

TRIALS, TRIBULATIONS, AND CELEBRATIONS

*African-American Perspectives
on Health, Illness, Aging and Loss*



Edited by Marian Gray Secundy
With the literary collaboration of Lois LaCivita Nixon

Trials, Tribulations, and Celebrations

**African-American Perspectives on
Health, Illness, Aging, and Loss**

MARIAN GRAY SECUNDY

EDITOR

with the Literary Collaboration of

LOIS LaCIVITA NIXON

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TRIALS, TRIBULATIONS,
AND CELEBRATIONS



I dedicate this book to my mother,
Hazel Yates Gray,
who always provides encouragement
for continuing productivity.
I promise that I will
keep on "keepin' on."
MGS

This anthology records the stories
and celebrates the spirit and strength
of our culturally diverse society.
It is dedicated
to the human need for story
and to each of us as storytellers.
LLN

Aunt Sue's Stories

 LANGSTON HUGHES

Aunt Sue has a head full of stories.
Aunt Sue has a whole heart full of stories.
Summer nights on the front porch
Aunt Sue cuddles a brown-faced child to her bosom
And tells him stories.

Black slaves
Working in the hot sun,
And black slaves
Walking in the dewy night,
And black slaves
Singing sorrow songs on the banks of a mighty river
Mingle themselves softly
In the flow of old Aunt Sue's voice,
Mingle themselves softly
In the dark shadows that cross and recross
Aunt Sue's stories.

And the dark-faced child, listening,
Knows that Aunt Sue's stories are real stories.
He knows that Aunt Sue never got her stories
Out of any book at all,
But that they came
Right out of her own life.

The dark-faced child is quiet
Of a summer night
Listening to Aunt Sue's stories.

Acknowledgments



This anthology has been 'birthin' for a real long time, and Lord knows we are delighted to see it born. In 1982, I was fortunate enough to be selected to attend a seminar in Literature and Medicine at Hershey Medical College in Pennsylvania where, thanks to the National Endowment for the Humanities, I met Joanne Trautmann Banks and was exposed to her brilliance, charm, and most importantly, inspiration. Leaving there, I resolved to set about putting together an anthology which would present the poetry, novels, short stories, and essays of African-American writers on the subject of grief and loss. The research which was undertaken has resulted in the book which you are now holding. And of course it could not have been finalized without the support, literally and figuratively, of numerous people.

Thank you from the bottom of my heart to Lois LaCivita Nixon, who joined this effort late in its inception and who, with competence, energy, and patience, has assisted me in bringing this project to full fruition; to Kay Watson who voluntarily labored over messy manuscripts, encouraged me to keep going, and tried her

best to keep me organized and calm; Joanne Trautmann Banks and Edmund Pellegrino, who served as mentors, returned phone calls promptly, and lent their ultimate support to us; Ethelbert Miller for always having the information I needed and cheerfully producing detailed resources upon a moment's notice; and Vanessa Stroman and Ruth Matthews McPherson, who allowed me to add one more set of duties to their already full and overflowing plates.

Marian Gray Secundy, ACSW, Ph.D.
Professor, Howard University
College of Medicine
Washington, D.C.

This project initiated by Marian Secundy allows for new visits with writers whose works remain, too often, out of mainstream reading. Many of the selections evoked memories of my association with the Peace Corps—both the training at Howard University and my subsequent assignment in Togo, Africa. The writings recall currents and tensions of the sixties that stirred us to “do something”!

My thanks to Nick Cunningham, M.D., head of our team of health care volunteers in Togo; his idealism and dedication set me on a lifelong path of interests that eventually led to Marian Secundy. I also want to express appreciation and gratitude to Delese Wear, Ph.D. (NEOUCOM); Roy Behnke, M.D. (USF); Jack Moore, Ph.D. (USF); and Howard Carter, Ph.D. (Eckerd College), who all contributed in special ways as the project developed.

Lois LaCivita Nixon, Ph.D., M.P.H.
Assistant Professor
University of South Florida College of Medicine

Foreword



We are driven, it seems, to distinguish ourselves, one from the other. A person says: "I am *A*, you are *B*, and that perceived difference allows me to know myself. Moreover, when you come too close to my defenses, I will fight you simply because you are not *A*." On the other hand, there are times—far less frequent, but probably even more intense—when *A* is lonely and says to *B*: "I want now to embrace you as my brother or sister. I yearn to make you one with my own soul, and I will mourn until we find our unity." So speak nation and nation, men and women, black and white.

