
REVIEW ARTICLE

Community outreach to patients with AIDS at the end of life in the inner city: Reflections from the trenches

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ABSTRACT

Indigenous community health outreach workers (CHWs), who serve as a bridge between underserved, difficult-to-reach minority populations and health professionals, can play a critical role in bringing palliative care to patients dying of AIDS and other illnesses in the inner city. Although the contribution of CHWs in the delivery of “curative” and preventive services has been well established, little attention has been given to CHWs in palliative care.

Integrating the medical literature with experiences of a team providing HIV palliative care in the Bronx, a descriptive typology of critical stages and components in the work of CHWs in end-of-life care in the inner city is presented. A longitudinal case narrative, told from the perspective of the CHW, is used to demonstrate the richness and complexity of the CHW’s role.

The article concludes with a description of the experience of the CHW, straddling two worlds—the world of the inner city patient and the world of the health care providers—and explores the special characteristics of the individuals who can fill this vital role in palliative care.

KEYWORDS: HIV, Palliative care, Outreach, Health worker, Therapeutic alliance, Marginalized

INTRODUCTION

Beginning with models developed in the third world, community health outreach workers (CHWs) have been successfully employed in the United States and elsewhere to bring health care to underserved and stigmatized populations (Warrick et al., 1992;

Castro et al., 1995; Elwood et al., 1995; Morse et al., 1996; Rodney et al., 1998; Chen, 1999; Rahimian & Pach, 1999; Fried, 2000; Jack et al., 2001; Felix-Aaron et al., 2002). Thus far, little attention has been given to the critical role that CHWs can play in bringing palliative care to patients dying of AIDS and other illnesses in our inner cities.

The CHW, known by 30 or more names in the world literature, plays a pivotal role in health care as “an indigenous outreach worker who is trusted and respected in his/her community, and who serves as a bridge between peers and health professionals”

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(Rodney et al., 1998, p. 371), who is “part teacher, part friend, part advocate” (Warrick et al., 1992, p. 24).

The usefulness of community health outreach workers in palliative care for isolated rural indigenous populations, in Australia, as well as in Canada and the United States, has been recognized (Fried, 2000). The roles of “a key worker” (Robinson & Stacy, 1994) and of the “ethnic liaison officer” (Jack et al., 2001) have been described in the delivery of palliative care to urban, minority populations in the United Kingdom.

Individuals with AIDS in the United States live predominantly in inner cities. They are young and are members of racial and ethnic minorities. Many are substance users, and an increasing number are women (Matheny, 2001). Though they may live near major health care centers, these patients are often as isolated and alone as if they lived in the wilderness. Their frequent histories of trauma, abuse, and/or drug addiction, compounded by their stigmatizing medical illness and the added burden of cultural and language barriers may leave them alienated from their families, community, and the health care system (Robinson & Stacy, 1994; Gibson, 2001; O’Neill & Marconi, 2001).

Despite the great advances heralded by Highly Active Antiretroviral Therapy (HAART), the total number of patients infected with HIV continues to grow (Selwyn & Rivard, 2003*b*). Individuals continue to engage in high-risk behaviors and continue to acquire HIV in undiminished numbers, encouraged by a mistaken belief that the disease is now curable.

Patients treated with HAART struggle with drug toxicities and side effects and the difficulties of adhering to a lifetime of complex, multidrug regimens (Brechtel et al., 2001). They face a 50% chance of virologic failure within 1–2 years from nonadherence, and progressive viral resistance patients may not show immune recovery despite HAART, and remaining vulnerable to opportunistic infections. Even when HAART remains effective, HIV-related cancer and Hepatitis C are killing increasing numbers of patients (Easterbrook & Meadway, 2001; Selwyn & Rivard, 2003*a*, 2003*b*; Volberding, 2003).

Although many patients are restored to high levels of functioning, many others require care as they enter the prolonged, symptomatic phase of late-stage HIV disease. In effect, our therapies have “converted death to disability,” which has required new expertise in providing comprehensive pain and symptom management and other palliative care services (Foley, 1994; Goulet et al., 2000; La Rue et al., 1994; Kelleher et al., 1997; Selwyn & Arnold, 1998; Selwyn et al., 2000).

