# Dying and Grieving
# in the Inner City

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The experiences of death, dyng, and grieving are universal. Yet few who read these words have lived through loss in the circumstances of urban poverty

This chapter is written not by sociologists but by health professionals with long experience in the inner city For the most part, that experience has been in one inner-city community. Readers can decide the extent to which these observations can be generalized to other poor and under-served populations.

## Children

This is not Mr. Rogers' Neighborhood. While there are unquestionably kind and concerned adults in the environment, it is filled with danger. Doors are triple-locked. Knowing too much about what goes on next door can get you killed, like it did your cousin Kenneth. Rasheeda's mother always made her come in off the stoop as soon as the streetlights came on, but a stray bullet found her in the parlor anyway. Most third graders know someone who has been a victim of street violence. For many the violence has claimed someone in their families, if not as a victim, then as a perpetrator now in jail.

AIDS has decimated families. Many children live with grandparents or in foster homes because both parents are dead, and many of those children acquired the virus at birth. Some of these are or have been very sick. Some die, others expect to die soon.

AIDS came to the inner city in all the well-known ways, but overwhelmingly by way of intravenous drug abuse. Drugs and drug dealing are everywhere. The dealers have cars and sharp clothes. They provide employment opportunities, even to kids too small to push a lawnmower or babysit. The money is far better than anybody ever earned babysitting. The glamour and the pride of good pay for easy work seduces many children into underestimating the dangers.

More than a few children have multiple primary caretakers while growing up. Death, jail, drug-related disability and mental illness, sometimes in combination, interrupt the continuity of parenting. Large numbers of children are in foster care; many more are placed indefinitely with aunts and grandmothers "until the mom can get straightened out."

## Young Adults

Older teens and young adults in great numbers come unprepared to adult roles. They have few marketable skills and poor educational backgrounds. If they expected to get a job at age 18,

they find that there are none, or at least far fewer than there are people just like them who are looking. Unless they have grown up in one of the too few households with consistent role models and expectations for achievement through hard work, these young people are ill-prepared for either continued schooling or successful competition in today's job market. The manufacturing base that once absorbed large numbers of the young, marginally educated urban poor has long since moved elsewhere, typically to underdeveloped countries.

That so many young adults seem directionless, discouraged, and disaffected is no surprise, given their circumstances and the circumstances of their childhood. Loss has been a constant companion and hope a stranger. Like young people everywhere, they do not think about the distant future or imagine themselves growing old. Unlike their privileged counterparts, they do not expect the near future to be better and many expect to die young.

## Grandmothers

Without grandmothers, the children of the inner city would be in unimaginably worse shape. Because AIDS, violence, and imprisonment have removed so many parents and because emptied-out mental hospitals have freed so many under-treated, but fertile, young adults to "begin their own families," middle-aged women (and, where those women are married, middle-aged men) are raising their second set of children. They are doing so out of duty and love, not preference. In many instances, their intervention is saving the children from chaos and likely disaster. In some cases, it is too late.

Such grandmothers are well acquainted with grief. They have lost their children to gunfire or prison or drugs or mental illness or "the virus." Now they try to protect and nurture children who have themselves known too much loss and may even be fatally wounded in body or spirit by their perilous early lives.

There are many many such grandmothers in the inner city. Just what will be the long-term consequences of this truncated generational cycle is hard to imagine. In the short run, one cannot help but be relieved that these often quite remarkable middle-aged women are able and willing to catch the children that fall from the tatters of their own children's lives.

## Obstacles to Dying and Grieving

It is perhaps easy to see some of the barriers to successful coping that are associated with life in poor neighborhoods of American cities. For many people, there is a deep sense of fear Crime, especially drug-related crime, truly is reason to be fearful. One must be on guard. Many children really do feel that they are safer if they carry knives or guns. The incidence of crime is probably under-reported because of fear

Fear breeds distrust. So does the reality of authority figures who fail to protect—or care. The service system, from schools to clinics to pohce to child protective agencies, is sometimes corrupt, often fragmented, and always overburdened. Gains in one segment seem to be matched by losses in another. The safety net, never very reliable, has recently developed new holes.