Where does it come from, this deep bifurcation of human need? Most explanations are cultural. The cause may lie instead in our biology or, more likely, in some transcendent combination of the two. In any case, this fine anthology addresses the need for separateness as well as the need for union, and therein lies some of its power.

Crisis, of course, is universal. Illness, aging, death—everyone encounters them. In these treacherous spheres, no one's distaste or fear is any more significant than another's. No one's triumph is

any less worthy. Put these classic tales of black suffering alongside such mainstream classics as "The Death of Ivan Ilych" or "Tell Me a Riddle," and potentially divisive questions of who *A* and *B* are melt away in the face of common human destiny. Therefore, it should be a great comfort to readers of every background to set black literary pieces into the mosaic of the larger community. Without them, in fact, the mosaic can never attain that wholeness and harmony of segments that since ancient times have been thought beautiful.

If this book engenders a feeling of oneness, it also offers to refine readers' identities, both personal and professional, by expertly tracing the impact of certain differences. *A* is not *B*. Blacks' experience of health and illness is not precisely the same as whites'. Placed, as it is here, within the context of shared human experience, the fact does not arouse defensiveness. On the contrary, understanding black perspectives liberates our knowledge, imagination, and skills.

For instance, the terror of early, violent death by drugs and murder in some urban black neighborhoods profoundly changes the behavior of a mother who seeks pediatric care for her growing son. But if we merely note that sociological observation, we have not done enough. After all, most intelligent educators and care givers have filed that and similar information somewhere in their brains. The point is, information cannot be activated until we deeply realize its truth—that is, until we imagine what that mother and her child endure. To achieve that goal, we need stories of all kinds to embody and dramatize the facts.

Nor is the study of contemporary black situations enough. History lives on in a people, sometimes unconsciously, rather in the manner of the embryological world wherein ontogeny recapitulates phylogeny. So if we want to know and imagine the lives of today's black patients, we must learn something of yesterday's. Langston Hughes, Claude McKay, Zora Neale Hurston, and many others, with their tales and poems of past racial struggles, provide this essential data.

This anthology will find its place in many educational settings. I am particularly grateful, however, for its contribution to the development of literature and medicine, an area of study that began its full-time academic life in medical schools in 1972 and that now supports a journal, provides the focus for conferences, and gener-

ally weaves itself into the humanistic education of physicians. In the summer of 1982 the field had the good fortune to attract Marian Secundy to an NEH-sponsored summer seminar at the Pennsylvania State University, at which time she realized that there were worrisome gaps in the reading lists. That the field has taken its insights mainly from white literature is due in part to the conventional education of most of its teachers and to the relative inaccessibility of some of the major black texts on medical matters. In part, too, the infrequent appearances of black writing can be traced to the initial problems faced by the mainly white students and clinicians, who were struggling to accept the literature of their *own* traditions as an integral part of medical education. Now that humanities courses in medical schools are no longer a radical presence, students are more likely to know that literature offers an important vehicle for hearing the depth of their patients' voices.

Those voices must also, of course, be heard in their breadth—that is, in their various philosophical dialects. In this respect the pieces collected here are bountiful. How in the world, for instance, is a white, middle-class, twenty-five-year-old male doctor, who wants to perform his role in the most intelligent and beneficent way, to approach a poor, aging, folk-educated, black, female patient? Suppose that her economic struggles and her attitudes toward such basic matters as family, health care, and death are mysteries to him. He may know that medical care, built on scientific generalizations, ultimately succeeds as an individual case history or story. But no facts from the patient's chart will stimulate his appreciation of her individuality like familiarity with some of the literature of her culture. Yes, his abstract understanding of the universality of medical crises will assist him. But without some concrete appreciation of that woman's differences from him, he may not make a healing connection with her. Substitute a twenty-five-year-old middle- or upper-class black doctor in the preceding formula and, given the narrow focus of most premedical education, he or she still may not understand what values the woman brings, along with her ailing body, to the clinic.

