

Chapter 23

Special Populations***Overview***

Certain groups — people who are young or old, homeless, or have substance abuse problems as well as refugees, prisoners, soldiers, religious leaders — experience internal and external barriers to accessing and remaining in care. Health care workers (HCWs) should recognise that recruiting and maintaining them in care requires personal contact and flexibility. Otherwise they may not access palliative care and if they do, they may not continue to do so and may die, in pain and without support.

Stigma is a major barrier to obtaining palliative care. Religious leaders, for example, may not seek care because community knowledge of their HIV status may mean the loss of a job or career prospects. Other barriers are related to a person's financial, social, or legal status and to challenges of providing care within certain institutions. People who are homeless, those who are refugees (legally or illegally) or live in internally displaced camps (IDPs), and those who have been recently released from prison may not be able to afford care or may not have legal status giving them access to health care. Providing palliative care within institutions such as the armed forces and prisons also has challenges. Two other groups of people with barriers to care, especially stigma, are people with substance abuse problems and homosexuals. The proportion of people living with HIV/AIDS in these groups is much smaller in Africa than in other parts of the world, but they still exist. HCWs should understand and accept the particular circumstances of all these individuals.

Authors

Julia Downing

At a Glance

Establishing Trusting Relationships

The Young and the Old

People Who Are Homeless

Refugees and Internally Displaced People

Prisoners

Members of the Armed Forces

Religious Leaders

People With Substance Abuse Problems

References

Adapted from Chapter 15: Special Populations, by Carla S Alexander, MD and Helen Schietinger, MA, ACRN, in: O'Neill, JF, Selwyn PA, Schietinger H, eds. *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS, 2003 Edition*.

Table of Contents

Overview	324
Establishing Trusting Relationships	325
The Young and the Old	325
People Who Are Homeless.....	326
Refugees and Internally Displaced People	328
Prisoners	329
Members of the Armed Forces	332
Religious Leaders	333
People With Substance Abuse Problems	333
References	334

Establishing Trusting Relationships

Providing palliative care to special populations has an additional level of complexity. Many people who are marginalised from society are mistrustful of the health care system or have difficulty understanding HIV/AIDS. They may perceive palliative care as second-class care, which they are being offered instead of curative medical care. Palliative care should be the result of an individual's empowered choice. The importance of gaining the trust of individuals in special populations becomes even more apparent when this dimension is added.

The following are important steps in establishing trusting relationships:

- Establish professional relationships with people in order to maintain communication.
- Work with them in their situations to identify some support.
- Obtain contact information/details where possible for carers or identify physical addresses, if they exist, so that they can be followed up when necessary.
- Arrange times to meet individuals next and where possible keep those appointments.
- Be open and honest with people at all times.

The Young and the Old

There are many different issues that may prevent the young and the old from accessing care.

Adolescents

Adolescents may have lived with HIV for many years, either having family members with HIV or being infected themselves from birth. Many are orphans and are having to bring up other siblings. Other adolescents will have become infected with HIV through early sexual contact, through abuse by an adult, marriage at an early age, or selling sex to survive and provide for their siblings. The responsibilities of many adolescents go far beyond what is appropriate for their age. This, coupled with their own ill health, brings many challenges both to them and the people seeking to care for them. Palliative care for children and adolescents is described in Part V of this book.

The developmental issues of adolescents are unique:

- They may feel omnipotent and immortal.
- They have not completely internalised cause and effect.
- They may mistrust adults in authority.

Adolescents commonly reject a diagnosis of HIV, believing that avoiding the issue is avoiding the illness. More and more children who were born with HIV are living into adolescence through good palliative care and the availability of antiretroviral therapy (ART). For them, taking drugs and accessing health care are part of life, and yet there may come a time when they rebel against taking medicines.

Some of the palliative care-related problems experienced by adolescents include:

Food and shelter: If they are orphans and struggling to bring up siblings they may have been chased out of their homes by relatives. They may be surviving on very little money and therefore have an inadequate diet.

Medication: They may not be able to afford medication, store it, or keep it safe.

