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Ronald E. Anderson *Editor*

World Suffering and Quality of Life

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Editor

World Suffering and Quality of Life

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Foreword

On Suffering: What We Do Not See

David B. Morris, Author of *The Culture of Pain*, and Emeritus Professor of English, University of Virginia, Charlottesville, VA, USA

We all believe in life.
We feel a certain devotion.
We feel called upon to live as good a life as we can.
We feel that we are in the dark and that even in darkness we must struggle to know what is best to do.

—Agnes Martin (1979)

“The philosophers have only *interpreted* the world in various ways,” as Marx wrote in his well-known “Theses on Feuerbach” (1888); “the point is to *change* it.”¹ Some suffering is certainly political and social in the sense that politics and societies create it—or create the conditions that permit it to arise and continue; with significant effort and luck, good politics and wise societies can help to un-create it.² *Praxis* here trumps *gnosis*. It is not necessary to define suffering perfectly or to understand suffering perfectly in order, no matter how imperfectly, to relieve suffering. Or, realistically, to relieve some suffering. We can relieve the suffering of a child who does not have enough food, for example, or who cannot afford life-saving medications or who has no access to disease-free drinking water. The ethical and pragmatic question is whether we, as individuals, will act. The political and social question is whether—and how—organizations and nations will act. It is the great virtue demonstrated by specific foundations, churches, doctors, social workers, teachers, students and ordinary citizens that they see a particular instance of suffering and—without waiting for politicians, philosophers, or perfect knowledge—they act effectively to relieve what they can.

¹Marx, K. (1983).

²See, for just two examples, Kleinman et al. (1997) and Sayad (2004).

Politics, while important, is never more than the art of the possible and never sufficient to address the full spectrum of human suffering, and in addition it encounters one near-fatal, but possibly preventable, blindness to which individual ethics also is subject: that is, politics, ethics, and good intentions can *address* suffering only where they *recognize* suffering. This is an implication in painter Agnes Martin's provocative prose meditation—a fragment of which appears as the epigraph to this foreword—entitled *What We Do Not See if We Do Not See*. The medical name *scotoma* applies to a visual-field defect that we all possess: a blindness of which the individual is unaware. *Anosognosia* is a rare deficit of self-awareness, usually the result of brain damage following a stroke, in which patients who suffer an impairment seem unaware that they are impaired. What don't we see, it seems fair to ask, in the suffering that we do not and cannot see?

I thought, for example, that I knew something about AIDS, but I was wrong. I knew something about AIDS in the developed world. I knew nothing about AIDS in Africa. I simply did not see it. My abrupt wake up came as a visiting faculty member on the Spring 2013 Semester at Sea voyage, where more than 600 undergraduates spend 4 months taking classes aboard ship and visiting countries from Asia and India through Africa. As I prepared my classes, I encountered the amazing book by Stephanie Nolen entitled *28: Stories of AIDS in Africa* (2007). Nolen—award-winning Africa bureau chief for Toronto's *Globe and Mail* newspaper—lived and traveled extensively in Africa, reporting from more than 40 countries. Her book offers 28 brief individual stories representing the 28 million Africans (at the time she wrote) infected by HIV/AIDS. Her book was my introduction to some of the confusing cultural, geopolitical, and global complexities attached to suffering. I began to see what I had not seen.

We see to some extent only what we are willing to acknowledge. HIV, as Nolan says, targets the topics that people generally “least like to discuss—the drugs we inject, the sex we have, especially the sex with people we aren't supposed to have sex with—and the interactions least open to honest discussion or to change.”³ Traditional African societies often treat the discussion of sex as taboo, so that the link between eros and HIV/AIDS lends extra difficulties to prevention and treatment. Most important, however, Nolan emphasizes that HIV thrives on imbalances of power. It got its foothold among sex workers, drug users, gay men, and migrants—the poorest and most marginalized members of African society—but once established it found power imbalances and routes of transmission (like the highways traveled by long-distance truckers) almost everywhere. Rwanda in 1986 was the first country to do a national survey of HIV prevalence. The nightmare results: 17.8 % of people in cities were infected. In 1990, nearly one in five adults in Uganda had the virus. By 2005, at least 20 million Africans had died from AIDS. This was devastation on a scale like nothing I had seen or could envision. Similar losses would depopulate the entire state of New York.