Ethnic and racial minorities are not being reached by such palliative care services (Sambamoorthi et al., 2000; Gaffin et al., 1996; Moss, 1990; Gibson, 2001; Grady et al., 2001; O’Neill & Marconi, 2001). Families with historically poor access to medical care are confused and suspicious about why their loved ones are dying from what they have been told is now a treatable illness and why palliative rather than curative care is being offered. Families, as well as medical providers, may simplistically “blame the victims” (Ryan, 1971), out of a mistaken belief that the only people who die of AIDS are substance abusers and the mentally ill who cannot comply with HAART. And living amid addiction, suspicious and fearful of the use of narcotics in pain management, they may reject palliative care even when it is offered.

HIV IN THE BRONX

The Bronx, with 1.3 million people living in some 44 square miles, is the poorest of New York City’s five boroughs, with 30% of its households living below the poverty line. It has the youngest male population (median age 28.7), the largest percentage of persons of color (77%), and is racially and ethnically diverse.

The Bronx is severely affected by the AIDS epidemic. Though the second smallest borough, it has the second highest rates of HIV-infected individuals (95/100,000), and age-adjusted HIV-associated death rate (35/1,000) in New York City. Sixty-two percent of Bronx AIDS cases are attributed to injection drug use (IDU), 23% to same sex contact, and 13% to heterosexual contact. Of 21,649 adults diagnosed with AIDS in the Bronx from the beginning of the epidemic, 58% are known to have died (NY City Department of Health, 1999, 2004; CDC, 2000).

Montefiore Medical Center is the major provider of health services, including HIV care, in the Bronx. The HIV Palliative Care Program at Montefiore is one of five Health Resources and Services Administration (HRSA)-Ryan White Care Act funded Special Projects of National Significance (SPNS) in the United States (O’Neill et al., 2000). The primary objective of the project, initiated in early 2000, is to establish a comprehensive program to integrate HIV and palliative care, focusing on the vulnerable and underserved population of the Bronx. From its inception, the HIV Palliative Care Program has included a community outreach worker (HLF) as part of its core interdisciplinary team, which also consists of a physician, nurse practitioner, social worker, chaplain, internist/psychiatrist, and bioethicist (Selwyn et al., 2003).

METHODS

Reviewing the medical literature on the role of CHWs in disease prevention/health promotion (Warwick et al., 1992; Castro et al., 1995; Rodney et al., 1998; Felix-Aaron et al., 2002), substance abuse (Elwood et al., 1995; Rahimian & Pach, 1999), mental health (Morse et al., 1996; Dixon et al., 1998; Anthony et al., 1988), and end-of-life care (Robinson & Stacy, 1994; Maull, 1998; Jack et al., 2001), and integrating these descriptions with our experiences in HIV palliative care, we identified seven critical stages in clinical care, with particular focus on the work of the CHW:

1. Meeting and engagement,
2. Cementing the relationship by addressing the most pressing need,
3. Addressing pain and addiction,
4. Deepening the relationship and providing a lifeline,
5. Advocacy and bridging to the doctors and the system,
6. Bridging to the family,
7. Family reconciliation, death, and bereavement.

The following case narrative, told from the perspective of the CHW, with reflections by a palliative care physician placing it a larger context, illustrates these components. The longitudinal care of one patient (patient's name and some case details have been changed), provides the opportunity to describe the richness and complexity of the role of the CHW in opening the door to palliation for those dying of AIDS in the inner city.

CASE NARRATIVE

Growing up in the South Bronx I witnessed many deaths. When someone died we talked about it briefly, got used to it and moved on until the next time. It just didn't surprise us.

I had worked in both HIV, as a HIV-testing counselor, and in Substance Abuse, first doing volunteer work with drug programs, then training as a counselor. I first heard about "palliative care" at a meeting of the Bronx HIV Care Network, and learned that there was a position available for an outreach worker on a team of doctors, nurses, and social workers working with people dying from AIDS. They said this was not a position for just anyone. I would have to deal with patients who were all going to die, and would have to be able to cope.