In fact, we need every bit of help possible when we attempt to handle medical turning points, whether as professionals or as patients. We are extraordinarily vulnerable when we face serious illness and loss from either end of the stethoscope. How fortunate we are, then, to live in a country where we have a multitude of

ethnic and racial groups, each of which has spent generations trying to decipher the meaning of human tragedy. Perhaps one measure of wisdom is our willingness to listen to the tales of that man of a different color on our left and that woman of a different color on our right as we walk together toward life's inevitable crises.

Joanne Trautmann Banks, Ph.D.
The Pennsylvania State University
College of Medicine, 1990

Ethnicity and Healing



Ethnicity imprints every person, even those who think they have shaken off or rejected its embrace. It binds those with common roots and separates them from those with different origins. It suffuses body and oral language, as well as the way we take in, or distance ourselves, from the world and other people. Even the white, mainstream American male who labels others as “ethnics” is himself indelibly ethnic. His “Americanism,” or the version of it he derives from his roots and locale, makes him as much ethnic as the most recently arrived immigrant.

Ethnic imprints may lie dormant or be overt, but they become most apparent in times of elemental challenge—in birth, marriage, illness, suffering, and dying. Ethnicity is a force in both the genesis and healing of illness. It contributes to the uniqueness of the experience of illness—the very uniqueness the physician must somehow penetrate, at least in part, if he or she is to heal effectively. It is, as a consequence, a moral obligation of the conscientious healer to comprehend and to empathize to some extent with the cultural identity of those he or she purports to heal.

This anthology is intended to help those who provide care for black Americans to understand something of the experience of illness as it is shaped by African-American culture. It is an invitation, as well, to appreciate the richness of the culture of the patients they see daily, but often really do not "see." Through the words and imagination of black writers, we can develop some feeling for the experiences of being a black physician, of the anguish and pain of discrimination, of the memory of lynchings, of the reality of drug addiction and poverty, of being black, of being old or infirm, or of dying.

The editors hope that these pieces will engender empathy, compassion, and some sense of the moral obligation we have to comprehend the special story of black people in America. These stories, poems, reminiscences, and reflections are far more effective teachers than didactic essays on the sociology, mores, or ethics of African-American life. Literature captures the imagination, evokes a vicarious experience, and reaches the person in a way no scholarly lecture could. These authors have experienced much of what they write about. They each have found a voice through which to communicate something of the predicament and suffering of black patients. Compassion means feeling what another person is feeling. This is a matter in which the heart responds first. Then the head follows.

Obviously, we can never get into the skin of another person. The pieces in this anthology can at best invite understanding for those who are sensitive enough to hear the message. Some, of course, will be so encased in their own ethnicity that even these powerful words will go unheard or unread, but no one with a sense of what it is to help and to heal can remain indifferent to the voices that sound through these pages, sometimes quietly, occasionally angrily, always poignantly.

These are not entreaties to pity. Through the strictures of the black experience in America we meet heroes and heroines, and victims—but not self-pitying victims. Even in their duress, they radiate the richness and strength of a culture closed to white people by obstacles—of language, lifestyle, and custom.

Paradoxically, as we learn more about the uniqueness of African-American culture, we are drawn closer to the common humanity we share with the subjects of these stories and poems. For in the

end, as Dr. Marian Secundy so wisely says in her introduction, there is more we hold in common than we recognize. All humans become ill, suffer, and die and are fearful, anxious, and vulnerable in the face of disease, dying, or disability. All seek health, help, and healing. Our finitude and our vulnerability are the universal experiences that weld all humans to each other.

It is manifestly impossible to gain any depth of perception about all the ethnic groups a physician or nurse is apt to encounter. But surely there is an obligation to learn about whatever group figures prominently among our patients. Beyond that, there is a special obligation to African-Americans. Their numbers are significant, and their assimilation into American life has been slow. Their forebears were not willing immigrants, but slaves. There are also the special features of the black health experience—the prevalence of poverty, the higher incidence of certain diseases, the alarming infant mortality, the limited access to health care, and the paucity of black health care professionals. Moreover, until recently with the rapid increase of Asian immigrants, African-Americans and Native Americans were the only groups who did not at least share, as other ethnic groups did, the common ground of Western European culture.

