I’m like, ‘Look, dude, like, nobody’s gonna buy...Nobody’s gonna do that, and I’m not gonna give them...away...I’m not gonna sell it’”. (Homeless Veteran Interview (HV), Site C).

“It’s something I’m not doing with the liver or the lungs or heart and of course I see that every day or the substance abuse I’m not dealing with that, you know, I could not begin to tell you in the 12 years I’ve worked in this situation the amount of people I’ve seen die directly attributed to alcohol and drugs. It’s just mind boggling”. (HV, Site B).

“Veterans and homeless providers identified that the stigma of having a current substance use disorder or a history of substance use creates problems in access to services, access to housing options, and now, access to pain management and EOL care. This stigma is inherent in the silos between homeless services and palliative care services within the VA system and compounded by the lack of substance treatment in all of health care”. (KI, Site A).

3) Added complexity of having a mental illness, PTSD, or TBI in addition to homelessness makes it difficult to provide good EOL care.

Providers and homeless Veterans alike discussed that having co-morbid psychiatric issues such as PTSD or a TBI, complicated the clinical picture, and complicated the best treatment options.

“...I am a Veteran I’ve been out since ’96 and I have multiple diagnoses of PTSD as well as traumatic brain injury and I wound up

getting myself in some trouble...dual diagnosis of alcoholism”. (HV, Site A).

“You have some guys that’s got real problems, PTSD...So you learn who is who and usually in one area we have, we got a good area because we watch each other’s stuff. Some areas aren’t so good”. (HV, Site A).

The co-occurrence of PTSD, TBIs, and other chronic mental illness is well known in homeless populations. However, the intersection of these illnesses and the need for EOL care has caused much frustration among the Veteran homeless population as well as for providers who don’t feel equipped to provide care in the context of this complexity. What many key informants stated was that departments for homeless care did not always know or communicate with departments such as palliative care or mental health care. Although lack of communication within different specialty areas is not unique to VA systems, it was clear that for the most vulnerable Veterans near the EOL, these silos made it more difficult to get care. When these homeless Veterans experience all of these issues, quality EOL care becomes a significant challenge in providing care as described but also in finding housing.

(4) In spite of homeless Veterans’ rapidly declining health at the EOL, which prevents independent living or realistic plans to abstain, current housing options are too often limited to places that insist on functional independence and a ‘clean and sober’ lifestyle.

Housing for homeless Veterans implies some level of independent living as well as a clean and sober lifestyle. For these homeless Veterans at the EOL, dependence and decline in activities of daily living is expected. This level of need is not accounted for in the majority of housing programs. In addition, most agencies require participants to be clean and sober, often not a priority for a homeless Veteran at the end of life.

“Many nursing homes or skilled nursing facilities aren’t willing even at the end of life to take patients with criminal histories, with drug addiction, substance abuse disorders. So there’s been, you know, pushback from both sides in terms of using, you know, the same skilled nursing facilities to do this kind of care. So...there’s been a void”. (KI, Site B).

“Particular problems related to homeless Veterans, I sort of associate it more with some Veterans who are also maybe actively using drugs and really don’t want to change that at the end of life. But there’s not a place you can send someone where they can actively use and get hospice care as an inpatient. So it’s difficult sometimes to match what the Veterans are wanting for their goals of care at the end of life with resources that are available”. (KI, Site A).

“There are many rehab programs don’t allow you to take pain medicine at all. And just because you’re facing something that you expect to end your life sooner rather than later doesn’t mean you can’t grow or you can’t get better than you are even if it’s temporary. So they’re not allowed to get to certain recovery beds, you know, if what they want to do is die clean and sober I want to help them do that... but if they have a palliative care ... it’s very common they just want to get off cocaine but they have a legitimate need for other things. The programs don’t differentiate”. (KI, Site D).

“These programs, guys that are on drugs and stuff, alcohol...

they got a program down there [for these people]...but they get them on that Veteran Affairs Supportive Housing (VASH), VASH takes about—well, five months”. (HV, Site A).

“If they are independent whenever they first come on to service... [usually] they’re profusely capable of living by themselves for a while, however that becomes more and more problematic as they begin to deteriorate”. (Focus Group Participant (FGP), Site C).

