Palliative Care for Homeless Individuals: Emerging Models

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Table of Contents

Introduction	2
Making the Case for Emerging Models	3
Exploring the Research and Field of Practice Defining Palliative Care and Hospice Choosing a Mobile Model Care Needs for Homeless Individuals Range of End of Life Care Services for Homeless Individuals Examples of End of Life Care Models Internationally	3 2
Patient Referral Process	
Program Funding	16
Conclusion Contributions	_
Sources and Interviews	

Introduction

This report was developed as a partnership between The University of Washington School of Public Health's Community-Oriented Public Health Practice Program and the University of Washington Medical Center (UWMC)/ Harborview Medical Center's (HMC) Mobile Palliative Care program for Homeless Individuals (MPCH). The goal of the report is to document the need for emerging MPCH programs and identify critical program components for successful implementation and sustainability. With HMC's MPCH venture in the initial pilot phase there is an interest and benefit to learning more about what others are doing. In serving this purpose this report aims to:

- Further document the need for flexible palliative care services that meet the specific needs of homeless individuals; and
- Compile and articulate the experiences and learnings of providers and researchers from around the world about the process of building and maintaining end of life care programs for homeless individuals.

In January of 2014, HMC began a pilot MPCH program based out of the Pioneer Square Clinic. Public Health – Seattle & King County (PHSKC) funded this program through grant dollars from the Health Resources and Services Administration (HRSA). The goal of the program is to address the end of life care and pain management needs of disenfranchised and hard to reach homeless individuals in the Seattle area, many of who have complex care needs. The program aims to support patients at the end of their life with holistic care and to give dying individuals more control of their care and death, with the goal of preventing unnecessary emergency room visits and long inpatient hospital admissions. As HMC evaluates the early results of their pilot, they are interested in understanding how other MPCH programs provide similar services in order to strengthen and expand their current program.

Most MPCH programs internationally have begun in the last 3-5 years. This expansion follows the growing acceptance of hospice care and general palliative care programs in the last 20 years throughout the developed world. Growth and acceptance of the field of palliative care in healthcare has paved the way for specialized programs such as MPCH, tailored to specific

populations. Health care providers currently working in the field that were interviewed for this project are in the process of developing new models of care to better serve marginalized communities to provide comprehensive, accessible and affordable end of life care.

Making the Case for Emerging Models

Older homeless individuals often need support managing chronic illnesses and pain. While there are a wide variety of homeless health programs that have been implemented nationally and internationally very few programs are designated to providing palliative care. MPCH has a unique focus on palliative care and providing services at a time and place in people's lives where they have increased care needs. To meet these needs, MPCH programs help homeless individuals manage pain and connect with other health care and social services. Initial findings from the Seattle-based MPHC indicate that the program is also reducing emergency room and in-patient hospital stays, improving quality of life and reducing the cost of care.¹

One of the goals of MPCH is to provide palliative care to a medically and socially complex population, reducing the use of unnecessary emergency department and in-patient hospital care. The Seattle-based program has data demonstrating 25% reduction in days spent in the hospital for individuals after six month enrollment in the MPCH program (1,611 total days 6 months prior, 1,208 total days 6 months post). More impressively, emergency room visits dropped by more than 50% after program implementation (344 visits 6 months prior, 158 visits 6 months post). Reducing the need for emergency interventions and hospitalizations both reduces costs and increases patient comfort and quality of life. MPCH is a model that shows promise in both being able to address the wide range of patients needs at the end of life, while also reducing the cost of care.

Exploring the Research and Field of Practice

Defining Palliative Care and Hospice

Palliative care prioritizes quality of life and symptom management for patients. The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and

spiritual."² This definition highlights the multifaceted approach that palliative care professionals take to address suffering. Palliative care is a growing field of medicine that addresses the wide ranging needs of seriously ill patients and their families. Despite an increase of palliative care services, a recent study of hospital data from developed countries estimated 69-82% people would benefit from palliative care who do not currently have the option.³

Comparatively, hospice services have been more institutionally established. Hospice services primarily funded by Medicare part A provide care for patients who are terminally ill with a life expectancy of six months or less. People admitted to hospice care are no longer seeking curative treatment. Hospice is provided at home or in care facilities and offers round the clock care for patients. Research has found that patients who use hospice live an average of 29 days longer, have lower health care related costs and report higher satisfaction with their care. Sinilar findings have been also been demonstrated among patients who use palliative care compared to those who do not. Palliative care services, however are available to anyone seeking symptom management and improved quality of life and are not restricted to people in the last six months of life like hospice services are.

Choosing a Mobile Model

The rigidity and structure of traditional hospice care is a poor fit with the needs and circumstances of homeless individuals. In addition, mainstream hospice providers are not trained and prepared to effectively identify and serve individuals without safe and reliable shelter. Examples of hospice rules and structures that can be incompatible with the needs of homeless individuals include:

- Life expectancy of 6 months or less
- Care provided in a facility or home setting
- Facilities that provide hospice services do not participate in harmreduction practices
- Hospice providers who have not been trained in cultural competency for homeless individuals.