³Nolen, S. (2007). Facts and figures cited in my discussion are directly indebted to Nolen's account.

What I learned aboard ship added another layer of complication. Among my new shipmates was Desmond Tutu, the Nobel-prize winning Emeritus Archbishop of Cape Town. Tutu played a major role in the peaceful transition from apartheid rule in South Africa as head of the Truth and Reconciliation Commission. He is far less well known, however, for his contributions in establishing The Desmond Tutu HIV Foundation, which he developed in the early 1990s and which is justly acclaimed as among the first public clinics in Africa to offer the (then) controversial and inaccessible anti-retroviral therapy.⁴ As our unofficial informant about African life and culture, Tutu advised his largely Western colleagues and students about the key African concept known as *Ubuntu*. *Ubuntu*—a Bantu word—refers to a traditional African alternative to the deeply entrenched Western tendency to identify humanness in our capacity for thought. *Ubuntu*, unlike the Cartesian *cogito ergo sum*, situates our basic human-ness in social connections.⁵ As Tutu once wrote, “*Ubuntu* says that we cannot exist as a human being in isolation. We are interconnected. We are family. If you are not well, I am not well.”⁶ On board ship, for the benefit of students and faculty, he translated it in the brief, simple, strikingly resonant statement “*I am because you are.*”

Suffering, among its multiple impacts, certainly helps to strain the affective social bonds that hold individuals together, and HIV/AIDS as a source of both illness and suffering struck the world of *Ubuntu* as much more than a sexually transmitted infectious disease. As it attacked the individual immune system, it simultaneously attacked and undermined the social cohesion at the heart of African identity. *Ubuntu*, unfortunately, can come undone or work in reverse. Nolen offers grim accounts of gaunt villagers demonized and left alone to die because fellow villagers suspect them of wasting away with Slim—the local name for AIDS. The widely shared stigma isolated patients, fractured families, and disrupted the ancient fabric of village life: as the number of AIDS victims increased among young parents, the number of AIDS orphans mounted. Villages could no longer look after the hungry children increasingly left to fend for themselves. In short, HIV/AIDS in Africa held a distinctively African profile, unlike anything I knew in the West.

My own work with pain required me to think too about suffering, and at a purely conceptual level we can tease them apart.⁷ I feel pain when I stub my toe, but I do not suffer. I might suffer from the loss of a spouse but not feel pain. Neurosurgeon John D. Loeser, internationally respected specialist in pain medicine, described the distinctive conceptual relations among pain, nociception, and suffering in a now-famous diagram reproduced in numerous medical texts.

⁴ See Desmond Tutu HIV Foundation (2015).

⁵ For additional discussion, see Battle, M. (2009) and Gade, C. B. N. (2012).

⁶ Tutu, D. (2014).

⁷ See Morris, D. B. (1991, 2010).

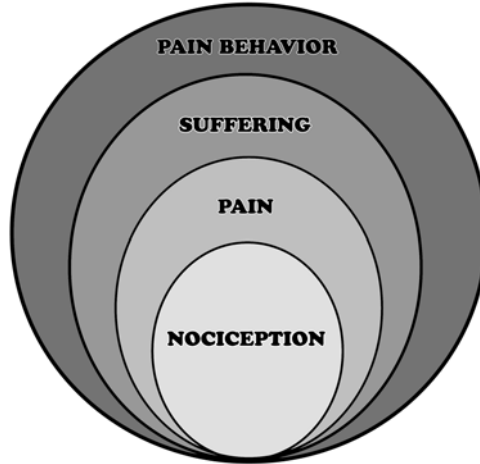


Fig. 1 John D. Loeser’s biopsychosocial model for the components of pain (Reproduced courtesy of John D. Loeser)

