MULTICULTURAL NEUROREHABILITATION
Jay M. Uomoto, PhD, is a rehabilitation psychologist and neuropsychologist and the Training Director for the Clinical Neuropsychology Postdoctoral Residency Program at the Veterans Affairs Northern California Health Care System. He is a Fellow of the National Academy of Neuropsychology and a Fellow of the American Psychological Association, Division 22—Rehabilitation Psychology, and he is Certified in Health Care Ethics. Prior to his current position, Dr. Uomoto served in the Department of Veterans Affairs Central Office as the National Mental Health Director for Veterans Affairs/Department of Defense Collaboration and was a Deputy Director for the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury. He also served on the faculty of the Department of Rehabilitation Medicine at the University of Washington and Emory University, in the Department of Clinical Psychology at Seattle Pacific University, and in the Department of Neuropsychology at the Barrow Neurological Institute.
Multicultural Neurorehabilitation

Clinical Principles for Rehabilitation Professionals

Jay M. Uomoto, PhD
Editor

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CONTRIBUTORS

Julie Alberty, PhD, Department of Clinical Neuropsychology, Barrow Neurological Institute, St. Joseph’s Hospital and Medical Center, Phoenix, Arizona

Juan Carlos Arango-Lasprilla, PhD, Department of Psychology, University of Deusto, IKERBASQUE, Basque Foundation for Science, Bilbao, Spain

Heather G. Belanger, PhD, ABPP (CN), James A. Haley Veteran’s Hospital, Department of Mental Health and Behavioral Sciences, University of South Florida, Department of Psychiatry and Neurosciences, Tampa, Florida

William L. Brim, PsyD, Center for Deployment Psychology, Uniformed Services University of the Health Sciences, Bethesda, Maryland

Alison N. Cernich, PhD, ABPP (CN), Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury, Silver Spring, Maryland; Veteran’s Affairs/Department of Defense Mental Health Integration, Office of Mental Health Services, Department of Veterans Affairs, Washington, DC

Nicole Ditchman, PhD, CRC, LCPC, Department of Psychology, Illinois Institute of Technology, Chicago, Illinois

Fernando Gonzalez, PhD, ABPP (RP), Ranchos Los Amigos National Rehabilitation Center, Downey, California

Stephanie L. Hanson, PhD, ABPP (RP), College of Public Health and Health Professions, University of Florida, Gainesville, Florida

Brick Johnstone, PhD, ABPP (CN), School of Health Professions, University of Missouri, Columbia, Missouri
Contributors

Joseph Keawe‘aimoku Kaholokula, PhD, Department of Native Hawaiian Health, John A. Burns School of Medicine, University of Hawai‘i—Manoa, Honolulu, Hawaii

Thomas R. Kerkhoff, PhD, ABPP (RP), Department of Clinical and Health Psychology, University of Florida (Retired), Gainesville, Florida

Pamela S. Klonoff, PhD ABPP (CN), Center for Transitional NeuroRehabilitation, Barrow Neurological Institute, St. Joseph’s Hospital and Medical Center, Phoenix, Arizona

Eun-Jeong Lee, PhD, CRC, Department of Psychology, Illinois Institute of Technology, Chicago, Illinois

Anthony H. Lequerica, PhD, Kessler Foundation, West Orange, New Jersey; Department of Physical Medicine and Rehabilitation, Rutgers, New Jersey Medical School, Newark, New Jersey

Vicky T. Lomay, PhD, Tsinajini Psychology Services, Mesa, Arizona

Jennifer Loughlin, PhD, Center for Transitional NeuroRehabilitation, Barrow Neurological Institute, St. Joseph’s Hospital and Medical Center, Phoenix, Arizona

Fred Loya, PhD, VA Northern California Health Care System, Martinez, California; Helen Willis Neuroscience Institute, University of California, Berkeley; Department of Neurology, University of California, San Francisco

Janet P. Niemeier, PhD, ABPP (RP), Department of Physical Medicine and Rehabilitation, Carolinas Rehabilitation, Carolinas Healthcare System, Charlotte, North Carolina

Ivan Panyavin, MS, Department of Psychology and Education, University of Deusto, Bilbao, Spain

Kavitha R. Perumparaichallai, PhD, Center for Transitional NeuroRehabilitation, Barrow Neurological Institute, St. Joseph’s Hospital and Medical Center, Phoenix, Arizona

Michael Pramuka, PhD, James A. Haley Veteran’s Hospital, Psychology Service, Tampa, Florida
Aida Saldivar, PhD, ABPP (RP), Ranchos Los Amigos National Rehabilitation Center, Downey, California

Charlotte Sykora, PhD, Ranchos Los Amigos National Rehabilitation Center, Downey, California

Jay M. Uomoto, PhD, VA Northern California Health Care System, VA Martinez Outpatient Clinic, Martinez, California

Shawn O. Utsey, PhD, Department of African American Studies, Virginia Commonwealth University, Richmond, Virginia