Confidentiality: If they have relatives they may not want them to know that they are sick. They may want to keep their sero-status private at school so that they are not bullied and stigmatised.

Stigma: Multiple stigmas may include having HIV/AIDS, being a young bride, and being a child-headed household.

Follow-up: Adolescents who are moved around from relative to relative or chased out of their homes may be difficult for HCWs to follow up. Also relatives may be reluctant to allow HCWs into their homes.

Older People

Older people may not seek care because they fear the stigma of HIV/AIDS as well as because they may be dealing with other health problems. A large number of older people are caring for their children's children, as their own children have died through war, HIV, or famine. Thus a grandmother may be caring for many orphaned grandchildren without support from her own children. For her, finding time and money to obtain her own palliative care is a challenge on top of meeting her grandchildren's essential survival needs. The elderly who have seen their children dying from HIV/AIDS may also fear the disease and believe that 'nothing more can be done for them'. This along with a belief in 'traditional medicine' means that they may put off accessing palliative care.

People Who Are Homeless

Providing palliative care to people with HIV/AIDS who are homeless is difficult because of the multiple physical, economic, and social problems they already face and because of their transience. However they have the same emotional and spiritual needs as others and can benefit greatly from this type of supportive care. The increased health risks of being homeless include:

- Poor nutrition
- Poor dentition
- TB
- Infestations (e.g., lice, scabies)
- Skin infections and skin breakdown

For people with advanced HIV disease, symptoms such as fatigue are more challenging since they may have few opportunities to rest and lie down during the day, even if they find a place to stay at night.

Street Children

There are two main groups of children on the street:

- Street children are those children who live on the street 24 hours a day and have no home to go to at all. They are most often abandoned, abused and/or their parents or extended families have already died from AIDS.
- Other children are visible on the streets at certain times but return to the home of a parent, relative or carer for some part of the day or night. Here they receive at least some oversight or care.

Palliative Care–Related Problems

Children on the streets are some of the most vulnerable and neglected members of society (Personal communication, Maggie Crewes). They experience some of the greatest barriers in accessing appropriate care. Some of their palliative care–related problems include:

Homelessness: Lack of shelter results in exposure to the elements and lack of security.

Abject poverty: Lack of resources results in poor nutrition, poor hygiene, and inadequate clothing.

Exposure and vulnerability: Children on the streets are exposed to general sickness as well as risks of injury.

Lack of belonging: Because they have no carer or caring community, the ‘community/home based care’ approach is a misnomer for these children.

Emotional vulnerability: Lack of adults to provide love and support results in emotional vulnerability.

Lack of spiritual support: Children on the streets have no spiritual community or pastoral care and support.

Lack of medication adherence: Not having adults or structure limits their ability to take medications regularly.

Lack of medication security: Not having shelter or resources results in a high risk of medications being stolen, lost, or sold for food.

Difficulty accessing medical care: Children may be turned away from hospitals or clinics due to lack of money, poor hygiene, lack of shoes, or a lack of knowledge of how to navigate the health care system. They are stigmatised as ‘street kids’ long before they have to deal with the stigma of HIV/AIDS.

Difficulty navigating services: Children do not know how to access services and how to care for themselves.

Substance abuse problems: Associated drug-taking problems, especially fuel sniffing, exacerbates all of the other challenges they face.

Fear of disclosure of HIV status: If they have been lucky enough to get into foster care, they may fear possible rejection from their foster carers once their HIV/AIDS status is known.

Interventions

Providing appropriate and adequate palliative care to street children with HIV/AIDS is difficult whilst they are still living on the street. Therefore care may have to include interventions such as:

Placement and family support: Reunification/resettlement with the extended family, along with assistance to the family, whilst at the same time addressing the issues that caused the child to leave in the first place.

Foster care outside the family: Emergency foster care with a family willing to take on a child who is both a street child and a child with HIV/AIDS.

Referral to a community agency: Collaboration with a non-governmental organisation (NGO) that already works with street children (e.g., Tigers Club in Kampala) to enable them to provide appropriate accommodation and care specifically for the child with HIV/AIDS.

