

## **Serious Illness and End-of-Life Care in the Homeless: Examining a Service System and a Call for Action for Social Work**

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### **Introduction**

According to the Mc-Kinney-Vento Act (PL 100-77), in the United States, a homeless person is one who lacks a fixed residence, often living in some kind of temporary shelter. In 2009, this definition was amended to include people who are in jeopardy of losing their housing in the next two weeks. It also includes those who have a strong history of not having permanent housing over time (SAMHSA, 2013). It is quite difficult to accurately count the number of people who are homeless in the U. S. at any point in time. Recent estimates suggest that close to 650,000 people could be considered homeless, with about 240,000 actually residing on the streets (HUD, 2013).

Generally, homeless people have been found to have higher rates of mental illness, serious and chronic physical illness and dental problems than the housed population. Specific conditions seen more frequently in homeless populations include hepatitis, tuberculosis, sexually transmitted diseases and anxiety (Notaro, Khan, Kim, Nasaruddin, & Desai, 2013). Chronic medical conditions like HIV/AIDS, hepatitis, dental problems and diabetes have also been found to be common among the homeless (Schanzer, Dominquez, Shrouf & Caton, 2007). Life expectancy for the homeless is 20 years less than those with stable housing. In fact, homelessness itself has been referred to as a fatal condition due to this drastically shortened life expectancy (Watt, 2000).

Given the health risks of being homeless, the experiences of serious illness and death are ever present in this population. Often chronic, treatable diseases become life threatening due to lack of adequate management. Contrary to popular belief, homeless people don't usually die of "exposure," but rather of the illnesses that strike them due to their circumstances and their lack of access to healthcare. One strong predictor of this lack of healthcare is the absence of basic health insurance coverage (Baggett, O'Connell, Singer, & Rigotti, 2010).

### **1 Serious Illness and End-of Life Care**

An important issue that arises when addressing healthcare in the homeless is the provision of care for serious illness and the provision of end-of-life care. Moller (2004) writes about the double invisibility of being seriously or terminally ill and in poverty. Through in-depth interviews, he detailed the lives, decline and deaths of homeless people in a Midwestern city in the United States. Lack of medical services for serious illnesses and end-of-life care were highlighted. Confusion and difficulty navigating the healthcare service system were significant barriers to end-of-life care among those he studied (Moller, 2004).

Another study in the U. S. reported on an in-depth analysis involving a physician and a homeless patient in a palliative care clinic at a university hospital in California. Similar to Moller's (2004) findings, this case study interview revealed that even when homeless people

had access to healthcare, these facilities usually did not provide care for serious and chronic illness. Additionally, no information or discussion of end-of-life care took place (Kushel & Miaskowski, 2006).

Serious illness among homeless drug addicts and their challenges to receiving adequate healthcare were highlighted by Bourgois and Schonberg (2009). Based in San Francisco, this ethnography detailed the experiences of those with life threatening illnesses that often occur on the streets. Homeless addicts were treated with blame and even hostility by medical professionals, particularly in emergency room settings. Others were given less than optimal treatment, like painful procedures without anesthesia, with no follow-up pain medication. More than anything, end-of-life care for this population seemed fragmented, confusing and difficult to access.

Researchers from around the world have begun to examine and discuss these issues surrounding end-of-life care in the homeless in greater depth. Kushel and Miaskowski (2006) discuss the stigma attached to hospice that limits this care for people in poverty. In Ottawa, a program was developed where the stigma related to hospice was confronted and palliative care was actually provided at the homeless shelter itself (Podymow, Turnbull & Coyle, 2006). Collier (2011) echoed this support for palliative care for the poor by suggesting that in Canada there is a need for palliative care units in homeless shelters, arguing that the shelter staff has an understanding and appreciation of the needs and values of the homeless people themselves. Obviously open discussion of end-of-life issues is critical to the success of these palliative care units. Others argue that this kind of open sharing and communication is difficult, as many homeless people fear and believe that their lives will end in sudden and and/or violent ways. Thus, they may not be open to these end-of-life discussions and planning sessions (Tarzian, Neal & O'Neil, 2005).