Marlene Vega, PsyD, Pate Rehabilitation, Dallas, Texas
Foreword

Multicultural Neurorehabilitation: Clinical Principles for Rehabilitation Professionals provides a much-needed view of how culture is implicated and intertwined with our attempts to serve the mental and neurological health of human beings. By “culture,” I am loosely referring to the rules, norms, patterns of behavior, values, and attitudes that characterize particular groups. In three major analyses of mental health services over many decades, we have learned about the importance of culture, as well as about problems that occur when culture is not appreciated. In 1978, President Jimmy Carter’s Commission on Mental Health noted that mental health services are often poorly delivered because they are not consistent with the cultural traditions of clients. In 2001, the U.S. Surgeon General’s Report called for culturally competent services because ethnic minorities often have poorer access to services and lower quality of care. Finally, in 2003, President George W. Bush’s Freedom Commission on Mental Health lamented the fact that the needs of culturally diverse groups are often underserved or inappropriately served and that the histories, traditions, beliefs, and value systems of clients should be incorporated into treatment.

Multicultural Neurorehabilitation: Clinical Principles for Rehabilitation Professionals reminds us that despite the greater attention on cultural factors in health and service delivery, we have been remiss in dealing with cultural issues involving persons with neurological disorders or diseases. The book proceeds to illustrate the dilemmas and issues facing service providers and researchers who work with ethnic and culturally diverse clients who experience disability because of central nervous system disorders, diseases, and traumas. It is all the more important because it is one of the few contributions that provides a comprehensive look at these issues and offers recommendations to remedy problems. The contributions made by the authors are pioneering, challenging, and substantive.

Human beings come from cultural backgrounds that may involve ethnicity, sexual orientation, gender, social class, and religious affiliation.
Foreword

These backgrounds are important to understand in neurorehabilitation. They raise important questions. For example, in trying to determine the neurological disability of a client who has suffered a cerebral hemorrhage, are assessment procedures valid across different cultural groups? How can one provide effective rehabilitation services to an immigrant who has limited English proficiency? Questions such as these are difficult to address because of the lack of research and theory on disability within the context of culture. Nevertheless, they are critically important, especially because, as noted by contributors to this book, disparities exist. Members of ethnic minorities who suffer from neurological disabilities are often receiving inadequate and lower quality services than mainstream Americans.

Interestingly, because “culture” loosely refers to the rules, norms, patterns of behavior, values, and attitudes that characterize particular groups, disability itself may be the basis for a cultural group. Disability culture can evolve and develop. Human beings are a part of many different cultures, some by birth (e.g., one’s culture as a man or woman) and others by choice or upbringing (e.g., religious affiliation). In the case of the neurological disability culture, I am reminded of the observation that many elderly persons who suffer from neurological problems join support groups concerned with health, medications, and aging. We see many military service members who experienced neurological injuries in combat joining the “wounded warrior” movement. Both in the cases of the elderly and the wounded warriors, we see the formation of cultures—group identification, similar attitudes, and behavioral patterns. Even those with disabilities who do not specifically identify with a disability cultural group are often forced into a disability culture because of reactions from others, limitations caused by the disability, and social stereotypes and stigmas.

How those with neurological disability or how disability culture is accepted by one’s other cultures is important to ascertain. For example, are Mexican Americans more tolerant of disability than other ethnic groups? What family or community resources are available to Chinese who have disabilities? How can service providers utilize existing resources in the client’s ethnic culture to achieve more effective outcomes? What are the best ways to reduce stigmas and misunderstandings over neurological disability that may exist within one’s ethnic culture? In the United States, the mainstream cultural orientation toward disability rights has been relatively strong and has resulted in important legislation such as the Americans with Disabilities Act.
Finally, there is growing realization that multicultural rehabilitation issues are pertinent to all human beings. No one is immune to neurological impairment and disability. They can affect, and probably have affected, everyone at some point in their lives. Brain traumas or neurological disorders can develop slowly or occur suddenly and immediately impact one’s functioning, social relationships, and socioeconomic standing. When they occur, rehabilitation is certainly more effective when cultural factors are utilized, as revealed in this book.

Stanley Sue, PhD
Palo Alto University
Preface

The basic categories of human mental life can be understood as products of social history—they are subject to change when the basic forms of social practice are altered and thus are social in nature.

—A. R. Luria

This is just the start of a conversation, and in this context a conversation regarding how we best develop and deliver effective neurorehabilitation services to all who walk through our rehabilitation doors. As Luria so eloquently stated, our mental life, which is our cognitive experience, is shaped by social history and practice. We are social creatures, and as such we cannot extract ourselves from the cultural influences and environments in which we live. The neurorehabilitation setting is a special and unique culture in and of itself. It is a microcosm of intersecting cultures, and we must understand that as such, neurorehabilitation service delivery requires thoughtful and intentional acknowledgment of cultural dimensions in all facets of care. Such acknowledgment should lead to actionable practices that ultimately maximize the effectiveness of neurorehabilitation processes (e.g., team functioning, culturally shaped rehabilitation therapies) and improve the quality of life for all of those engaged in rehabilitation care.