One study finds that "many people never make it into our health care institutions at all, despite having very real needs. Barriers of culture, economics, and other circumstances create gaps between a growing number of citizens and the health care industry." Over the last 20 years, mobile health care and street outreach programs have developed as one solution for providing care to those who can't or won't access more traditional models of care. HMC and others have identified a need for palliative health care services for homeless individuals who are unable or unwilling to utilize traditional palliative care or hospice services. This has led to the development of a mobile program that can flexibly go where individuals live including on the streets, in shelters, supportive housing or elsewhere.

Care Needs for Homeless Individuals

Poor mental and physical health can be both a cause and effect of homelessness. Individuals experiencing homelessness are at greater risk of many acute and chronic illnesses as well as physical disabilities, substance abuse and mental health problems. Homeless individuals have shortened life expectancies, between 42-54 years, and often experience health problems similar to traditional geriatric patients. Homeless persons aged 50-65 frequently fall between the cracks of governmental safety nets: while not technically old enough to qualify for Medicare, their physical health, assaulted by poor nutrition and severe living conditions, may resemble that of a 70-year-old. Yas

Data from the Seattle-based MPCH program indicates that they are serving homeless individuals with health conditions that are representative of aging homeless population at large. Some initial data from 100 of the Seattle-based program participants indicates that 57% have one or more mental health diagnosis, 80% have a chemical dependency diagnosis and the average total number diagnoses is 6. Program participants have a wide range of complex medical and behavioral health needs as well as requiring pain management support. HMC's MPCH program and others like it, serving a particularly vulnerable population with complicated health problems, can provide individuals with the medical support they need to have agency in their end of life planning and care.

Range of End of Life Care Services for Homeless Individuals

There are very few palliative care services for homeless individuals world-wide. Beyond formal palliative care programs, end of life care for homeless individuals is supported in a variety of different programs and settings. There are mobile care programs that serve homeless individuals and end of life care programs through hospice and medical respite, however there are few that specifically combine a mobile model and palliative care services. End of life services for homeless individuals are provided in many ways, some of the models discussed in this report include: aging in place, supportive housing, hospice, and MPCH Programs.

Aging in place services are provided in many shelter and low-income senior housing programs both in the U.S. and internationally. UK-based St. Mungo's is an example of an aging in place model. St. Mungo's, in partnership with Marie Curie Cancer Care, developed a <u>resource guide</u> for supporting homeless individuals in a shelter system at the end of their life. The guide provides a framework for addressing access barriers palliative care for homeless individuals, and gives shelter staff information on how to care for and have end of life conversations with people who are dying in the shelter. Their guide is designed to give shelter staff and homeless individuals support in end of life decision making and connections to health care providers and other resources that help keep people out of hospitals and in shelters while honoring end of life wishes. 14

Supportive housing is another setting for palliative care. Supportive housing models are used internationally to provide permanent and temporary low-income housing for homeless individuals experiencing multiple comorbidities. These housing models typically combine access to housing with other vital services including mental health, clinic services, social services and case-management, and more. This model aims to provide stable housing for some of the most ill and vulnerable houseless individuals while also removing barriers to access care and social services. This unique combination of stable housing and services makes them a useful setting for palliative and end of life care. Research addressing supportive housing models have found that they improve homeless individuals' health and well-being while also reducing the

cost of care. ¹⁵ There are several organizations in the Seattle area providing supportive housing services to homeless individuals. Many of the referrals to the Seattle-based MPCH program come from healthcare providers at local supportive housing sites. ¹⁶

Medical respite programs can be a source of palliative care post hospital discharge for homeless individuals. The medical respite model offers homeless individuals an alternative to going back to living on the streets after being discharged from the hospital. Respite facilities provide homeless individuals with medical care, pain management and social services while recovering after a hospitalization. Data released by the National Health Care for the Homeless Council identified 73 respite programs in the U.S. that provide care to homeless individuals with an average stay of 42 days. ¹⁷ Research indicates that homeless individuals who are placed in respite programs have 50% fewer hospital readmissions within 90 days of being released from the hospital. ¹⁸ Respite provides a necessary and cost effective transition from the hospital for homeless individuals. Seattle's medical respite program, the Edward Thomas House, is operated by HMC.