In the United Kingdom, a nurse leadership program concluded that hospice services should be made available to homeless people. Cultural issues, language and lack of outreach were identified as potential barriers to providing hospice care (Hindmarch, 2012). Violent neighborhoods, fear of crime and safety concerns have also been discussed as barriers to the provision of end-of-life care, particularly hospice care to homeless patients (Soares, 2003; Hughes, 2005).

These afore mentioned barriers to care were further explored through focus groups with low income African American and Latino individuals in the United States. When asked about barriers to utilizing hospice services specifically, respondents identified some major concerns including a general lack of awareness of the services. They also mentioned cost and language barriers as potential problems. Finally, lack of trust in the health care system was highlighted as an important barrier to using hospice services (Born, Greiner, Sylvia, Butler & Ahluwalia, 2004). Cagle (2009) also identified lack of trust of hospice as a potential barrier to service for the homeless. Being homeless also causes logistical problems for end-of-life care providers, such as the inability to locate patients, or lack of reliable power supplies for equipment or refrigeration for medication.

Finally, a large study examined attitudes toward end-of-life care in the homeless, by conducting focus groups with 53 homeless individuals. Respondents reported poor relationships with service providers and felt like they were treated with a lack of respect in the medical system. These factors were mentioned as barriers to considering end-of-life care among the homeless (Song, Bartels, Ratner, Alderton, Hudson & Ahluwalia, 2007).

The present study sought to expand on this literature and explore the area of serious illness and end-of-life care in the homeless in greater depth. The purpose of this study was to examine the service network of a medium sized city in the Midwestern United States in an attempt to understand the service system for serious illness and end-of-life care, particularly for those without stable or permanent housing. This study was exploratory in nature, and an open examination of the service system, including potential barriers to service was conducted. Although the focus of this study was on the perceptions of the providers, the voices of some homeless adults were included as well. This was done to potentially broaden the perspectives that might otherwise be limited to the experiences of the key informants.

## **2 Method**

This study utilized a needs analysis method by identifying key informants in the community who represented medical facilities or programs that dealt with end-of-life services for the homeless population. This approach allows one to identify and understand a social concern, with an emphasis on the examination of need and the provision of service (Rossi, Lipsey & Freeman, 2004). Key informants are critical in that they know the culture and are willing to talk about it (Ryan & Bernard, 2010).

### **2.1 Agency and Respondent Selection**

Ten community experts were selected through a snowball sampling procedure. An initial interview with the program director of the overnight homeless shelter led to the identification of pivotal people in the healthcare network that serves the homeless and non-homeless poor in a medium sized city in the Midwest. In this Midwestern city, approximately 1,040 people are homeless on any given night, with almost one-third of these people being families with children (COHHIO, 2013).

In addition to these community experts, two women and two men residing at the overnight homeless shelter were interviewed. The purpose of these interviews was to provide some initial insights from the perspective of the homeless, rather than relying solely on the identified experts. These respondents were approached at the shelter by the investigator and asked to participate in an interview. After the purpose of the study was presented, consent forms were signed. No compensation was provided for participation.

Informed consent forms were signed by the key informants and interviews took place at the sites where they were employed. The interviews lasted approximately 1-1 ½ hours each. All informants were asked to describe their programs, access and funding. A specific focus was on the provision of end-of-life care and healthcare for serious and chronic illness in general in the homeless population. These questions were based on an interview guide that allowed for expansion and the addition of specific questions based on the agency site (Patton, 2002). The guests at the shelter were interviewed in a private room at the shelter.

In attempting to understand the healthcare service system for the homeless, the following community experts were interviewed: 1) the program director of the overnight homeless shelter, 2) a nurse supervisor of a federally qualified health center for the homeless, 3) a social worker who is a housing/outreach specialist in the community, 4) a psychologist working with the housing/outreach specialist, 5) a hospice social worker, 6) a funeral director, 7) a social worker at the healthcare respite center, 8) a social worker from the largest hospital in the city, 9) the director of a low-income health clinic, developed and run by volunteers, 10) an administrator from a private, faith-based health clinic for low income patients.