The attitudes of self-reliance, self-worth, and social competence that middle-class parents, teachers, and health professionals attempt to instill in all children are a hard sell among urban poor children in the 1990s. There seems to be a pervasive sense that control lies elsewhere than in oneself, that neither effort nor goodness is rewarded, and that external forces, not individual choices, will prevail. Even those souls whose faith allows them to believe that goodness and

peace and spiritual riches will abound are inclined to think that this will come about by God's agency not by humankind's, and surely not by theirs. Resignation reigns.

Institutions serving the urban poor also tend to be poor. From schools to grocery stores to motor vehicle agencies, the inner-city service sector outlets are understaffed and shabby. Even those whose staff members do not share in the resignation and defeat of their clientele often lack the combination of extra money and community support that seems to make the crucial difference between a school and a good school, between a clinic that is merely open for business and a clinic that is a healing environment.

Consider the experience of Hessie, a 59-year-old, single, licensed practical nurse who had lived all her life in a poor neighborhood of a poor city. Hessie had a 24-year-old son with "mental problems" who shared her household. She developed lung cancer, which spread to the brain and bones.

Hessie was clear that she wanted to be cared for at home, with no aggressive treatment of her already advanced disease, but with vigorous attention to pain and other symptoms. Hospice home care was arranged with Hessie's son, Ben, as the principal caregiver, though Hessie had expressed concern about whether Ben could manage.

One night soon after the home care plan was implemented, Hessie became quite confused, presumably as a result of her brain tumor. She would not allow Ben to care for her and accused him of trying to kill her. In a panic, Ben called 911 and Hessie was taken to a local hospital. When her confusion cleared, Hessie refused to return home, insisting that Ben "can't handle it."

Financial barriers proved daunting as the hospital staff tried to arrange an inpatient hospice placement. Hessie had a private managed care policy through her employer, but it would not cover indefinite inpatient hospice care. A covered "transitional" program was limited to fourteen days. Hessie was too young for Medicare, too "wealthy" for Medicaid, and too poor to pay. The nearest hospice that would provide free inpatient care had a waiting list and was in another state, too far for frequent visits by friends and family.

Accordingly, a network of neighbors and church friends was patched together to support Ben in caring for Hessie at home. Without much confidence in this plan, but with no better alternatives in sight, Hessie returned home.

Only two days later, the stress proved too much for Ben. Hessie had become markedly confused again and Ben, thinking that the confusion was a drug side-effect, stopped her medication. He distrusted the neighbors and church friends, barring them from the house. After three days without gaining entry, Hessie's frustrated friends phoned the hospice nurse who finally convinced Ben to let her in.

The hospice nurse found Hessie in terrible pain and being force-fed by Ben, who was convinced that he could prevent his mother's death if she would only eat well enough. Both Hessie and Ben were relieved when the hospice nurse arranged for immediate rehospitalization.

Hessie arrived at the emergency room in terrible pain. It took hours to get her onto the oncology floor and to get her pain under control. Hessie stayed in the hospital until she died nine days later. The hospice nurse cooperated with Hessie's oncologist in her care. The hospital was reimbursed at the hospice per diem rate.

This account of Hessie's dying leads to several observations. Hospice home care faces major challenges in caring for the urban poor. Problems that are occasional in the suburbs are frequent

in inner-city neighborhoods. Hospitals are not equipped to provide excellent palliative care. Yet a higher proportion of urban residents die in hospitals than do people from suburban and rural areas. "Systems of care" remain an elusive goal; fragmentation and discontinuity seem more common, despite the caring and committed efforts of individual professionals. Meanwhile, many of the chronically under-served do not seem to have the information, skills or, most importantly, expectations that are needed to make the system work for them.

## Strengths

There are some features of inner-city life that have potential to provide support in the experience of coping with death and the restorative work of bereavement. Some of these features can be seen in the foregoing account of Hessie's dying. Though they were largely frustrated in carrying through their plan, and though the plan was more or less cobbled together, the "church ladies" were willing and available to help. In many affluent communities, one would be hard pressed to find a cadre of women prepared to go into a home to provide bedside and household care.