Hospice services for homeless individuals are often located in shelters or freestanding facilities. These services, like more traditional hospice models, are specifically for people in the last six months of their life and who are no longer seeking curative treatment. This model can be difficult to accept for some homeless individuals who are ill and preparing for death much earlier in their life than many. With the support of Medicaid and Medicare reimbursement, hospice services for homeless individuals exist in most major U.S. cities and furthered with the recent expansion of Medicaid in many states. Regardless of the possibility for reimbursement, the current capacity and structure of these services falls substantially short of meeting the growing need. MPHC programs expand upon and offer an alternative to the existing structure of hospice services for homeless individuals who require more culturally appropriate and flexibly-delivered palliative care

Examples of End of Life Care Models Internationally

One example of hospice care for homeless individuals from Canada is the Ottawa Mission. The Mission in partnership with Ottawa Inner City Health, provides a 14 bed acute hospice program for homeless individuals as well along with a new seven bed chronic palliative care unit. The acute unit provides a higher level of medical care and patient management, while the chronic palliative care unit provides less intensive medical intervention with lower staffing levels. Both units provide as needed 24-hour care for patients using nurses and volunteers.¹⁹

There are very few MPCH programs in operation world-wide, all of them outside of the United States. A total of four mobile palliative care programs were identified as currently operating or in development through internet research and interviews with experts in the field of homelessness and end of life care. Only the Toronto-based Palliative Education and Care for the Homeless (PEACH) program was identified as comparable to the current Seattle-based MPCH program. The PEACH program provides "quality early, integrated and safe palliative care for the homeless and vulnerably housed populations with a focus on prioritizing dignity for all." Individuals in Calgary, CA and Queensland, AU are in the process of establishing MPCH programs. Programs and institutions in the developed world are trying a range of homeless programs and pilot projects, however few specifically focus on the need for palliative care.

Common MPCH Program Components

This section identifies the most commonly observed structures and practices of existing MPCH programs and other end of life programs for homeless individuals based on research and interviews with providers. In the process of interviewing providers, similar experiences, challenges and learnings emerged. Many of these programs are currently focused on building sustainable resources and capacity. Dr. Dosani, who runs Toronto's PEACH program mentioned above is clear about where to start when developing a new MPCH program.

"At the beginning it is about referrals, it's about connecting to home care, it's about coverage, it's about creating interdisciplinary teams that wrap-around patients and having right cases."

- Naheed Dosani²¹

These program components identified by Dosani will be expanded upon below to add depth and clarity to their importance.

Patient Referral Process

Most of the programs researched for this report used a wide referral network including housing/shelter, social service and health care providers. Many referrals fall outside of the traditional medical referral path, encompassing the interdisciplinary care model referenced by Dr. Dosani.

"We accept referrals from a grassroots network, we get referrals from social workers, nurses, doctors, hospitals. Our number one referral source is from social workers who work in shelters. From there we meet with the patient, talk to their primary healthcare provider, have them sign a waiver to release their medical records and from there we see if they are an appropriate case."

- Naheed Dosani²¹

The Seattle-based program receives most of its referrals from nurses based at supportive housing sites. These nurses work closely with residents to identify individuals' health needs, goals and options for care.

"It took us awhile to centralize our referral system and get the word out to partner organizations and others serving this population but as more people have worked with use and are more familiar with our services we are seeing an increase in referrals."

- Colette Conlisk¹⁶

The PEACH program identified the centrality of developing relationships with hospital discharge planners who are responsible for helping patients identify services to meet their needs after hospitalization. This helps address the need for wrap-around care described by Dr. Dosani.

"We connect with discharge planners at high yield sites. We have good working relationships with all of those discharge planners...it is an important place to get referrals."

- Naheed Dosani²¹

Knowing where older homeless individuals seek care and connecting with health care and social service providers in those places is key to being able to

successfully identify appropriate patients who would benefit from care they can receive in these programs.

Program Staffing Models

The MPCH programs studied have broadly similar staffing models. The PEACH program in Toronto has .2 FTE physician and a .6 FTE nurse. The Seattle-based team has a nurse practitioner funded at .5FTE and a nurse funded at .5FTE.

"The PEACH team is not the nurse, me and the patient. These patients come in with care teams that already exist often or a case worker. So the PEACH team for each patient is actually different. Each patient has a unique team wrapped around them that are funded from different sources. The key players are our team, publically funded home care, and others."

- Naheed Dosani²¹

Current MPCH program providers struggle to piece together wrap-around services and care teams for most patients. Providers uniformly feel that their staffing models do not adequately allow for the extensive care coordination necessary to meet patient needs, as well as fulfill the administrative tasks related to referral, intake and reporting.

"while we also always thought she [program nurse] would do frontline work, in reality she does 5% frontline work and 95% coordination. We would like to get a social worker, but we are a physician funded organization. We were really lucky we were even able to get a nurse. What we do instead is work with the social workers who are available through other programs instead. We are used to working barebones."

- Naheed Dosani²¹

One staffing challenge is that MPCH programs are run through hospital/medical-based organizations that are based in the provider/ nurse model. However, these emerging specialty programs may benefit from interdisciplinary support from social workers or others with non-medical training.