Having witnessed so much death, I was excited by the idea of making a difference in the experience of

people who were dying. I would have the chance to bring patients and their loved ones to appreciate one another after so many battles, to come to a place of acceptance and caring, and letting go. I accepted that responsibility, and it has become my mission and reward.

Maria R: The Woman Who Never Was

Maria R is a 54-year-old Hispanic Woman with AIDS, who has been unable to tolerate HAART. She suffers from advancing cervical cancer with recurrent PID that has left her with excruciating pelvic pain. She also has intermittently unbearable pain from shingles.

Maria doesn't officially exist. She is an undocumented native of the Bronx, without a birth certificate or a social security number. She never knew her real parents, who apparently abandoned her as an infant. She was taken in and raised by a caring woman in the neighborhood, who never sent her to school. When Maria was a young teenager, the woman died and Maria was left to fend for herself on the streets of the Bronx, where she became the victim of abuse, multiple rapes, and the ravages of drug addiction.

Maria lives in a room in the basement of an old hotel that has been converted into Single Room Occupancy (SRO) housing for the homeless. She has been in and out of the hospital, but due to her undocumented status, Maria has had no continuity of medical care. She was referred to the HIV Palliative Care team by a Montefiore medical team that provides outreach to homeless individuals with HIV.

1. Meeting and Engagement

I was the first team member to make contact with Maria, who was living in the basement of a once grand, but now decrepit, SRO hotel. Her airless room had no windows, it stank of the insecticide that was used in a losing battle to control the roaches, and its ceiling was crisscrossed with sweating pipes. Paradoxically, this squalid underground room was one of a few special rooms reserved by the management for those residents of the building who were sober and not actively using drugs.

A small, slight woman, Maria was wary at first, remaining standing and looking me over. She slowly warmed up after I told her that I was from the neighborhood and was here to try to help. I showed her the small brown bag I was carrying and told her that I had brought coffee for both of us, then asked if I could sit in the chair by her bed, because I was going to stay for a while. Her face lit up with a crooked smile; she gestured for me to take the chair,

sat down on her own bed, and visibly relaxed. As the conversation progressed, I encouraged her to let me know what was going on and what she needed. I took it slow, at her pace, without pressure, mindful that most patients with HIV are assuming that they will be judged and stereotyped upon revealing their personal information.

Pain was clearly her greatest problem. She rated her pain as a 10 on a 0–10 scale, and complained bitterly that the nurses and doctors had failed to take care of her pain in the hospital. Maria didn't understand why she was suffering so much, and angrily blamed the doctors for mistreating her.

Reflections

Outreach means meeting people where they live, in their apartments or SRO rooms, in shelters, soup kitchens, and on the streets. In “The Tipping Point,” Gladwell (2002) has called this “the power of context.”

The CHW not only comes to the neighborhood, he comes from the neighborhood. As an insider he is met with less suspicion. The CHW has credibility, not shared by other members of the palliative care team, and is able to “act and talk like the ‘home-boys,’ gain trust” (Elwood et al., 1995, p. 253) and “appreciate the context of . . . street culture . . . creating trusting relationship” (Rahimian et al., 1999, p. 1993).

Creativity and flexibility play an important role in establishing contact. Carefully thought out self-disclosure by the CHW substantially enhances engagement (Dixon et al., 1998). Bringing coffee or food, offering to go for a walk in the park, and identifying and engaging the patient in something that interests without any other agenda are powerful interventions. They demonstrate action, which speaks far louder than words in conveying a sincere offer to help (Shern et al., 2000).

Patience is an essential ingredient, as well. A number of visits may be necessary to establish a working relationship.

2. Cementing the Relationship by Addressing the Most Pressing Need

Maria was in severe pain, and relieving that pain was my first priority. I picked up my cell phone and told Maria that I was calling our nurse practitioner “right now,” because we needed to help with her pain. The nurse practitioner agreed to come to the hotel the next morning.