“I know that some of our difficulties are with the chronically homeless who...even if we can put them into a hospice program, or we can put them into a housing program, they have been homeless for so long that they’re unable to manage in a structured setting...I had a...chronically homeless patient that I worked with for a long time. And we had put him into the, our CLC [Community Living Center, which is a VA nursing home] here...I had put him into community nursing homes in order to provide him with the structure he needed, and it just didn’t work”. (FGP, Site B).

Diverse participants noted that many of the challenges are related to the relative isolation of homeless care providers from palliative care providers, and from mental health providers.

“So it’s been my experience that I mean there is a big gap between our homeless programs that serve people who are able to live independently and Veterans who need a higher level of care. My concern is that it seems from my perspective the challenge has been agencies that struggle with serving homeless folks even if they’re set up to provide end of life or supportive care because of all the additional and unique and challenging issues that the homeless population tend to come with. So I feel like there are services and support systems out there. The problem is, you know, accessing those services”. (Focus Group (FG), Site B).

Potential Solutions

Potential solutions to the challenges of pain management for Veterans with unstable housing/substance issues/mental illness at EOL were proposed in focus groups and considered in detail at the Forum meetings as well as part of this secondary analysis. One of the ideas generated from the Forum was to educate VA and community homeless and EOL care providers in the fundamentals of each other’s work, including more targeted education regarding symptom management and psychiatric and substance co-morbidities in the setting of unstable house.

This targeted education regarding this complex interaction between homelessness/mental illness/substance use/ and EOL was discussed in depth as a way to facilitate pain management strategies as well as reduce the stigma associated with some of these disorders.

Another strategy identified by several focus group members was to consider less orthodox pain management strategies such as medication patches, weekly medication boxes, and home visits. Home care is further complicated because of not “having a home”. Whenever this specific strategy was identified by the experts in palliative care, the reality of being homeless would surface again.

To help address the mismatch between current housing programs and the inevitable functional decline that occurs at EOL, the Forum members recommended pilot testing a harm reduction approach

within current VA rehousing models. Harm reduction reduces the adverse consequences of substance use without requiring abstinence [23]. Current medical respite programs might be upgraded by educating current staff in EOL care and adding skilled nursing, pharmacy and/or other providers to improve their ability to care for homeless Veterans at EOL. Study participants described a number of diverse programs outside the VA that use the harm reduction model to provide palliative care.

“This is a new program to the center and it’s targeting our most vulnerable Veteran populations. It’s mostly for Veterans with mental illness and who have decided to not become abstinent from any substances yet. We also work with being the most vulnerable also people that are towards the end of life sometimes and, you know, when there’s not really a place for them to go”. (KI, Site A).

“It’s a harm reduction model where people are not required to be clean and sober, you know, they can come in, maybe they, the type of Veterans or the type of people who are often served are let’s say an IV drug user who developed endocarditis and needs antibiotics for a number of weeks or somebody with wounds that need to get off their feet for a while and need wound care. And I think some palliative care as well like chemotherapy and such where, you know, or they’re recovering from surgeries and that kind of thing. That harm reduction model, which allows people to be there who may not have stuck around in inpatient setting or a lot of the clean and sober environments that we’re trying to shoe horn people into. I think a large part of it is, you know, really good staff there. They provide addiction treatment services if people are inclined and from what I understand they’ve done a pretty remarkable job of getting people housed actually from, directly from medical respite into some sort of housing” (FGP, Site B).

Discussion

Among the most critical challenges to providing excellent EOL for Veterans with unstable housing is the very high prevalence of psychiatric disorders and substance abuse. The authors identified several themes related to the intersection of homelessness, substance use, mental illness, and EOL care: 1) Complexity of Substance use and pain management in context of possible diversion of medications; 2) Homeless Veterans feeling the stigma of having a substance use issue; 3) Added complexity of having a mental illness, PTSD, or TBI in addition to homelessness makes it difficult to provide good EOL care; and 4) In spite of homeless Veterans’ rapidly declining health, which prevents independent living or realistic plans to abstain, current housing options are too often limited to places that insist on functional independence and a ‘clean and sober’ lifestyle [23]. Care providers in Veteran homeless settings expressed feeling competent to assist Veterans with co-morbid psychiatric and substance issues in find housing, but felt more challenged regarding EOL care. Palliative care providers voiced a lack of knowledge about treating the homeless Veterans with complex psychiatric and substance issues.