From a different perspective, my thinking about pain produced an hourglass diagram that places individual consciousness in the center, where a clean, conceptual demarcation between pain and suffering is harder to maintain. “Our concepts of pain, impairment, and disability,” Loeser’s colleague Wilbert E. Fordyce writes, “must consider environmental factors as well as the person.”⁸ The extensive sociocultural environment, as solid as a medieval cathedral and as diffuse as Augustinian theology, affects pain in complex ways, mediated by multiple biological systems, but, no matter how complex its organic processes, no matter how fully we sympathize with the pain of others, we experience pain only in and through an individual consciousness. When we temporarily turn off consciousness, via anesthesia, sleep, or drugs, we turn off pain. Consciousness, therefore, is at the center of the hourglass:

So too suffering. In an integrative, biocultural model, the focus moves both inward and outward: inward toward the micro-level processes of cell biology (good nutrition can work wonders) and outward toward the macro-level sociocultural environments: families, villages, states, religions, media, and international agencies or multinational corporations. Intervention at any level in such an interconnected model is likely to have an impact at other levels.

⁸Fordyce, W. E. (1995).

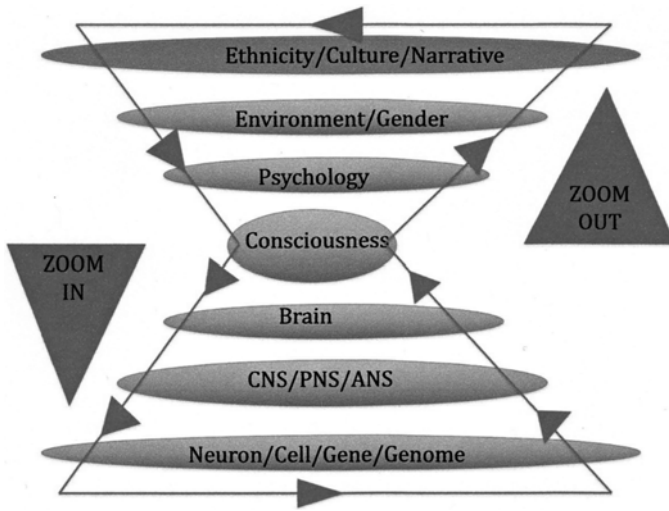


Fig. 2 An integrative model of pain (Reproduced Courtesy of David B. Morris)

A truly integrative and biocultural model should be three-dimensional and spin, but at least a flat, static version marks a significant distance from the popular belief that pain is an electrochemical signal that registers a direct one-to-one relation with tissue damage. Human suffering, like pain, involves complex interrelations among social and biological dimensions as they play out, inescapably, in a single consciousness. Even collective trauma, as in the Holocaust or in the forced marches of Native Americans, register their added cultural burden in the consciousness of each individual member of the group.

“The brain,” as John Loeser puts it, “is the organ responsible for all pain.”⁹ Suffering too requires the human brain in all its complex biological networks. *What we do not see if we do not see*, on the other hand, is how suffering plays out in an individual consciousness situated within a particular culture. A global perspective cannot afford to overlook the ways in which cultures and consciousness, at the level of single individuals, rework the experience of suffering. Agnes Martin, in her writing, certainly recognizes the difficulties and darkness in which most of us struggle to know what is best to do. Her paintings, however, confront us with almost the opposite of anguish and confusion: a serene and geometrical perfection that hovers somewhere above or beyond the materiality of everyday life with its almost inescapable pain and suffering.

⁹Loeser, J.D. (1991).