Referral to a specialist palliative care organisation: Placement with an agency that cares for children with HIV/AIDS.

Referral to an inpatient unit: Placement in an inpatient palliative care unit/hospice for abandoned children for whom the other options are not possible.

Homeless Families and Adults

A definition of homelessness is not having a stable residence in one’s name, which can mean:

- Living on the street 24 hours a day and sleeping on the street
- Staying with a relative or friend at night but wandering the streets during the day
- Getting accommodation through an NGO or government agency that serves people who are homeless

People become homeless for a variety of reasons, but often because of poverty or because they have been chased from their homes for reasons including having HIV/AIDS. Many people on the streets also suffer from mental illness, especially in the African setting where this may not be understood and individuals may be seen to have been ‘cursed’.

The challenges of providing palliative care to adults who are homeless are similar to those of caring for children living on the streets. They will often wait until their health problems are quite severe before seeking medical care. Palliative care, which is by definition continuous and involves an ongoing relationship between the provider and patient, may also not be a familiar concept to them.

To provide palliative care to adults who are homeless, HCWs may have to address a number of practical issues:

- Adapting the clinic structure and method of providing care
- Prescribing small amounts of medicine or permitting individuals to come daily for medication where appropriate

- Linking palliative care with food and housing programmes
- Educating patients about the expected course of the disease
- Helping patients to be reunited with their families if appropriate and supporting the families to care for them
- Supporting the NGOs and government organisations working with the homeless to facilitate provision of palliative care to people with HIV/AIDS
- Where there is no other support, working with homeless people to try and support the person with HIV/AIDS

Refugees and Internally Displaced People

A refugee is a person who 'owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership or a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country' (United Nations, 1951). Normally, governments guarantee the basic human rights and physical security of their citizens. However, when civilians become refugees this safety net disappears.

An internally displaced person (IDP) is 'someone who has been forced to flee his or her home, but who has not reached a neighbouring country and therefore, unlike a refugee, is not protected by international law and is not eligible to receive many types of aid' (UNHCR, 2004). Over the past few decades the number of IDPs has increased significantly. In Africa there are over 4.5 million refugees/ IDPs who are of concern to the UNHCR (2004) and for whom palliative care should be available.

Ideally, even in refugee settings people with HIV-related illness can be cared for in their own home or shelter, with support from their family, friends, and community. Links are needed between the homes, clinics, and hospitals within the refugee camps and beyond to specialist services within the country. For the provision of palliative care, refugee camps should develop links at the different levels of care available. The provision of palliative care within refugee and IDP communities has many challenges, including:

Pain control: Appropriate analgesics such as oral morphine may be inaccessible. Drug authorities in the receiving country may not be functioning well or may not have authority for the refugee-affected areas. Humanitarian aid agencies are unable to provide narcotics in their emergency medical supplies (Holmes, 2003). The World Health Organisation (WHO) and the International Narcotics Board are addressing this situation so that adequate palliative care can be provided to the refugee population. Guidelines have been prepared to assist national authorities with simplified regulatory procedures (WHO, 1998).

Tuberculosis (TB): In many countries where conflict leads to displacement, TB is the most common opportunistic infection in people living with HIV/AIDS and the most common cause of death (Holmes, 2003). A TB control programme can only be implemented if the security situation is stable and refugees are expected to remain for at least six months, as TB requires a long course of treatment.

Communication: Problems with communication and transport are often obstacles to effective care and referral.

Unpredictable nature of the care setting:

The status of people in refugee settings is unpredictable. Refugees may travel home or be transferred to another camp at short notice.

Large number of children/orphans: The conflict that led to displacement may lead to large numbers of orphans or unaccompanied children requiring care. The community may therefore become overwhelmed, needing financial and practical support for affected households to enable them to care for the children (Holmes, 2003).

Breakdown in community structures and networks: In the refugee system a home-based care system may rely on care from family members with support from HCWs at the nearest health facility. However, workloads in clinics in refugee settings are often high and the work is stressful.