These community experts represented the full extent of medical services available to low income and homeless people in this Midwestern city. Although only one person from each agency was interviewed, the range of agencies and experience of these interviewees was deemed sufficient by the primary investigator to provide an accurate understanding of the service system. All of those interviewed had been in their respective agencies for a number of years, ranging from a low of five to a high of over twenty.

All interviews were transcribed and topic coded. In order to address the issue of bias in data interpretation, an independent rater also read and coded the transcripts. Both of the raters then met and discussed the independent codes that were generated, highlighting the similarities and differences in the codes (Patton, 2002; Merriam, 2009). Following this in-depth discussion, themes for analysis were derived by combining identical or similar codes into overriding themes (Glaser & Strauss, 1967). Based upon this collaboration, analysis, and consensus, the following themes were identified and will be discussed: Lack of services for serious, chronic and life threatening illness, Barriers to access to services, Stigma, End-of-life care.

### **3 Presentation of Themes**

#### **3.1 Lack of services for serious, chronic and life threatening illnesses**

All of the respondents talked about a lack of services for homeless patients with chronic and serious illnesses. Lack of funding and available resources were cited as the most compelling reasons for this lack of services. Thus, people potentially needing end-of-life care had nowhere to go. Although medical services were provided in the community to both low income and homeless patients, these services tended to be for acute conditions, rather than serious chronic illnesses. Dental and eye care were cited as being especially lacking for those in poverty. Although in and of themselves these kinds of ailments may not be life threatening, left unattended, they can lead to serious, chronic and even life threatening illness. This is a critically important issue, as the majority of homeless patients do suffer from chronic and serious conditions that require care.

Although there is a small respite program in the community that was studied, it only includes three apartments. Patients can recover or recuperate in these apartments, but there are no medical professionals on site. One social worker visits the apartments daily, providing case management and referral services. According to the social worker who serves as a housing/outreach specialist, this respite program only really serves patients for a short time. Once they are ambulatory, they leave the respite program. The majority of key informants interviewed were not even aware that this program existed, nor were the homeless men and women who were interviewed.

Frustration with lack of services was expressed by the homeless men and women who were interviewed. In detailing the struggle to attain medical care, stories were told about chronic back and neck conditions, epilepsy and cancer that were being undertreated. Obtaining adequate pain medication for these conditions was next to impossible according to these homeless respondents. Often, the clinics that service low income and homeless adults will not dispense narcotic pain medications due to the fear of abuse of these medications.

Even when services for chronic illnesses are available, treatment is difficult due to the general lack of prior health care services that patients have received. The supervisor of the medical clinic for the homeless talked about the chronic problems that are seen like diabetes, asthma,

COPD, hypertension and heart disease in the homeless population. She described the unique nature of treating these conditions in this population by saying:

“We are different with our folks in that they tend to have not had regular health care prior to coming here. Any of those issues they are experiencing are probably out of control or more advanced than they should be. The diabetics aren’t under good blood sugar control. The hypertensives aren’t on meds.”

The director of the overnight shelter shared her frustrations with the lack of available care for chronic and serious illness. In addition to lack of funding being a problem, she pointed to the hospital as having some responsibility in not adequately treating chronically sick people, and discharging them before it was appropriate to do so. She said:

“The hospital social workers will many times release the people back here to the shelter that are completely inappropriate to be in a shelter. We are not a nursing care facility.”

She went on to describe the case of a woman who was in congestive heart failure at the shelter, taking 20-30 medications at multiple times during the day. In looking at the macro picture, she commented:

“There are many systems at play here. Everybody has their own agenda and their own end game and their own requirements. We have no hospitals for the poor. There are high end providers. If you look at the dollars they spend on our clients who are homeless, it is not a lot.”

Frustration with the lack of available services was illustrated by a homeless woman who talked about her husband’s chronic health condition. Basically, his uncontrolled epilepsy has prevented him from working and has worsened his mental health problems due to frequent seizures and the stress associated with managing a chronic illness. His lack of appropriate medical care for this chronic condition, she believes, was a direct contributor to his job loss, their housing eviction and their need to stay at the shelter.