"So much of my job is coordination and social work. I'm a nurse by training. There are days when I feel ill-equipped to be a grief counselor. I have nursing skills, and I occasionally get to use them, but sometimes I wonder if there is another set of skills that are more necessary to meet the needs of our patients and

for the success of the program." - Colette Conlisk¹⁶

Most programs studied acknowledged the need for additional administrative resources as well as more comprehensive mental health care, social work and grief counseling to provide optimal support. Lack of these support and training resources are challenges to the development of viable programs.

Program Size

Program capacity for mobile-specific programs varies to a degree and is generally larger than similar palliative programs that are site-based with a limited and fixed number of beds. The PEACH program in Toronto has cared for over 65 homeless individuals since the program began in July of 2014.

"At any time we have between 18-25 patients on our caseload. We see about 40-45 cases a year. Our goal was to do about one new intake visit a week our first year. We did 47, which we felt pretty good about."

- Naheed Dosani²¹

The Seattle-based program has a larger caseload, with about 30-45 patients receiving care at any given time. Providers in the program see about 18-20 patients a week as well as providing case-management via phone. Most patients are seen at least every other week unless they need to be seen or followed-up with more frequently. In contrast, site-based programs are limited by the number of beds they have. For example, the hospice program at the Ottawa Mission has 14 beds for hospice-enrolled individuals and recently added another seven beds for individuals who need more chronic, long-term care with an extended life-expectancy allowing them to serve 21 patients at a time, half the capacity of the mobile program in Seattle and at a higher program cost per patient per day.

"We identified that some people are on the palliative care path, but that it may be a year or two before they are ready to die. Having the flexibility of both acute [hospice] beds and chronic palliative care allows us to be more flexible."

- Marg Smeaton²²

Patient Eligibility Criteria

Programs have a limited capacity, and therefore must be intentional about who they accept. For any program serving homeless individuals it is important that the program first define homelessness. Definitions of homelessness vary considerably and MPCH programs must be clear about their criteria as it relates to admission. Some programs may define homeless as those without shelter,

while other program definitions may also include people living in shelter, transitional housing, unstably housed, etc.

Another important patient eligibility criterion is disease status and prognosis. MPCH Program participants must have a life limiting illness for which they need care managing their pain and quality of life. The Seattle-based program accepts individuals into the program with a life expectancy of 6 months or less; the PEACH program in Toronto does not have a specific life-expectancy requirement.

Note: Many programs contacted both have life-expectancy requirements and also make exceptions for patients who have a longer life-expectancy on a case-by-case basis. These exceptions are often made for homeless individuals who are the least likely to receive other kinds of care and who are struggling to manage pain on their own with their primary care provider.

Naheed Dosani uses the <u>Mississauga Halton Regional Hospice Palliative Care Early Identification & Prognostic Indicator Guide</u> to identify whether patients qualify for the program.

"We have to be cognizant that in our program we have a low threshold for admission because homelessness cuts the lifespan by 50%, so we view homelessness as a terminal diagnosis. Homelessness in and of itself is life limiting and could be a palliative diagnosis, so when you add another diagnosis it is a slam-dunk. Especially if their goals are not treatment oriented. For those seeking quality of life treatment [from the PEACH program] this document makes a world of difference."

- Naheed Dosani²¹

Most programs have limited mental health service capacity, which limits admission to patients with minor and/or well managed mental health needs, effectively limiting access to palliative programs for many homeless individuals.

"A significant challenge we face is access to enough mental health care. We have a psychiatrist who comes to the hospice once a month and there is a social worker on staff at the mission, but it is never enough and it limits our capacity to care for some individuals that need palliative care."
- Marg Smeaton²²

End of Life Planning Conversations

Advanced care planning (ACP) is an important element of end of life care for everyone, not just homeless individuals. ACP allows people to decide who they want to make decisions for them when they are incapacitated, the kinds of life saving treatment they would like to receive, what will happen to their body and possessions after death, and any other decisions about their care or death they want to express.²³ In general individuals who complete ACP are more likely to receive appropriate care and less likely to receive unnecessary or undesired care. In one study, among the general population 90% of those who completed ACP died in their desired location compared to 50% of people who did not complete ACP. ACP has also been shown to improve patients symptom and pain management and increase patient comfort and happiness at the end of life while also reducing healthcare costs.²⁴ John Song, an Internist working at the University of Minnesota Medical Center conducts research about ACP specifically with homeless individuals.

"We know that advanced care directives improve care in the general populations. I feel that they are even more important for homeless individuals. They can often end up in the hospital without anyone to advocate for them on their behalf, and have [healthcare] interventions that they don't want. Also we found that usually next of kin is not who they want making healthcare decisions for them. An important part of an advanced directive for homeless individuals is the power of attorney. We found that these conversations are most productive when they happen with a trusted shelter worker or case-manager. Often healthcare providers do not have the skills, desire or time to guide these conversations."