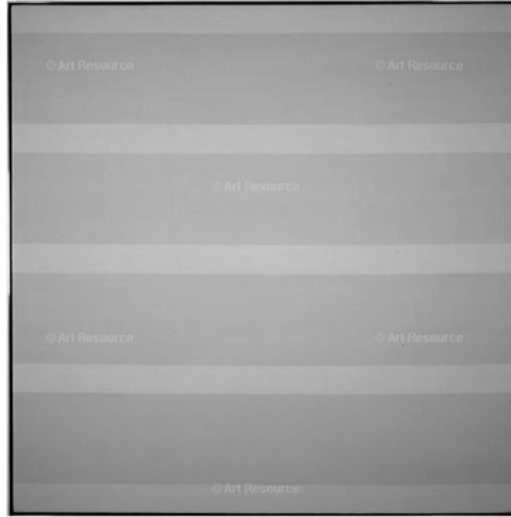


Fig. 3 Agnes Martin. *Untitled #7*. 1992. Acrylic on canvas. 72" × 72" (Photo credit: Davis Museum at Wellesley College / Art Resource, NY)

“My paintings,” she wrote in 1966, “have neither objects nor space nor time not anything—no forms. They are light, lightness, about merging, about formlessness, breaking down form.”¹⁰ Such a vision may seem to ignore the awful facts of human suffering, but perhaps it also recognizes suffering or a dimension of suffering in ways that we do not see if we do not see. That is, did Nelson Mandela during his 27 year imprisonment—18 years on brutal Robben Island—imagine patterns of racial and social harmony that others perhaps did not see? Did such a vision help sustain him in times, such as the death of his son, when daily suffering reached a crescendo pitch?

The value of a global perspective on suffering may lie less in its power to reveal a sameness in suffering, exposing core similarities or universal responses, than in awakening us to its subtle differences within a particular culture and an individual consciousness, its potential for radical strangeness, even its almost inexplicable and limitless possibilities, as in ancient Greek tragedy or in the abstract paintings of Agnes Martin, for recognizing (where others see only evident turmoil, hunger, privation, and sorrow) larger and perhaps mostly invisible patterns: God’s will, Fate’s unseen hand, Zen emptiness, Ubuntu connectedness, the geometry of a harmonious life. The ultimate goal of course is to relieve suffering. From a global perspective, however, such a goal requires not only that we address the suffering we see but also that we strive to recognize suffering in the lives of individuals who may not closely resemble us, who may not suffer in ways that we are familiar with, and thus—accounting for our own scotomic blindnesses or built-in cognitive and visual-field defects—to address the suffering that we do not see.

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¹⁰Martin, A. quoted in Wilson, A. (1966).

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Preface

Goals This book grew out of a desire to compile in one place the ideas, perspectives, and findings of researchers who are pioneers in understanding human suffering around the world. Though suffering is a universal experience, these reports reveal surprising diversity in approach, emphasis and findings. Some conceptualizations highlight close associations between suffering and various worldviews including humanitarianism, human rights, caring, and healing.

“Global” and “suffering” may be household words, but not until this collection has a book explicitly tackled the topic of *world suffering*. In this pioneering book project, I sought to build momentum for a research tradition that might ultimately help reduce world suffering. Toward this end, I assembled leaders who have explored the fields of suffering and quality of life (QOL) to write exemplary essays and reports showing examples of what is known, how to improve methods to study suffering, how to collect new and better data, and otherwise how to expand knowledge about suffering around the world. Those reporting research results used quite different methodologies: case studies, surveys, in-depth interviews, participant observations, and secondary data analysis. Not only do these pages explicate the concept of world suffering, they show how it can be investigated on a global scale, and, perhaps most importantly, reveal how suffering relief remains central to the purpose of human societies.

As we link the notion of freedom from suffering with indicators of QOL, we achieve a new depth of knowledge. In taking this approach, progress in research on suffering or QOL spills over from one to the other, offering new perspectives for both. This collaborative writing project explores ways to improve research on suffering by using paradigms and methodologies from QOL research. It also offers improvements to QOL research by taking into account pain and suffering. The reader will gain a wealth of insights about the interaction between suffering and quality of life, the most up-to-date characterization of worldwide suffering, and a grasp of the implications of these data for local and global policy on health and social well-being.

Processes Over the past several years, in preparation for writing a short book, *Human Suffering and Quality of Life* (Anderson 2014), I digested hundreds of articles and books on suffering. In reviewing the bodies of literature on suffering, pain and quality of life, I found the diversity of approaches and opinions startling. Such divergence made the mission for this book even more compelling.