Reflections

Studies on CHWs targeting a multiplicity of health problems demonstrate that it is critical to address

patients' most pressing needs, immediately and concretely, in order to establish credibility and begin to develop a relationship. By coming to their homes to assess their patients' needs, CHWs begin to demonstrate that they, unlike other health care providers the patients may have known, are both accessible and responsive.

Frequently, help with the basics of food and shelter must be provided before other issues can even begin to be addressed (Morse et al., 1996; Rahimian & Pach, 1999). In palliative care, pain management is usually the first priority (Doyle et al., 1998).

3. Addressing Pain and Addiction

The medical team had prescribed many pain meds such as Oxycontin, Fentanyl patches, and Actiq, but Maria reported that the pain relief lasted only for short periods.

Each visit I found her in pain, and spoke to her medical team. I learned that they were not increasing Maria's pain medication because they had become convinced that her husband, Jose, who unofficially lived in the SRO with her, was an addict who was selling her medication on the street.

I began closely monitoring Maria's medication and sizing up her husband. I met several times with Jose, who freely admitted to using drugs in the past, but told me that he had been clean for many years. I was convinced that he was not using drugs now. I had a number of conversations with Maria's doctors, confirming that Jose was very dedicated to her and trying to persuade them that he was not stealing and selling her medications. Visiting her at home so often, I told them that she was in so much pain that she clearly wasn't getting enough medication for effective relief. I also told them that even if I was wrong, and Jose was selling some of her medication, we still had to treat Maria's pain.

I encouraged the team to ask Maria and Jose to be as honest as possible about the pain and the medication. But I warned them that they had to be realistic when they worked with people who had used drugs. Terrified by pain or even the chance of pain, patients might not always give an honest answer to doctors.

Reflections

Physicians have a hard time treating pain, and studies have repeatedly demonstrated undertreatment of acute pain (Marks & Sacher, 1973), cancer pain (Grond et al., 1996), and pain in AIDS (Breitbart et al., 1996). Racial and ethnic minority populations are at higher risk for undertreatment of pain (Bonham, 2001; Morrison et al., 2000). Patients with current or past substance use who are

medically ill and in pain are doubly disadvantaged and most likely to get inadequate analgesia (Portenoy et al., 1992). Physicians have negative feelings toward them, assuming that their complaints of pain are routinely exaggerated to get opiates in order to misuse them. Unable to rely on what these patients say, physicians are forced to make their own decisions about how much pain the patients are in. It is estimated that only 15% of HIV-infected individuals receive adequate therapy for their pain (Breitbart et al., 1996). Irrespective of drug-use history, pain should be routinely evaluated and treated based on what medically ill patients report (Breitbart et al., 1997).

Pain and addiction are not mutually exclusive problems. Severe pain needs to be well treated. And addiction treatment requires realistic goals. "It took you thirty years to become an addict, now its not going to take a week to get everything right." The work has to be infused with an acceptance of ongoing use, and of relapse—"they stop coming in . . . then come back in." (Rahimian et al., 1999, p. 2002).

4. Deepening the Relationship and Providing a Lifeline

I kept in close contact with Maria over the next couple of months, visiting regularly, sitting and talking in English and in Spanish. I told her that she was an amazing survivor of the streets, expressing my genuine respect and telling her how much I was learning from her.

I spoke with her doctors frequently, communicating her concerns and advocating for her care. She suffered from periods of depression and felt comfortable enough with me to let me know about suicidal thoughts. I brought our psychiatrist to the hotel to see her, and with antidepressant medication added to our counseling, her spirits improved.

I also did things that simply needed doing, sometimes calling the pharmacy to deliver medication so that she would not run out, sometimes picking up prescriptions and bringing them myself when Maria was in pain. One day she said, "If it wasn't for you, I don't know where I'd be or what might have become of me."

Reflections

Many patients struggling with advanced AIDS in the inner city are isolated, often having burned all their bridges through active addiction. At times they may feel that living is useless or consider suicide (Angelino et al., 2001; Schwartz & Selwyn, 2001). The effective intervention is to listen non-judgmentally, and to "empathically witness" their struggle (Kleinman, 1988; Erlen et al., 2001).