Coordination of care: It is easier to support community efforts to respond to palliative care needs in a stable community than in refugee settings, where trust and communication has often broken down.

The WHO/ UNAIDS (2000) describe care and support activities for people living with HIV/AIDS at three levels of complexity and cost. Palliative care is seen as an essential activity, so in the post-emergency setting in refugee camps it should be possible to provide at least the essential activities including palliative care. How this is achieved will depend on the prevalence of HIV in the refugee or displaced populations. When HIV is common and many people are sick and dying the capacity of the community to cope is reduced and good coordination of care is essential (Holmes, 2003).

Prisoners

Throughout Africa millions of people are behind bars in prison. In Uganda, there were 20,000 inmates in 2004, and although no recent studies have been done, in 1998 the HIV prevalence in prisons was 20%, higher than in the general population (Kaddu, 2004b). The mandate of the prison service is to protect society by providing safe, secure, and humane custody of offenders while rehabilitating, reforming, and re-integrating them back into society as law-abiding citizens. Justice is a core value of prison service and the right to health care is considered a fundamental right for inmates. In 1993, the WHO established guidelines for prison authorities to make strategies and policies aimed at providing care to those infected with HIV/AIDS.

Although palliative care is an important aspect of HIV/AIDS care, providing palliative care within prisons poses unique challenges. In prisons concern for security determines how medical care is provided. Palliative care, with the goals of preventing further deterioration and maximising the patient's comfort and functioning rather than curing the disease, is less readily adapted than primary medical care to the rigid hierarchical structure and culture of a prison environment. It is difficult to provide such care in a manner that meets both the individual's need for symptom relief and the institution's need for security and control.

In Uganda, a special committee was established to address these problems (see Box 23.1: Case Study — Uganda). In Bloemfontein, South Africa, at the Maximum Security Prison a professional nurse has trained inmates in home care for people with AIDS, under the supervision of the local hospices. The inmates then help to care for each other.

Box 23.1:

Case Study: Uganda

The Prisons AIDS Control Programme (PACP) was established in Uganda in 1993. The PACP appointed a palliative care committee comprised of custodial staff, counsellors, social and health workers, and inmates. The committee's objective is to ensure that palliative care is available to all prisoners and staff living with HIV/AIDS.

The Activities of the Committee Include:

- Counselling
- Home- and cell-based care
- Limited provision of food supplements
- Treatment of opportunistic infections and symptom control (including pain control)
- Training of palliative care providers (both staff and inmates)
- Referral of inmates to specialist centres as appropriate

The Achievements of the Committee to Date Include:

- Administrative commitment and full support of policy makers have been obtained.
- Over 50 heads of prisons and their staff have been trained.
- Over 2,000 inmates have been trained to care for fellow inmates.
- Community sensitisation in the prisons has reduced stigma associated with HIV/AIDS.
- Voluntary Counselling and Testing is ongoing.
- Inmates have access to information.
- Treatment for opportunistic infections is reasonably available.
- Training has been provided for other countries' prison services (e.g., South Africa).

The Way Forward Includes:

- Establishment of a discharge planning programme for inmates on release
- Collaboration with other organisations to incorporate them into a wider programme of promoting and strengthening palliative care amongst the prison community
- Strengthening of the provision of ART
- More training of palliative care providers and more involvement of inmates relatives and friends. (Kaddu, 2004a)

By definition, palliative care requires compassion and therefore requires deviation from the correctional norm whose goals are segregation, stigmatisation, and punishment. Dying inmates need increased medical attention, expanded visiting hours with family and clergy, access to special foods, and relaxation of routine restrictions (Dubler, 1998). The structure and rules within prisons vary across the continent. However the challenges to providing palliative care may be seen across the board, including:

Lack of confidentiality: Protecting an inmate's medical confidentiality is difficult, especially if the inmate requires frequent visits to the prison clinic or hospital.

Inadequate medical advocacy and negotiation: Whilst the HCWs might be responsible for an inmate's care, the plan of care must be decided within the prison structure and in negotiation with prison staff.