- John Song²⁵

In a randomized trial Song found that when offered, 44% of homeless individuals participated in creating an advanced directive. 59% of individuals who received guidance from a counselor completed an advanced directive compared to 30% who were given materials to complete on their own. ²⁶ Some important components to include in end of life planning conversations specifically for homeless individuals include what they want to happen to their body when they die, who they want to be notified, who they want making

decisions for them at the end of their life when they die, and what should happen to their belongings. It also gives homeless individuals an opportunity to decide if they want to reach out to people who they have been estranged from. Song found that it is important to tailor ACP to homeless populations.

"Our new patient intake is done by a nurse and includes end of life planning. They talk about what kind of funeral they want, what kind of care they want at the end of their life, if they want to contact anyone from their biological family and who of their street family they want with them. Most people who receive palliative care here sign a do not resuscitate (DNR), but some people choose to get transferred to the hospital"

- Marg Smeaton²²

Geographic and Site-based Limitations

All programs studied have some geographical referral limits based on funding requirements, population demographics, travel limitations or a combination of these factors. MPCH programs identified for this project all use a home-visit model seeing individuals in transitional housing, a shelter or on the street instead of using a van/mobile setting for patient visits.

"Ontario is broken up into 14 different districts known as Local Health Integration Networks (LHIN). Inter City Health Associates where I work is only funded to support patients who are homeless from Toronto Central LHIN, therefore I am only funded to see people who are homeless and dying from Toronto Central LHIN. There are actually barriers for patients from different LHINs. This is especially challenging with a transient patient population."

- Naheed Dosani²¹

Urban downtown cores are "home" to the majority of homeless individuals or at least where they spend much of their day. It is also where many social services are consolidated. This centralization may make it easier to have a specific geographical boundary for a program.

"Ottawa Inner City Health is an umbrella organization that has nine different programs housed in different shelters mostly within the downtown core of the city. Most of our programs are within a 12 block radius, serving the homeless population in the downtown. It is important to focus the work where your population is, that is why providing care in shelter settings has been successful for us. We go to them, not the other way around."

- Marg Smeaton²²

The Seattle-based program sees homeless individuals in the downtown Seattle core, specifically in Pioneer Square as well as a few patients who live in Ballard, a neighborhood across town. They offer a very limited number of weekly clinic drop-in hours but provide most of their visits outside of the traditional clinic setting. This can have pros and cons, since the mobile model requires staff to spend a significant amount of time traveling around the city.

"A huge part of my day can be eaten up just trying to get from patient to patient. This is the only way to see many of our patients, but it means we do need to think about where someone lives when we take them on. Also if we had more time and space in clinic it may allow us to see more patients without having to go to them as often."

- Colette Conlisk¹⁶

However, there are also benefits to the mobile model in terms of access for the intended population. Naheed Dosani from the PEACH program in Toronto disagrees with Conlisk's proposal to extend clinic hours. He doesn't endorse or offer clinic-based office hours in his program.

"There is no point in doing that [hosting clinic hours]: we go to where people are. The work we are doing requires you to think differently. Having a physical space in my opinion is absolutely pointless."

- Naheed Dosani²¹

Smaller Programs Benefit from Larger Infrastructure

MPCH programs are bolstered by larger healthcare organizations and institutional partnerships. This relationship provides necessary infrastructure and support that would otherwise be unavailable due to program size and financial limitations. Supports provided include:

1. Access to electronic medical records and other shared information systems.

"Ottawa Inner City Health is an umbrella for nine different bedbased programs and clinics in downtown Ottawa. We share one health record system and providers rotate in and out of the different programs. Every Thursday the providers get together to discuss patients across the sites. This allows all the providers to understand what is going on with all of the patients, keeping our system flexible. If a patient needs to move from a program with less care to one with more we can make that transition pretty seamless for individuals."

- Marg Smeaton²²
- 2. Back-up healthcare providers, specifically those who can assist with providing prescriptions and stepping in for providers while sick or on vacation.

"Inner City Health Associates (ICHA) is a group of 60 doctors doing a variety of work. One of the doctors has a kind of palliative background and covers for me when I am away. If push comes to shove the primary care lead in our organization can prescribe or even our medical director. Coverage for me is easy, but coverage for our nurse is harder. We have no funded coverage for her [the nurse]."

- Naheed Dosani²¹

The Seattle-based program lacks the kind of institutional support and access to providers who are trained and comfortable filling in for providers in this program when necessary.

"There is very little institutional support for this program. If either of us is out it means that referrals aren't getting processed. If the ARNP isn't available, it means that no one can

get a prescription. It is very hard to make a system like this sustainable. That's why he [ARNP] always has his phone with him, even on vacation.

- Colette Conlisk¹⁶
- 3. Access to larger care networks and organizational partners that can help provide wrap-around services, refer patients, and strategic partnerships.

"Find a place that refers at high volumes. We have two sites that refer quite frequently, to the point were I visit every week. One is the largest men's shelter in Toronto and they have a managed alcohol program within it. We get 1-2 referrals a week from that program because people are suffering from end-stage liver disease. You want early referrals from program partners. It is important for people to know what you do and that you are good at it."