Some physicians and nurses might argue that all of this is well and good, but they can practice good medicine or nursing without empathy. Medicine is, after all, an objective enterprise, and physiology is physiology. While no doubt some physicians and nurses are remarkably gifted with the attributes of compassion, the likelihood is that most overestimate their capacities for empathy. Moreover, it is precisely the canons of "good medicine" that make the effort to learn about the cultural milieu of our patients morally mandatory.

Ethnicity enters into every step of the healing relationship—from data collection to the implementation of the treatment. To be sure, some ethnic factors like the incidence of race-related diseases, drug sensitivity, or nutrition are objective. But at most stages ethnicity plays decisive roles that are more qualitative than statistical.

The first step in helping a sick person is to decide what is wrong. This we do by observing, recording, and interpreting signs and symptoms. Ethnic background often influences the way a patient perceives pain or reacts to it, describes symptoms or decides which are more important, and determines which to reveal and which to conceal. ✓

The second step is to establish a list of probable diagnoses and possible treatments. Ethnicity here may give weight to certain diagnoses as more probable than others. Race-specific drug sensitivity or toxicity can materially alter the therapeutic regimen.

The third step is to arrive at a treatment which is not only technically "correct" but in the patient's best interests as perceived by the patient. The patient's values determine what constitutes health and the good life and the costs he or she is willing to sustain to achieve them. The values a patient chooses may be subtly or overtly shaped by ethnicity. Care givers must know and respect those values even if they contravene their own values or those of the dominant culture.

Finally, the treatment must be incorporated into the lives of the patients if they are to be healed, especially if the illness is chronic. This step depends upon educating the patient about what is to be done and why. Ethnicity may be an obstacle or an aid. The patient must in turn be convinced that the treatment is worthwhile; but what is worthwhile in one cultural milieu may not be in another.

Clearly, ethnicity shapes the way a patient and a physician see, interpret, and communicate the predicament of illness to each other. At the moment of their interaction, each is a unique person at a particular point in life. How each perceives the other may enhance or impede the healing purpose of their encounter. To ignore ethnicity is perilous not only in human terms but in terms of objective medicine as well. It is conceivable in overwhelmingly acute trauma or illness for a care giver to treat a patient with a minimum of compassion or empathy; yet, even this is illusory since most clinical choices are value-laden. When the patient's cooperation and compliance are needed, as they are in most illnesses, effective treatment without empathy is impossible.

When physician and patient share the same ethnic roots, many of the barriers to healing inherent in the experience of illness can be removed. Understanding the patient's reactions, values, choices, and style is crucial in arriving at mutually comprehensible clinical decisions. Trust is an essential and ineradicable ingredient in being healed, and it is far easier to generate among cultural compatriots than among those from diverse ethnic backgrounds. Some of the inequality in knowledge, if not power, is removed. Compassion, which entails experiencing something of the patient's experience, is deepened.

Simply sharing the same ethnic origins, however, is not sufficient. Sometimes physicians or nurses consciously want to distance themselves from their own ethnic group because of differences in socioeconomic status, the patient's lifestyle, or a desire to become assimilated into the dominant culture. Repudiation of one's own roots is too often necessary for success in American society. Under such circumstances a compassionate person alien to the patient's culture may be better suited to treat a patient whose ethnicity is overt.

* * *

This collection can be read profitably by anyone who provides care for African-American patients. It is especially suitable for medical students and residents who are beginning to form their attitudes toward the different kinds of patients they are called upon to treat. Read and then discussed in small groups under the guidance of an appropriately skilled teacher, the selections in this anthology will enlighten, move, and inspire.

While those outside the African-American experience will profit most, there is much here for black Americans as well. Some have drifted away from their roots. Some perhaps are even ashamed of them. These African-Americans will find here refreshment and a revitalization of pride in their own rich heritage as well as insight into the predicament of some of their less fortunate brothers and sisters.

This anthology is a model other ethnic groups might well emulate. Hispanic-Americans and Asians have their own unique experiences which shape the way they see health and illness, recovery, and death. What this collection (and similar ones for other ethnic groups) illustrates is that the more we probe into the ethnicity of our fellow humans, the more we will understand our own ethnicity. Most important, we will come to understand that under the differences of language, style, custom, and physiognomy, there is a common substratum of humanity that unites us.

Edmund Pellegrino, M.D.
Director, Center for the Advanced Study of Ethics
Georgetown University, 1990