Patients whose first language is not English may be able to convey the facts, but not the emotional context, of their experience when they communicate in English. This can happen even if they have acquired some degree of English fluency. To capture the depth and breadth of their feelings, it is imperative to conduct conversations with them in their primary language. "Un poco de espanol" on the part of providers, and "un poco de ingles" on the part of the patient just won't do (Hardt, 1987). Several efforts in community outreach to Spanish-speaking populations have highlighted this issue by referring to their fluently bilingual CHWs as "promotoros" (Warrick et al., 1992; Castro et al., 1995).

As the literature reports, CHWs serve as a support and lifeline to clients:

"CHW's keep clients alive. . . . [They help] clients comply with their medical regimens. . . . [Clients] noted that the mortality benefit derives from the CHW's supporting [them] during periods of psychological stress, which enables the clients to avoid destructive coping behaviors, such as abusing drugs or suicide" (Felix-Aaron et al., 2002, p. 91).

Health Promotoros have been described as "part teacher, part friend, part advocate . . . not only did the women find the educational aspects of the program new and helpful, but also the caring, warmth and encouragement offered by the promotoros was a lifeline for many" (Warrick et al., 1992, pp. 24–25).

Critical components in developing the therapeutic alliance are respect and trust. Respect is demonstrated by repeated home visits that indicate acceptance of patients and their surroundings. Trust is built on a track record of availability (by pager or phone, when feasible) that matches team promises.

5. Advocacy and Bridging to Doctors and the System

Maria landed back in the hospital, infected and in further pain. She rejected a nursing home, telling us that her tiny, stifling, bug-infested room in the basement had become her home. She also rejected a home health aide because she didn't want a stranger in her house, and insisted that her husband was taking care of her.

The medical team was large and changed over the course of the month. With so many strange faces, Maria became increasingly nervous and suspicious that she wasn't being well cared for. I was a steady-ing figure for her. When I spoke with her doctors and

accompanied them on visits, she grew calmer and somewhat more trusting.

The team decided to send Maria home with a PCA pump, which had finally gotten her pain under control. But there were major obstacles. Maria was undocumented and had no insurance to pay for outpatient and home care. I pushed the social workers, and together we finally got Maria her first temporary Medicaid card. At the last minute, VNS almost canceled the arrangements when they insisted that Maria have a phone in her room, or they wouldn't provide home care. Finally we got a phone installed in her SRO room. The PCA pump was delivered and the nurses were able to begin to control her pain.

Reflections

Advocacy activities and scheduling an array of appointments often dominate the CHW's schedule. Patients need someone to help them negotiate impersonal bureaucratic systems and seemingly "foreign" cultures (social service agencies, treatment facilities, providers, and case workers). With limited English literacy, they may need help completing the forms required for assistance (Morse et al., 1996; Warrick et al., 1992).

6. Bridging to the Family

Maria's husband, Jose, her two daughters, and three young grandchildren were the key supports in her life. In addition to meeting with Maria and her family, I made a point of finding times when I could sit down with each family member separately.

Maria's husband, Jose, clearly loved her. I saw it in how dedicated he was when they were together, and how he spoke about her when we were alone. I spoke to him as one man who had coped with devastation to another.

I met with her daughter, also named Maria, who lived nearby with her husband and two children in a family shelter apartment. They were working but struggling to make ends meet. Maria came to her mother's room almost every day and cared for her. She looked to me for help in understanding why her mother was dying of AIDS in the HAART era and for support as she saw her mother growing sicker and sicker.

Maria's other daughter, Rose, had escaped from the "hood" and was starting to make a new life, with her husband and new baby, in a little house an hour north of the city. Maria beamed with each mention of her daughter and granddaughter, and spoke with joy of the several times she had been able to travel to their house.

I talked with both of Maria's daughters like a father, and like a brother, as we shared the trials of her mother's illness. And with Rose, I shared her journey up and out of the Bronx, the pride and guilt she felt, all of which I knew only too well.