Other strengths can be seen in the case of Helen, who was also in the terminal stage of cancer. A 75-year-old single grandmother, she lived in two large rooms with fifteen other people, five or six of them small children.

Though Helen was eager to go home, social workers and nurses in the hospital busied themselves with developing options for alternative care settings. "We are still trying to find a good place for you, they assured her.

"But I have a place," she insisted. 'just let me go home."

"Now, Helen, you don't want to have all those people around when you don't feel well. And the children right on top of you?!"

"Your middle class is showing," Helen said with a smile. "Those are my people. They won't bother me."

Helen went home promptly. She died peacefully a short time later, in the midst of the warmth and bustle of the household.

Such strong family support exists side by side in the inner city with homes where dying cancer patients would be at risk of a caretaker appropriating prescription medication for sale or their own use. While it is commonly emphasized that one should always carefully assess the actual needs and preferences of the dying, Helen's story reminds us of two corollaries especially relevant to inner-city America: Generalizations are useful in their place, but individuals and individual families cover a wide spectrum; and, if professionals make assumptions, rather than careful inquiries, their "middle class" is almost certain to show itself.

Helen's story also suggests another feature of inner-city life that may represent an advantage for some. As mentioned earlier, the environment affords many people more experience of loss and thereby more opportunity to learn how to respond to it and grow through it. There seems to be less denial of the possibility of loss, and less separation from death. The readiness with which Helen chose to die at home, a three-generational, densely packed household, and the apparent easy acceptance of that plan by others in her family may both reflect and reinforce an acceptance of dying that may not be nearly as common in affluent communities.

## Implications for Caregivers

Good care always begins with good listening. Helen pointedly reminded one very seasoned and sophisticated professional that the middle-class orientation, background, and attitudes of most care-givers necessitate awareness that urban poor clients may have both obstacles and strengths that are hard to perceive.

The remedy is to ask what is needed, rather than to assume, and then immediately set about identifying and overcoming obstacles so that those needs get met.

It has been useful for some working in inner-city environments to remember Maslow's theory of need satisfaction. In very simple form, Maslow taught that until human beings' most basic needs are more or less satisfied, they will not attend to or pursue fulfillment of higher-level needs. His hierarchy of needs looks like this:

I. Physiological needs (e.g., food, oxygen, sleep)
II.  Safety needs
III.  Needs to belong and to be loved
IV  Esteem needs
V  Self-actualization needs

The urban poor, for whom some of the lower-level needs are matters of uncertainty may not be able to address some of the developmental tasks that we sometimes associate with the last days of life:  life review, putting one's affairs in order, saying one's good-byes. In Hessie's case, almost all the energy expended both by her and by her professional caregivers was quite appropriately focused on providing a safe environment. For Hessie to have sat down with her son or with a hospice volunteer to reminisce over a family scrapbook would have had to come well after more basic needs were satisfied. It is sad that, for Hessie, there was too little time for scrapbooks after fulfillment of these needs. That does not mean that scrapbooks should or could have come first. Maslow's concept seems to apply very well to the care of dying persons generally, especially among those for whom food, shelter, and safety are uncertain.

All people who experience significant loss should have support and practical assistance. Exactly what kinds of support and help are most needed must await *care-full* listening and assessment. It may be helpful, however, to recall that many of the urban poor need assistance with such ordinary tasks as transportation or reading consent forms, as well as guidance through difficult decision-making processes and emotion-laden events.

For those whom the fates have blessed with security education, status, self-esteem, and the attitudes and expectations that come with privilege, it can be humbling to know people who endure and even triumph despite disadvantage. While it is commonplace for those who work with dying people to speak of how uplifting and inspiring the work can be, there may be special spiritual reward for those who work with dying poor people: incredible dignity in the face of indignity, faith in spite of social wrong and political betrayal, and generosity in the midst of want. It is a blessing to be in the presence of such amazing grace.

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