### **3.2 Barriers to access to service**

One of the biggest barriers to accessing healthcare services is the difficulty inherent in navigating the medical service network and understanding health insurance. In this Midwestern city, there are separate medical facilities for homeless people and people who have a low income, yet are not homeless. One clinic is even more specialized, and will only see patients who are employed, low income, with no insurance. It is difficult for patients to understand and navigate these different types of facilities. The director of the homeless medical clinic talked about the large number of patients that must be refused treatment because they don’t fit the criteria of being homeless, yet are not aware of the other health care options in the community.

At this same homeless medical clinic, access to services is often a problem, even if the patients qualify for service. The director of the homeless shelter talked about long waiting times at the health clinic for the homeless. She talked about the policy at the homeless medical clinic where patients must wait in line in the morning and leave when the clinic closes for lunch. If a patient has not been seen before lunch, they must return another day and wait. So, sick patients often wait outside for an entire morning only to be turned away.

Speaking about these barriers to access to service, the nurse supervisor at the homeless medical clinic talked about the waiting times as being unavoidable due to the sheer volume of patients requesting and needing service. Many of the patients that are turned away because they are not homeless have been referred to the clinic from local hospitals. She highlighted the lack of awareness about the different health clinics and their eligibility requirements among health and social service professionals.

Since the demand for service is so high, homeless patients often must wait even longer periods of time to be seen by any kind of physician specialist. It is important to mention that in the case of serious and chronic illness, specialty care is often a necessity. A homeless patient talked about trying to be seen at the clinic for chronic back problems. After being given some medication by the nurse, she was told that she had to wait two months to see the physician. During this visit, it was recommended that she consult a spine specialist. According to her:

“I had to wait three months for a back doctor. I waited three months and he told me they were still waiting. I waited another four months. It’s been two and a half years and I’m still waiting.”

### 3.3 Stigma

Negative attitudes toward the homeless and their right to adequate healthcare abound and were discussed extensively by the respondents. These attitudes restrict access to care and further complicate care for chronic, serious or life threatening medical conditions. Lack of knowledge about poverty and homelessness were cited as reasons for this stigma. Public perception tends to be that the homeless are mainly drug addicts or mentally ill. The social worker at the small respite program expressed frustration with this sentiment and suggested that it affected access to quality services. She said that the face of homelessness has truly changed, yet public understanding has not. According to her:

“A lot of people have the idea that our patients are drug addicts and have mental health issues. That’s the case for some, but we’re seeing a different face of homeless now. We have patients in the clinic who have doctoral degrees that lost their jobs and they just can’t find work. So, to be judgmental with the perceptions of homelessness compared to what it really is, I think people need to be more educated.”

The problem of stigma toward the homeless was discussed as being rooted in the debate around health care as a right or privilege. The respondents argued passionately that access to health care should be a basic human right for all. There was strong sentiment that there are different health care systems for the rich and the poor and that the stigma attached to poverty created this division. This quote from the supervisor of the medical clinic for the homeless represents this perspective. She said:

“Health care is for people who have money and can afford to have it. We can talk all we want about “Bubba” sitting on his butt and not working, and I’m not supporting him. I don’t know any “Bubbas.” In the 2,600 people we saw last year, I didn’t see one of them who didn’t want to get out of where they were.”

Interestingly, the key informants in this study felt that the stigma attached to poverty was promoted by many members of the medical community themselves. This was seen through discussion of the treatment of homeless patients in the various emergency rooms in the city. Discharge practices of the hospitals were also pointed to as evidence of the stigma toward

those in poverty. Often, homeless patients were discharged directly to the shelter, sometimes even following surgery. The housing/outreach specialist added to this discussion by talking about the treatment of the homeless by the local hospitals. She said:

“My overall perception is that people in extreme poverty are very likely to be treated differently....sometimes very rudely, especially if they don’t have a social worker with them or if they come in the middle of the night.”