Reflections

Making strong connections with the most important family members is critical. Family members are both the key to the patient's peace and palliation and patients in their own right, in need of support during the dying process and afterward, during their mourning (Williams et al., 1997).

The most effective CHW is able to relate creatively and flexibly to each family member. In an outreach program to the mentally ill in Baltimore, a set of "family outreach workers (FOW's) . . . mothers of mentally ill people," were identified and trained to go out into the inner city and work with patients and their families. The FOW's were able to be "understanding mothers" to patients often alienated from their own mothers, and were also able to be "fellow mothers," empathizing and providing a healing experience and a bridge (Dixon et al., 1998).

7. Family Reconciliation, Death, and Bereavement

Maria remained in her basement room with her husband. As her AIDS advanced, she grew thinner and weaker, spending more and more time in bed. She finally agreed to accept a home health aide, and her nurses and doctors came regularly. She was comforted by Jose and by her daughters, who were by her side frequently. I helped Maria and the family to accept Maria's disease and approaching death and to focus on helping her to be as comfortable as possible. Her pain was well controlled as I went away for a week's vacation.

When I returned the following Monday, there were two messages on my voice mail. The first was from Maria's primary care doctor, letting me know that Maria had died. The second was from Rose, asking me to call as soon as possible, saying tearfully, "We need your help." I knew how poor this family was, and realized that I hadn't discussed funeral arrangements and expenses with them. Taking a deep breath, I picked up the phone and called Rose. I could hear the pain and relief in her voice as I encouraged her to tell me the details. She and her sister and Jose had all been with her mother as she slipped away that Saturday, dying comfortably, asleep and in no pain.

Rose then told me about the family's struggle to come up with the money to pay for a funeral and burial. Sadly, she told me that they had finally decided to cremate her mother, because a full fu-

neral, coffin, and burial plot were far beyond their means. I told her that I would see her at Maria's wake later that day.

I wished that we could pay for the funeral, but knew that the program didn't have the money. Calling our administrator, I was able to get authorization to have a flower arrangement delivered to the funeral home. When I got there, I saw Maria lying in a plain wooden coffin, in a small room, surrounded only by her husband, daughters, and grandchildren. Our flowers were beautiful, the only adornment in that barren room. Maria's doctor came, and was soon deep in conversations with a hand on Jose's shoulder. No longer "the addict" the medical team had feared, he had finally come to be seen as Maria's loving husband.

Reflections

As patients grow sicker, the HIV Palliative Care team maintains closer contact and makes them as comfortable as possible. Contact with family increases, for emotional support (Koenig et al., 2001) and help with concrete issues. Families need help in practical planning for the patient's death at home, and in making affordable and realistic funeral arrangements. Advance planning for the family's future, including the disposition of any children, is critical.

Patients are encouraged to discuss issues and/or secrets that would help bring closure to their lives. Although reconciliation and resolution of relationships can and does occur for some, for others it is an unrealistic goal, and the events of their past lives complicate an already emotionally difficult situation.

Attending the wake and funeral and continuing to work with families, in their homes or by phone, in the months after the death are the final part of the work.

Experience and Perspective of the Community Health Outreach Worker

In order to do this work, you must go in with a mindset not to be surprised by what you see, feel, or even smell. You must be nonjudgmental and compassionate, gentle yet direct when needed, and above all, patient. It requires a feeling, a certain style that is second nature because of life experience, "having been there and done that," which is not taught at any school. Many individuals that are street-wise are good manipulators and sometime only another "good manipulator" can see through that. In time I learned how to be effective as a professional and something of a friend, to keep a balance.

Being fully educated about the virus, modes of transmission, OI's and medications was critical, as

was knowing about drug addiction. I learned to be able to pick up on pain, even when patients were afraid to say so, and to understand its treatment.

I believe death means going somewhere peaceful where there are no worries, and this has let me convey something comforting to loved ones.