Findings and recommendations from the current study are remarkably similar to those of a study conducted in Canada [8], such as discrimination and stigma experienced by both cohorts [17]. Although the population and number of homeless in Canada are different, especially given the better access to health care in Canada,

this study adds insights by virtue of focusing on the US Veteran population and the importance of understanding the intersection of substance use/mental illness on EOL and housing challenges.

Strengths/Limitations of the Study

This study has several noteworthy strengths. Data were obtained from a wide and geographically diverse range of community and VA providers with expertise in either homeless and/or palliative care, and notably from chronically ill homeless Veterans themselves. The use of multi-disciplinary focus groups from palliative care, homeless programs, and mental health programs enhances the validity of our findings. Moreover, many of these providers had never spoken to each other prior to the research meetings, but commonalities were quickly identified and barriers to communication began to break down, providing a potential model for ways to improve care by bridging silos. The convening of a national forum of focus group participants and national leaders in palliative care and homeless care inside and outside VA produced consensus on a wide variety of possible solutions. This diverse group of individuals also demonstrated and facilitated the recommendations on breaking barriers among the different silos of care.

There are also a number of limitations to this study. First, the research team encountered a major contextual issue. At about the same time as the research team began the site visits; news outlets were publicizing problems within the VA with Veteran access to care [24]. Many key informants, particularly those in leadership positions, expressed a reluctance to talk about barriers to care in this context. The presence of non-VA employees (e.g., community partners) at focus groups and the forum may have either aggravated or ameliorated this impact. Second, we relied on local site investigators and coordinators to recruit interviewees and focus group participants. Thus, the data collected are limited by the knowledge of the local site investigator. This limitation is at least partially mitigated by the fact that local site investigator expertise varied among participating sites from homeless care to palliative care to research. Finally, the study sites in each city had difficulty finding homeless Veterans at EOL. Thus, while we interviewed many homeless Veterans with multiple physical, psychiatric and substance issues, fewer than half were identifiable as being at the EOL.

Transferability may be limited to US Veterans. However, there is striking similarity between our findings and those of other researchers [8,11] Issues of stigma and discrimination, lack of access to safe and adequate pain management, and lack of providers who understand how to treat concurrent EOL and substance issues were echoed in this study. The burdens of co-morbid mental illness, PTSD, and TBIs add to the complexities of working with HV who additionally have substance use issues. To our knowledge, this is the first study to analyze these additional complexities at the intersection of homeless Veterans, end of life, substance use and significant psychiatric disorders. Stigma was also identified by HV, of not only homelessness but especially with having a substance issue. Access to care, especially needing care from multiple providers in multiple settings, Not only do homeless Veterans deal with provider misunderstandings, they also have to live in a world where opioids have 'street value.' Thus, these Veterans, already vulnerable because of their physical condition at the end of life, are often assaulted and/or robbed for their

medications. They are left with a series of Faustian choices: pursue the drugs and alcohol they have been accustomed to using, sometimes illegally; experience inadequately controlled pain as the price for improved shelter; or risk being robbed or worse. These choices often amount to a 'Catch 22' for these homeless Veterans: either continuing their old lives, which are dangerous but familiar, or try to remain in a clean and sober environment without adequate pain relief.

Conclusion

In summary, homeless Veterans who are approaching EOL with substance use problems live in the intersection of palliative care and homeless care structures and therefore often get sub-optimal care. The forum's recommendations for provider education and increased flexibility in housing criteria have the potential to ensure that these Veterans, already stigmatized by their homelessness, will be able to spend their final days without pain, in safe and supportive environments. Pilot testing the addition of a harm reduction framework within the existing models of Housing First [25] would be an excellent way to test new approaches for EOL care for homeless Veterans. Re-visiting housing options could mean better pain management and less stigmatization. Whether they may also be more cost-effective than frequent emergency room visits should be measured.

High quality palliative and EOL care has been a focus in the United States for at least the last decade. Unfortunately, the homeless population has been largely left out of planning for this important goal. Homeless Veterans, who have served their country, deserve better.

Acknowledgement and Funding

The funding for this study was provided by The Department of Veterans Affairs, Health Services Research and Development, "Planning Palliative Care for Homeless Veterans who are at the end of life", Project No. IIR 10-322. The funding source had no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; and in the decision to submit the article for publication.

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