Finally, a homeless female patient supported the conversation about stigma by talking about her breast surgery at the major local hospital. After undergoing surgery, she was discharged directly back to the shelter. No social worker or any other social service or medical professional even mentioned the respite apartments as an option.

### **3.4 End-of-life care**

A great deal of conversation during the interviews revolved around the topic of serious illness and death among the homeless. There was widespread agreement that death was a taboo subject, particularly when talking about the poor. Respondents agreed that end-of-life care is not very well developed or visible in this community. The social worker from the respite program underscored the importance of dealing with end-of-life issues with the homeless population as she pointed out that:

“The death rate for homeless, like the average age right now is in the later 40s or early 50s. Most people who are chronically homeless don’t live past the age of 60.”

Interestingly, among these experienced social service professionals interviewed for this study, there was a general lack of knowledge about death among the poor and end-of-life care in general. For example, the director of the shelter, who encounters illness and death on a regular basis, seemed surprised at the mention of hospice care as an option, saying that she had never known of any of the clients at the shelter being involved in hospice care.

In much the same way, the supervisor at the health clinic for the homeless reported a lack of attention to end-of-life care, particularly hospice care. She said that of all of the patients she had known, she could only think of one who used hospice care. The social worker at the respite center indicated that there was a great need for end-of-life care since there was no staff supervision at the respite apartments, other than her presence a few hours a day. In her experience, only two patients had worked with hospice in the prior five years.

The hospice social worker talked extensively about end-of-life care issues and hospice care in particular. Interestingly, she seemed surprised when asked if hospice as an organization was involved with end-of-life care of the homeless. One barrier to service that she discussed was the fear that some people have that the purpose of hospice is to actually euthanize patients. With this kind of misinformation, it is difficult to generate patient referrals. Other barriers really affect services to the poor, like the requirement of having two physicians certify that a patient is terminally ill. With a general lack of health care, many people in poverty do not have any relationships with physicians.

This same hospice social worker remarked that her organization used to be more open to serving people in poverty. Now, nurses and social workers are more reluctant to enter certain neighborhoods, and they would certainly be uncomfortable working in a homeless shelter. In thinking about end-of-life care, she advocated for change by saying:

“You know, maybe it begs the question about our structure. If people are fearful, maybe we need to send people in twos or maybe we need to change our structure so they feel they can go where they need to go. We need people that are willing to go give care wherever you are.”

Supporting the need for hospice care for the homeless, the funeral director expressed frustration with healthcare service providers saying that very few had any idea about end-of-life care. He is the only funeral director that deals with the indigent in this community, and reported that it is often difficult to get things done, as healthcare providers do not know where to begin. This represents, according to him, that “double taboo” of being in poverty and near death. A homeless woman echoed these sentiments and put it quite frankly by saying, “people who are in poverty eventually die on the streets.”

#### **4 Discussion**

The themes generated through these interviews with key informants and homeless men and women support the previous literature which suggests that much greater attention needs to be paid to serious illness and end-of-life care in the homeless population (Cagle, 2009). It adds to the literature in that the findings were from in-depth conversations with not only service providers, but homeless individuals themselves. When structured healthcare services do exist, staffing is a problem and referral to specialists is next to impossible. Patients must often wait long periods of time to see a physician for the most basic medical care. Lack of transportation, confusion and the complexity of the system add to the barriers to service.

Perhaps the stigma of serving the poor or as Moller (2004) discusses, the double invisibility of being both poor and at the end-of-life comes into play. This was certainly seen in the present study where engaged, committed and experienced service providers seemed unaware of end-of-life care and issues with the homeless population. Despite the fact that all of the service providers seemed to understand the importance of healthcare for the homeless, they were unable to take that next step toward designing programs that addressed end-of-life care. It was revealing to note that the providers seemed overwhelmed with acute healthcare needs. As a result, planning and implementing services to address chronic and serious conditions seemed impossible.

Kushel and Miaskowski (2006) have advocated for clinicians to discuss end-of-life issues with homeless patients. This recommendation is supported by the present interviews. Before these discussions take place, however, social workers and other staff need to become more comfortable with and conversant on the topics of end-of-life care. It is quite surprising that those interviewed knew so little about these topics.