Following the patients wherever they were was quite challenging. I've been to more hospitals in one week than I had previously seen in all of my life. At first, dealing with hospitals and health professionals created a problem. Maybe it was because I was a young Hispanic who didn't dress like most of the staff, or maybe they felt that because I wasn't a "doctor" they had no obligation to me. Whatever it was, I stayed calm and found a way to get my answers and accomplish what I went there for. After some time everyone everywhere got to know me and I was respected and treated as a professional.

Reflections

Health care teams often seek out potential CHWs through community organizations like churches. They are looking for people born and bred in the target communities, but people who stand out. Strong candidates often have more education and have one foot in their communities, but one foot out. They are fluent in two languages, two cultures, two worlds—the world of the street and the world of downtown—the world of doctors, lawyers, and businessmen (Dixon et al., 1998; Rahimian et al., 1999).

Even more importantly the CHW must stand out in energy, initiative, and interpersonal skills, have a way with people, an intuition to know when and how to "go with the flow" (Morse et al., 1996).

Gladwell (2002) states that the success of any social change "is heavily dependent on the involvement of people with a particular and rare set of social skills" (p. 33). He describes the three critical qualities/types of people who are capable of effecting change: "connectors," "mavens," and "salesman." "Connectors . . . their ability to span many different worlds is a function of something intrinsic to their personality, some combination of curiosity, self confidence, sociability, and energy" (p. 49). "Mavens have the knowledge and the social skills. What sets mavens apart, though, is not so much what they know but how they pass it along . . . mavens want to help" (p. 67). "Salesman . . . with the skills to persuade us when we are unconvinced of what we are hearing" (p. 70).

One health team found gifted CHWs by asking potential candidates (identified by community opinion leaders) to organize and run focus groups in their communities. They offered jobs to the ones who demonstrated remarkable ability to connect

with participants, to move them to change (Dixon et al., 1998).

Impact of the Work on the CHW

The gratitude of people who have never had a stranger really care, stay in the trenches with them over time, do concrete things for them, is something I carry home every day. There was a lesson to be learned from each and every one of them. For me it was a great experience, though it was not an easy thing playing many roles at different times, with clients and with professionals.

A relationship between the patient and oneself can build so well that I become emotionally involved and wish I could do more to relieve the suffering. When you see a child or mother that you have become attached to looking hopeless as their loved one is dying, it can be heartbreaking and overwhelming. Growing extremely attached is not a good thing, and one must learn how to separate emotions. Only sometimes the heart gets involved. Many times in my dreams I saw the faces of my patients; some became more than just another case. At times I found myself remembering the jokes the patient shared, the smiles they showed, the strengths they had, or the courage and uniqueness they displayed.

As a professional you must know when you are becoming overwhelmed, keep a balance, and be able to share with the team, family, and friends, and seek your own therapy.

Reflections

Warrick describes how the “health promotoros experienced increased satisfaction in helping others . . . increased self esteem . . . increased social status and prestige in their communities . . .” (Warrick et al., 1992, p. 25). But this is a complex process. Beyond the stress of becoming emotionally involved with dying patients and their families, the CHW has to “negotiate a variety of roles interpersonally and intrapersonally.” In the same day, sometimes in the same few minutes, they “talk like the ‘home-boys,’” and then turn around and have a “business-like manner with health professionals.” The CHW experiences the stress and strain, the cognitive dissonance, of living and working in two different worlds, and fitting imperfectly in both. He is not in the same place he began in the community; neither is he a full-fledged professional like others on the palliative care team, with their higher education and degrees (Elwood et al., 1995).

CONCLUSION

Delivering palliative care to this hard-to-reach population necessitates going beyond the traditional

approaches of the mainstream health care system. The patients’ lifestyles and life circumstances, language, culture and health beliefs, past histories of medical treatment, and lack of access to health care and social service systems affect not only how care is delivered, but also the range of services that must be provided.

The indigenous community health outreach worker can provide a personal bridge to this community. He is, however, not just a member of the community but a special individual with special abilities. Incorporating such individuals into our efforts to provide the full range of health care, from primary prevention to curative treatment to palliation at the end of life, is critical if we are to care for our most vulnerable and disadvantaged people.

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