Inadequate pain management: Providing access to appropriate analgesic medications, in particular oral morphine, can be a problem in the prison environment.

Lack of accommodation for illness: The prison environment may not provide inmates who have advanced disease with opportunities to lie down or rest during the day. Prison infirmaries, if they exist, may be more appropriate places for inmates who are weak or in pain.

Tuberculosis: The risk of TB transmission within crowded institutions such as prisons is great.

Inadequate compassionate release: Whilst this option may exist in some prisons, often the process is so long that an inmate will die in prison before being released.

Lack of support from relatives: Inmates are often disowned by their families once they enter prison, and when support is provided it usually decreases over time.

Judgemental attitudes and stigma of society: Once released or taken to a non-prison health facility, inmates must cope with the stigma of being a prisoner before dealing with the stigma of having HIV.

Poor discharge planning: This varies with different institutions. In some prisons discharge planning is almost non-existent and inmates may have less access to health care after being released.

When a person who has recently been released from prison needs palliative care HCWs should be aware of the following issues:

- The person may have been released on compassionate grounds because of advanced disease.
- If receiving ART or other medication in prison, he or she may no longer have access to the drugs.
- He or she may have no one in the community for support and thus may have no resources or places to stay.

Members of the Armed Forces

Members of the armed forces have their own unique challenges for the provision of palliative care (Personal communication, Cassette Wamadu). The armed forces include the army, navy, air force, presidential guard, police, and other similar organisations unique to each country. Often members are moved about from barracks to barracks, sometimes with their families but often without. They are also moved around the country and to other countries without prior notice. At times this may be confidential and not even their families know where they are. This poses challenges in providing care for persons with HIV/AIDS and also for their families. Moreover, if they are no longer fit enough to work, they may be retired from the armed forces and lose their livelihood as well as their accommodation.

Members of the armed forces are often reluctant to go for counselling and testing or seek treatment for fear of the impact on their careers and the stigma of having HIV. They may delay accessing palliative care and suffer needlessly. Some challenges of providing palliative care within the armed forces include:

Separation from friends and families: A person may receive care without the support of family. Likewise a family member may be receiving palliative care and die whilst the person is away on active service.

Lack of a palliative care framework: The armed forces often have no clear framework or policy regarding the provision of palliative care. Although there might be an awareness of the need, there may be no palliative care strategy in place. Thus staff have no clear guidance for providing such care.

Lack of resources: The armed services often have limited resources and therefore limited support for the provision of palliative care.

Large numbers of people with HIV/AIDS: The infrastructure of many armed forces is inadequate to cope with the care needed by personnel with HIV/AIDS and their families.

Few health care workers: There may be few HCWs within the armed forces, many of whom are not trained in palliative care.

Lack of accommodation: Regulations may restrict the care that is possible. For example, some barracks have strict rules about visitors, preventing members of the extended family and friends from visiting and contributing to a person's care.

Poor discharge planning: When individuals are being retired from the services due to advanced HIV disease there is often a lack of discharge planning and support.

The armed forces should collaborate with NGOs and other governmental organisations in the provision of palliative care to persons with HIV/AIDS. Personnel need support and training to enable palliative care to be provided to the armed services within the structure of the armed forces and to develop policies to support the provision of such care. For example, in South Africa two large military hospitals have hospices and there are doctors trained in palliative medicine working for the military.

Religious Leaders

HIV/AIDS does not discriminate but affects all sectors of society. One group for whom stigma is a big issue is leaders of faith-based organisations. Spiritual and religious leaders such as pastors, priests, and imams are respected and looked up to in their communities. Due to the nature of the illness and the fact that many people consider HIV/AIDS to be a punishment from God for sexual indiscretions, spiritual leaders may be judged even more harshly than others for having HIV/AIDS. For these reasons religious leaders may avoid care or may seek care outside the community to avoid having their HIV status discovered. Providing palliative care to them poses a challenge.

People With Substance Abuse Problems

Drug injecting is not a significant means of HIV transmission in Africa. However, substance use, including alcohol, is associated with risky sexual behaviour that leads to HIV transmission. Also, people with substance abuse problems who acquired HIV by other means are at increased risk for health problems and for not receiving adequate health care.