To obtain the chapters for this volume, I emailed invitations to about 100 authors of academic books or articles related to suffering. Each was charged with writing something important pertaining to *world suffering* in 5,000–7,000 words. I received about 70 good abstracts and asked for the authors to write chapter drafts.

Over a 9-month period, I worked with these authors and obtained reviews in order to create high quality, in-depth but succinct essays or reports for this volume. Together, the 32 chapters assembled here represent the best of contemporary thought and cutting edge research on world suffering and quality of life. The authors live in 16 countries and represent each major continent except Antarctica. The authors don't necessarily agree on precisely how to define suffering, but their work contributes to a cumulative body of knowledge on suffering that ultimately will be enormous.

The authors chose to focus on one or more of these types of suffering:

- Physical suffering, especially what we typically call pain
- Mental suffering, including depression, anxiety, existential suffering, other severe mental illness
- Interpersonal suffering, that suffering caused by social rejection, social isolation, and deficits in social interaction
- Social suffering (resulting from local or global social institutions that harm specific categories of people, such as the poor, the disabled, etc.)
- Co-occurrences of all these four types of suffering, which I call “total suffering”

By bringing a more precise and complete vocabulary of suffering into every day and humanitarian discourse, we have the basic tools to collaborate to alleviate suffering and reduce its future occurrence.

Audiences As I assembled the chapters, I divided them in many different ways, including by study methods used and key themes. From this process, the principal audience communities became more apparent. Anticipated audiences include:

- Those concerned with understanding pain and suffering and their effects
- Researchers wanting to assess the ongoing quality of life of different groups or sectors of the world
- Those studying community, including online community, and the role social suffering and interpersonal deficits, such as isolation, have on members of these communities
- Those supporting or participating in humanitarian activities, including human rights, development and otherwise improving the human condition
- Healthcare providers and informal caregivers, especially those who struggle with suffering

- Anyone who wants to alleviate suffering, including reduction of global inequality from which many people live with life-consuming, intense suffering

Challenges In today's world, it is nearly impossible to escape images showing violence, famine, disease, and other calamities. As noted in Chap. 6, media scholars tend to agree that social media and other new technology, combined with narcissist marketing of humanitarian aid, produces half-hearted concern for global suffering. Thus, the public sees second-hand a barrage of disasters, epidemics, wars, and terrorism. Existing institutions such as human rights organizations and humanitarian relief agencies rally support for relief from these calamities. But often their appeals fall flat because the giving public has not been socialized in the humane values that demand social responsibility for all tragically suffering human beings.

Avoiding preventable suffering is an ultimate human concern. This means that human beings must come to terms with it and understand it as a central social responsibility in exchange for life. Research on suffering will help us identify and evaluate how best to act responsibly.

In contrast, unpreventable suffering, such as natural death, can be a tragedy that we learn to approach with serenity and accept as part of life. Toward that end, some of the chapters here offer enlightenment on how suffering can become a source of meaning and an aid to making peace in a cruel world.

Minneapolis, MN, USA

Ronald E. Anderson

Acknowledgments

A book this size—with 46 authors, 32 chapters, and a foreword—requires a village to conceive, produce, and deliver a new, literary life. My mixed metaphor, if nothing else, hints that the book’s production had its moments of excitement and pain as well as hard, tedious but challenging work.

The book project began in Buenos Aires at an ISQOLS (International Society for Quality of Life Studies) in July 2012, when I met Esther Otten, editor of health, well-being and sociology publications at Springer Science + Business Media (commonly known as Springer) in Dordrecht, The Netherlands. She expressed interest in my work on the topic of suffering, and by the end of the year, I had presented two successful book proposals to Springer. After finishing the first book in June 2013, I immediately initiated the 12 months required to assemble the contributions to this book.