- Naheed Dosani²¹

"We found that just having medical care wasn't enough. Social service providers are your partner when it comes to talking to homeless individuals about end of life decisions. It is important that they are working with someone they trust"

- John Song²⁵

Training The Next Generation

Palliative care services in hospitals and out-patient settings are growing rapidly in the U.S. and other developed nations. However, in the U.S. palliative care has only been a board-certified medical specialty since 2008 resulting in fewer than needed trained palliative care providers. There are even fewer providers who have the interest and competencies to work with homeless individuals. The success of small palliative care programs serving homeless individuals requires that the next generation of medical providers receive specialized training. Today's medical residents, nursing externs and social work students can gain end of life care skills, and the culturally competency needed to work with homeless individuals and bolster the modest staffing levels of these small programs.

"I always have a resident on. We are booked for an elective for something like two years. So there is always someone with an M.D. who can liaise and do basic care. At least a senior resident. These residents are critical to the on going success of this program."

- Naheed Dosani²¹

Access to Low-Intervention End of Life Beds

In-patient end of life care are among the most intensive and expensive medical services, accounting for one out of every four Medicaid dollars spent.²⁹ Individuals hospitalized at the end of their life are also more likely to receive unwanted care interventions. Compounding the unnecessary costs associated with inpatient end of life care, most patients do not choose the hospital as a place to die.³⁰ However, when homeless individuals are in their last days of life they can often end up in the hospital because they don't have an alternative. MPCH programs studied identified a growing need for low-cost, low-intervention beds for homeless individuals, who may dislike the structure and regulation of a hospital or hospice setting. In some communities, medical respite, skilled nursing facilities (SNF) and supportive housing are used as alternatives to hospital-based palliative care for homeless individuals.

"In Oakland, CA at Highland Hospital they are managing to get people into SNF beds and then getting hospice layered on top of it; like an outside hospice. It is mostly people who are dying at Highland who they are managing to get out into these other situations which is a creative solution. But it feels very catch as catch can. There isn't a system."

- Margot Kushel³¹

It is often hard to get homeless individuals into a SNF and once they are there staff are not formally trained and/or equipped to provide palliative care or specifically meet the needs of homeless individuals. There is a need to develop a model of care for homeless individuals that provides a safe place to receive culturally competent care in their last days of life.

"This is where being a mainstream palliative care physician is helpful. We have developed relationships with mainstream palliative care facilities. Do we face resistance from these facilities? All the time. There are also opportunities to get people into hospice, long-term care, etc. We advocate for admission. We have places and we consider them partners. Some of these partnerships have been more successful than others. We never discharge a patient, even when they get admitted to a facility, we never sign-off."

- Naheed Dosani²¹

The Seattle-based MPCH program is developing a partnership with a supportive housing provider who is opening a facility near HMC in the next few years. This partnership will provide four beds for MPCH program patients in the last days or weeks of their life who do not have safe shelter. This partnership will both provide a place for people to die on their own terms, outside of a hospital at lower cost.

"We are excited about this partnership. As it stands now many of our patients end up dying in the hospital because it is really hard to find beds for them. Most facilities are either illequipped to address an individual's medical needs, or they are not use to working with homeless populations. Having a safe place for people to die, while getting the care they need in an appropriate setting is really important and valuable" - Colette Conlisk¹⁶

Program Funding

The Seattle-based program is funded for 2014-2016 with HRSA funds locally administered by PHSKC. The budget for the program is approximately \$100,000 a year. The PEACH program in Toronto has a similarly sized budget. Up to this point MPCH programs have successfully operated with small budgets using a traditional medical model including a provider and a registered nurse (RN). In contrast, traditional palliative care programs include social workers, chaplains and other support staff to meet a holistic range of patient needs. As MPCH programs are currently structured and funded program components such as grief counseling, program coordination, specialty referrals, and social work support consume a significant amount of MPCH nursing staff hours.

MPCH programs may benefit from including a social worker in their care model, especially because on average homeless individuals have more social work needs than the general palliative care patient population. Due to current budget constraints these programs are also not able to provide the level of mental health care, grief counseling, social services, and case-management that would benefit many. As MCPH models develop it is critical to consider the social work and mental health resources that many program participants will need, as well as program administrative demands when building and working to expand MPCH program budgets.

Many of the programs outside of the U.S. are funded primarily by their national healthcare systems. In Ottawa the mission's palliative care providers, nurses and other healthcare staff are paid for by the government. All equipment, food and other costs are paid for through private donations to the mission.

"The provincial government reimburses the hospice \$42 a day per bed per hospice bed that is filled. The cost per day for a traditional ward bed in Canada is something like \$3,000. The government knows it is better to help support our shelter hospice program where each bed costs about \$220 a night. The work we do doesn't just save money, it also improves people's quality of life. It works better for everyone."