The main substance abused in Africa is alcohol. Abuse of illicit drugs is an increasing problem in South Africa and some other countries, however, and the practice of 'glue sniffing' is common amongst children who live on the street. Although injecting drugs is uncommon in Africa, it is becoming more common in parts of southern Africa.

Substance abuse, including alcoholism, can create barriers to providing people with palliative care. Whilst the approach to palliative care for the substance user is fundamentally the same as for any other patient, the needs relating to their abuse are key to the care that is given. Some of the challenges for palliative care in substance users include:

Inadequate pain control: Pain is often poorly managed in the individual with a history of substance abuse (Passik, 1998). HCWs often assess pain in substance abusers as manipulation to obtain drugs. To manage pain appropriately HCWs need a systematic and thoughtful approach. They must understand that a history of substance use does not preclude someone from having real pain (see section on substance abuse in Chapter 4: Pain Management).

Other medical problems: Substance users are often at higher risk for diseases besides HIV, such as TB; hepatitis B, C, and delta; chronic liver disease from alcoholism; and sexually transmitted diseases.

Withdrawal symptoms: Active users are at risk for withdrawal (from opiates, alcohol, barbiturates, and benzodiazepines), which can be a life-threatening emergency.

Injection-related complications: Injecting drugs can result in complications such as skin and bone infections, blood infections, and hepatitis B.

Lack of trust of providers: Palliative care providers may find themselves faced with a mistrustful or even hostile patient requiring considerable effort, time and compassion.

Poor adherence: The behaviors related to substance abuse, including heavy drinking, can prevent adherence to medication regimens.

Illegal activity: Some substance abuse is illegal and therefore individuals may be reluctant to disclose their use for fear of criminal prosecution.

Unstable social situations: Substance abusers often live in chaotic social or family situations that make home care nearly impossible. Medications with a street value may be sold or stolen, violence is common, reliable carers can be difficult to identify, and providing safety for members of the care team may be difficult.

Psychiatric morbidity: There are high rates of psychiatric co-morbidity among substance users, and these problems need to be addressed where possible.

Attitudes of health care workers: Substance users are often seen as the source of frustration, mistrust, and negative interactions. However, when HCWs understand the basic principles of addictive disease, they can overcome their negative attitudes. Providing palliative care can offer opportunities for understanding, empathy, and healing.

References

Dubler NN. 1998. The collision of confinement and care: End-of-life care in prisons and jails. *Journal of Law and Medical Ethics*. 26:149–156.

Holmes W. 2003. *Protecting the Future: HIV Prevention, Care, and Support Among Displaced and War-Affected Populations*. International Rescue Committee HIV Field Control Manual. Bloomfield, CT, U.S: Kumarian Press, Inc. Available at: <http://www.theirc.org/>. Accessed 8/05.

Kaddu M, Nabatanzi F. 2004a. *Presentation on palliative care in the Uganda Prisons Service*. Kampala: Uganda Prisons Service.

Kaddu M, Nabatanzi F. 2004b. Palliative Care in the Uganda Prisons Service. *PCAU Journal of Palliative Care*. 17:25–27.

Passik SD, Portenoy RK. 1998. Substance abuse issues in palliative care. In Berger AM, Portenoy RK, Weissman DE, eds. *Principles and Practice of Supportive Oncology*, 1st ed. Philadelphia: Lippincott-Raven Publishers.

United Nations. 1951. *The 1951 Convention Relating to the Status of Refugees*. Geneva: United Nations.

United Nations High Commission on Refugees (UNHCR). 2004. *Refugees by Numbers* (2004 edition). Geneva: UNHCR.

World Health Organisation (WHO). 1998. *The New Emergency Health Kit*. Geneva: WHO.

World Health Organisation/UNAIDS. 2000. Key elements in HIV/AIDS care and support – September. Available at: <http://www.emro.who.int/ASD/rapid/WHOUNAIDSCARE.doc>. Accessed 8/05.