During that time, I sent dozens of email requests for help to Esther Otten, as well as Tuerlings Hendrikje and Miranda Dijksman, both editorial assistants in social sciences at Springer in Dordrecht. Without their guidance and help, it would have taken twice as long. I am very grateful for their support throughout.

Here in Minnesota, I began the project doing everything myself, but as the number of authors and potential authors of chapters expanded toward 100, I found local support for the editorial and administrative work. Letta Page and Sherri Hildebrandt provided excellent copy editing of every document, and they also gave invaluable advice on content and presentation of ideas. Kathryn Albrecht served as the project’s expert on citations and references, checking every chapter and helping to fill in the missing details. Carol Miller managed the time-consuming process of communicating with every author to get their approvals of the edited papers as well as the authors’ signed consent forms. It is amazing what can be done with highly skilled assistants working together using only email communication.

While the writing, reviewing, and editing process took only a year, it seemed much longer, because the authors and I learned so much in the process. I will forever feel grateful to my new friends and what they contributed to this work. I predict that the authors of this volume’s chapters will evolve into a community of scholars and

researchers who will continue to generate theoretical and practical knowledge—both qualitative and quantitative—about global, human suffering.

Many authors helped by reviewing papers and finding additional prospective authors. Special thanks to authors Iain Wilkinson, Nancy Johnston, and Daina Harvey in this regard. The preface that immediately follows this page gives additional details about collaborating with the authors and implications for the future.

Several well-known scholars, whose tight schedules made it impossible to contribute to the book itself, nonetheless gave their enthusiastic moral support, boosting my morale with the encouragement they gave for the book. They include: Craig Calhoun, president, London School of Economics; Paul Farmer, professor and global health leader, Harvard University; Richard Estes, professor emeritus, University of Pennsylvania; and Alex C. Michalos, professor emeritus, Brandon University and editor, *Social Indicators Research*.

This research and writing project benefited greatly by two small grants to Ronald Anderson from the University of Minnesota Office of the Vice President for Research and the University of Minnesota Retirees Association (UMRA).

Finally, I wish to thank my wife, Nancy Kehmeier, for her ongoing support for the project. Not once did she claim to suffer from social rejection due to my preoccupation with this intense and time-consuming project.

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Ronald (Ron) Anderson is Professor Emeritus at the University of Minnesota. He received his Ph.D. in sociology from Stanford University in 1970. From 1968 until retiring in 2005, he served on the faculty of sociology at the University of Minnesota. From 1990 to 2005, he coordinated several international studies of the social and learning effects of information technology within primary and secondary education in 20 or more countries in each study. From that and earlier work, he wrote or edited seven books and over 100 articles. Since retirement, his research interests have focused on suffering and caring.

Part I
World Suffering: A Challenge to
Humanity, Humanitarianism and Human
Rights

Chapter 1

Implications of World Suffering for Human Progress

Ronald E. Anderson

1.1 Introduction

Suffering ranks high on the list of what it means to be human, yet the desire and action to alleviate our suffering, and that of others, ranks even higher. However, for many historic reasons, suffering tends to be repressed and largely ignored. This escape from suffering may account in part for the ease by which large numbers of people can be indifferent to the tragic suffering around the world.

Despite each individual's unique suffering, it is possible to study suffering among not only individuals, but families, groups, communities, nations, and the world. Study after study, conducted in different communities and countries, reveals that despite small cultural differences, the structure, patterns, and oftentimes meanings of suffering, ring true across all social contexts around the globe (Anderson 2014). I had expected that many of the most interesting findings would be comparative (across communities or countries), but this was not the case. Instead, the most intriguing results were from the uniqueness of a study's methodology. Progress on social policies regarding suffering requires multiple methods: subjective and objective measurements; qualitative and quantitative data collection; formal and informal analytical approaches, in both research and policy.

A comprehensive discussion of suffering naturally leads to considerations of alternative strategies for the relief of suffering. Separating chapters into the categories of humanitarianism, caregiving, quality of life (QOL), community systems, and human rights, led to the realization that to some extent, these are parallel types of strategies for the relief of suffering. And while funding is a prerequisite for solving

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