Finally, the lack of hospice involvement in end-of-life care for the homeless was supported by these interviews. Some of the same barriers to care that have been discussed were mentioned (Soares, 2003). However, some programs have overcome these barriers calling for hospice programs in shelters (Collier, 2011). In this study, it was striking that these concerned, engaged professionals that witnessed serious illness and death frequently in the homeless population had not really given much thought to the role of hospice care, nor had they made referrals. Even a social worker employed at the major hospice agency in the city had never considered providing hospice care to the homeless. It seemed like the urgency of medical care was such that attention and passion for the delivery of services at end-of-life was not a priority.



## 5 Social Work Implications

Education and support for hospital based social workers about chronic illness and end-of-life care with this population is appropriate and urgently needed. The present study suggests that very sick homeless patients are often discharged based on the recommendations of social workers to the streets or to the shelter, both of which are inappropriate solutions. The director of the shelter made an interesting comment when she said that she didn't think this practice was malicious, but rather, that the medical social workers had never really been in the shelter, and their discharge decisions were not based on direct experience. In attempting to support the dignity and worth of the patients, social workers should advocate for better discharge practices, and should gain more direct familiarity with the needs of serious and chronically ill homeless individuals. Hospital based social workers need to be educated about the healthcare needs of the homeless, the gaps and barriers to services and the options for care at the end of life. Hospital social workers could be leaders in advocating for these healthcare services.

Obviously, there needs to be much greater communication and cooperation between agencies as they attempt to serve the homeless population. The lack of such cooperation found in the present study was striking. In a medium sized city, it should be possible to develop a coordinated system of care. Social workers can play a pivotal role in the development of such a system. For example, most of the interviewees in the present study were not well informed about the respite apartments for seriously ill patients, and thus did not refer appropriate patients. As a profession that focuses on case management and referral, social workers could be trained to be leaders in identifying appropriate patients and making those referrals. The recommendations gleaned from a study on public hospital palliative social workers serve as a model for this kind of coordination (Parrish, et. al., 2012).

The lack of hospice involvement in end-of-life care with the homeless has important implications for social work practice. The confusion about the role of social workers related to hospice care in nursing homes has been explored (Munn & Adorno, 2008). This same discussion should take place about the role of social work and hospice care for the homeless. Social workers could lead the way in educating others about the value of hospice to care for the homeless. Again, this education and training needs to take place with professionals in the community and in local hospice organizations themselves. Knowledge about hospice and its role in end-of-life care with the homeless was extremely limited in this study, with few respondents being aware of any homeless patients that had ever accessed hospice services. Even the social worker from hospice said that their agency did not serve this population, nor had they really considered it. This is a significant gap in service that social work as a profession could address. Hospice social workers could become leaders in advocating for the needs of the homeless at end-of-life. Clearly, adaptations in the hospice model must be made, but to just ignore the needs of this population promotes inequality and injustice. This advocacy can help promote hospice care as the standard of care at the end of life for all.

Finally, alternative models generated through creative thinking can improve the care for chronically sick or dying homeless patients. Some have advocated for an increased use of residential hospice programs specifically for the homeless (Cagle, 2009). Others have suggested that palliative care units be integrated into the shelters themselves (Collier, 2011). This suggestion, although creative, would involve a strong commitment on the part of shelters to provide this care. Often, shelter staff is overwhelmed with the general care of the homeless that they are already providing. In this model, hospice social workers and nurses would actually work in the shelter system. The present study suggests that fundamental changes in the way these professionals view the homeless would need to occur. This could begin with

greater emphasis in graduate programs and in continuing education offerings on healthcare for the homeless.

None of these alternatives are viable however, until social work as a profession highlights end-of-life issues among the homeless population. Social work is in a unique position to be such an advocate, with our placement in community based agencies and in health care facilities, and emphasis on case management and referral. Now is the time to address these issues, educate the community and our social work profession to improve access of the homeless to healthcare for serious and chronic illness, and ultimately the end-of-life care that they deserve (Davis-Berman, 2013).

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