- Marg Smeaton²²

In the U.S. programs are funded through public grants, individual donations and reimbursement from Medicaid and Medicare. The Seattle-based MPCH is primarily funded through public grants with minimal reimbursement for services. Federal dollars are available to reimburse for some palliative care services and housing costs. Supportive housing services are not yet recognized and paid for by health systems, making it hard to develop and sustain these programs.

"Where we have really fallen down is out-patient palliative care. I think in some ways this has to do with our completely siloed payment structures, our lack of coordination of EHRs, the in-patient out-patient divide, but at the end of the day I don't know what needs to change to address these [financial] challenges."

- Margot Kushel³¹

Margot Kushel and other U.S. based providers and researchers interviewed for this project acknowledged that in the US, collaboration between community partners offers some of the most optimistic opportunities for palliative care programming for homeless individuals including:

- Partnerships of medical, housing and social service organizations working together to fund elements of a collective team working together.
- Negotiating with Medicaid managed care plans to develop coverage options for early palliative care and housing outside of the hospital system for homeless individuals on Medicaid.

As palliative care providers and homelessness advocates continue to identify the breadth and depth of care necessary, the need for services continue to grow among aging homeless individuals. Emerging models such as MPCH can serve as a platform for further program development and an opportunity to build an interconnected network of programs and services to address the palliative care needs of homeless individuals.

Conclusion

I had the opportunity to speak to many people in the field of palliative care, homeless advocacy, homeless health care and researchers for this project. I walked away from these conversations knowing more about what is happening in the field of end of life care for homeless individuals and personally excited about the work that people are doing across the country and internationally. Experiences of today's MPCH providers point us toward the needs of the future and can be summarized by the following recommendations:

- Train culturally competent medical and mental health providers to address the palliative care needs of homeless individuals.
- Develop flexible program models, such as MPCH that address the specific needs and limitations of homeless individuals.
- Create sustainable funding models that support emerging program models.
- Integrate MPCH programs with larger health care systems, providing structure, technical and staffing support and a referral base.
- Collaborate with palliative care providers and professionals working in homelessness services to build effective, holistic, and flexible care models that can be tailored to different communities.
- Develop unified definitions and criteria, systematic delivery systems, and opportunities to shared resources to best serve homeless individuals.

As the aging population expands and homelessness continues to grow throughout the world, there will be an increased need for palliative care services for homeless individuals. Current providers have documented the ways in which standard palliative care models do not meet the needs of homeless individuals. Homeless individuals need flexible program admission criteria, harm-reduction prescribing practices, and access to care outside of clinic and hospital settings.

"This is going to be a continued problem as this population continues to age. I think that we need to start talking about it and exploring funding options... we need to come together and start imagining what a comprehensive, large-scale, integrated solution looks like."

- Margot Kushel³¹

The MPCH programs and other innovative services are designing solutions to address the need for palliative care for homeless individuals. While current programs are a good first step in identifying and caring for individuals who are better served outside the traditional healthcare system, they could be more effective with added institutional support allowing them to better address the complexity and scope of palliative care needs.

An important next step to expanding and sharing this emerging model of care includes palliative care providers and homeless advocates continuing conversations about the palliative care needs of homeless individuals. What emerges from those collaborations and early pilot projects will serve to leverage financial support for the palliative care needs of homeless individuals.

In the last 50 years there have been great strides in understanding and addressing the economic, social and cultural causes and implications of homelessness. This work has been important to understanding the impact of homelessness in differing populations including veterans, teens, HIV+ individuals, substance abuse issues and people with mental illness. The aim of this project is to build on this legacy of addressing the needs of homeless individuals by mobilizing programs and organizations nationally and internationally to collaborate to build a strategic response to the need for palliative care.

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Sources and Interviews

- 1. Cagle JG. Weathering the Storm: Palliative Care and Elderly Homeless Persons. *J. Hous. Elderly* 2009;23(1-2):29-46. doi:10.1080/02763890802664588.
- 2. World Health Organization. Definition of Palliative Care. Available at: http://www.who.int/cancer/palliative/definition/en/. Accessed October 25, 2015.
- 3. Murtagh FEM, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat. Med.* 2014;28(1):49-58. doi:10.1177/0269216313489367.
- 4. Davis MP, Gutgsell T, Gamier P. What is the difference between palliative care and hospice care? *Cleve. Clin. J. Med.* 2015;82(9):569-71. doi:10.3949/ccjm.82a.14145.
- 5. Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window. *J. Pain Symptom Manage*. 2007;33(3):238-246.
- 6. Pyenson B, Connor S, Fitch K, Kinzbrunner B. Medicare cost in matched hospice and non-hospice cohorts. *J. Pain Symptom Manage*. 2004;28(3):200-210.
- 7. Miller S, Rynd T. Quality of Life at the End of Life: The Public Health Perspective. *Public Heal. Aging* 2005; Summer: 41-47.
- 8. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N. Engl. J. Med.* 2010;363(8):733-42. doi:10.1056/NEJMoa1000678.
- 9. Withers J. Street Medicine: An Example of Reality-based Health Care. *J. Health Care Poor Underserved* 22(1):1-4. Available at: https://muse.jhu.edu/article/414326. Accessed May 7, 2016.
- 10. Post P. Mobile Health Care for Homeless People: Using Vehicles to Extend Care.; 2007. Available at: https://www.nhchc.org/wp-content/uploads/2012/02/mobilehealth.pdf. Accessed May 7, 2016.
- 11. O'Connell J. *Premature Mortality in Homeless Populations: A Review of the Literature*. Nashville; 2005. Available at: http://santabarbarastreetmedicine.org/wordpress/wp-

- content/uploads/2011/04/PrematureMortalityFinal.pdf. Accessed November 28, 2015.
- 12. Hearth Inc. Who are the Elderly Homeless? *Facts* 2010. Available at: http://www.hearth-home.org/homeless-elders/. Accessed November 28, 2015.
- 13. National Coalition for the Homeless. *Homelessness Among Elderly Persons*. Washington D.C.; 2009. Available at: http://www.nationalhomeless.org/factsheets/Elderly.pdf. Accessed November 28, 2015.
- 14. Kennedy P, Sarafi C, Greenish W. *Homelessness and End of Life Care*. London, UK; 2013. Available at: https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/current-partnerships/homeless_report.pdf. Accessed April 2, 2016.
- 15. Abt Associates, Advocates for Human Potential Inc. *Building Your Program-Permanent Supportive Housing*.; 2010. Available at: http://store.samhsa.gov/shin/content/SMA10-4510/SMA10-4510-06-BuildingYourProgram-PSH.pdf. Accessed April 2, 2016.
- 16. Interview with Colette Conlisk, RN. 2015.
- 17. National Health Care for the Homeless Council. 2015 Medical Respite Program Directory: Descriptions of Medical Respite Programs in the United States.; 2015. Available at: https://www.nhchc.org/wp-content/uploads/2011/10/2015-medical-respite-program-directory.pdf. Accessed April 3, 2016.
- 18. Kertesz SG, Posner MA, O'Connell JJ, et al. Post-hospital medical respite care and hospital readmission of homeless persons. *J. Prev. Interv. Community* 2009;37(2):129-42. doi:10.1080/10852350902735734.
- 19. Podymow T, Turnbull J, Coyle D. Shelter-based palliative care for the homeless terminally ill. *Palliat. Med.* 2006;20(2):81-86. doi:10.1191/0269216306pm11030a.
- 20. Associates ICH. PEACH. *Programs* 2014. Available at: http://www.ichatoronto.ca/programs/peach. Accessed November 29, 2015.
- 21. Interview with Naheed Dosani, M.D. 2016.
- 22. Interview with Marg Smeaton, Manager of Health Services. 2016.
- 23. HCH Clinicians. HCH Clinicians Can Help Homeless People Die with Dignity.

- Heal. Hands 2004;8(1). Available at: http://www.nhchc.org/wp-content/uploads/2011/09/endoflife.pdf. Accessed May 7, 2016.
- Scott IA, Mitchell GK, Reymond EJ, Daly MP. Difficult but necessary conversations--the case for advance care planning. *Med. J. Aust.* 2013;199(10):662-6. Available at: http://www.ncbi.nlm.nih.gov/pubmed/24237095. Accessed March 18, 2016.
- Song J, Wall MM, Ratner ER, Bartels DM, Ulvestad N, Gelberg L. Engaging homeless persons in end of life preparations. *J. Gen. Intern. Med.* 2008;23(12):2031-6; quiz 2037-45. doi:10.1007/511606-008-0771-1.
- 26. Interview with John Song, M.D. 2016.
- 27. Certification for Hospice and Palliative Medicine Specialists. *Am. Acad. Hosp. Palliat. Med.* 2015. Available at: http://aahpm.org/career/certification. Accessed April 11, 2016.
- 28. Punke H. Workforce Shortage Threatens Future of Palliative Care. *Becker's Hospital Review*. http://www.beckershospitalreview.com/hospital-physician-relationships/workforce-shortage-threatens-future-of-palliative-care.html. Published November 5, 2013. Accessed April 11, 2016.
- 29. Wang P. Cutting the High Cost of End-of-Life Care. *Money* 2012. Available at: http://time.com/money/2793643/cutting-the-high-cost-of-end-of-life-care/. Accessed May 8, 2016.
- 30. The Dartmouth Atlas of Health Care. End-of-Life Care. Available at: http://www.dartmouthatlas.org/keyissues/issue.aspx?con=2944. Accessed May 8, 2016.
- 31. Interview with Margot Kushel, M.D. 2016.