Much has been written in the areas of multicultural and diversity issues in many areas of health care provision, and studies exist that demonstrate health care disparities in ethnic minority populations, lower socioeconomic groups of individuals, and many groups who have experienced discrimination and stigma by group membership alone. Much less has been written about issues of multicultural diversity in neurorehabilitation settings. Here, we are referring to those who are engaged in rehabilitation

of primarily central nervous system disorders, across many different stages and levels of care. To this end, this book is a collection of chapters written by expert scientist-practitioners in neurorehabilitation whose work has been in settings and populations that represent a diverse population of individuals seeking improved quality of life after acquired central nervous system injury and dysfunction.

Through a dialectic among a diverse group of clinicians, researchers, survivors of central nervous system injury, and their loved ones, we can move our knowledge forward toward more effective delivery of neurorehabilitation services. I hope this book can be a catalyst to such a dialectic. In this book, considerations of race and ethnicity, disability culture, military and veteran culture, and cultural aspects of religiousness and spirituality are all considered. The authors in this book wrote from their own perspectives as clinicians and researchers, representing diverse cultural backgrounds and neurorehabilitation contexts and roles. Hopefully, this book will generate more discussion, research, and literature on multicultural neurorehabilitation.

This project began several years ago, and it was originally meant to be a coauthored book with my good friend and colleague in rehabilitation neuropsychology, Dr. Tony Wong (Department of Physical Medicine and Rehabilitation at the University of Rochester Medical Center and Director of Neuropsychology at the Unity Health System in Rochester, New York), who tragically passed away suddenly in April 2011. His passing was a substantial loss to the field of cross-cultural neuropsychology and to neurorehabilitation.

Dr. Wong deeply appreciated within-culture variation in neuropsychology and balancing this with cross-cultural considerations. Once, at a national neuropsychology conference, an audience member questioned some assertions about testing individuals from a nonmajority culture that had been made during a symposium on cross-cultural neuropsychology. Dr. Wong’s response was thoughtful and respectful. He provided information on the available science in cross-cultural neuropsychology and admitted that the science was insufficient (and still is) to provide a definitive answer as to how one can interpret certain test findings in a patient from a different culture. He, however, infused the discussion with significant wisdom by stating that neuropsychology is always a clinical endeavor, requiring the clinician to not only be aware of potential cultural considerations but to proceed forward with the best one can do under those circumstances, knowing that doing informed and educated clinical
work is better than doing nothing at all. He added that we cannot ignore or always have the luxury of specifically selecting those whom we evaluate and treat, many of whom will represent a wide diversity of cultures.

Dr. Wong and I had many conversations about the vision for this book, and we agreed that it should be a scholarly yet practically oriented book—something that clinicians, researchers, administrators, and policy makers could embrace. This book is therefore dedicated to Dr. Wong and his much too short career of scholarly inquiry. Sadly, we do not have any of Dr. Wong’s written thoughts that were to be a part of this book, but I truly hope that we embody his spirit of empathic clinical concern and innovative academic inquiry and, in doing so, honor his legacy in the area of multicultural neurorehabilitation.

Jay M. Uomoto
PART ONE

DIVERSITY AND THE WIDER CONTEXT OF MULTICULTURAL NEUROREHABILITATION
It is important to have a thorough understanding of the neuroepidemiology of central nervous system disorders to incorporate cultural diversity into the neurorehabilitation care of patients with these disorders. An awareness of the incidence and prevalence rates of neurological disorders and syndromes, and the potential disparities that exist in delivering such neurorehabilitation care, is vital to tailoring culturally competent care to each individual. It can be difficult to obtain representative data from large epidemiological studies that reflect the rates of these disorders among the array of cultural groups beyond ethnicity, age, and socioeconomic status. This chapter emphasizes traumatic brain injury and stroke—two of the most common neurological disorders seen in neurorehabilitation facilities and services—to narrow the scope of our discussion.

To address the preceding issues, we begin by reviewing existing neuroepidemiological studies that include representative samples of individuals from different cultures. Because many of these studies were not conducted to explicitly examine cultural differences in the incidence and prevalence rates of neurological disorders, the data compiled are not terribly helpful to our discussion. Only more recently have efforts been made to specifically define the population to better determine cultural differences.

Figure 1.1 shows how many articles appeared in PubMed on the subjects epidemiology and traumatic brain injury between 1964 and 2014. As with many areas of study, the number of articles about these topics increased
considerably over the past 5 to 10 years. The earliest article about traumatic brain injury epidemiology was published in approximately 1963.

Figure 1.2 shows the number of articles on epidemiology and stroke that appeared in PubMed during the same years. Again, much more literature on stroke epidemiology has been written over the past few years, and it is very likely that these studies include data about racial and ethnic minorities.

Many of the earlier articles were generally categorized under epidemiology. What we know today as a neuroepidemiological study did not truly appear in the scientific literature until the early 1970s. The study of traumatic brain injury has seen a clear evolution in the sophistication, breadth, and depth of findings concerning neuroepidemiology as it affects racial and ethnic minorities.

Figure 1.1 *Articles on epidemiology and traumatic brain injury published from 1964 to 2014.*

Source: PubMed.
London (1967) conducted one of the earliest studies on the incidence of traumatic brain injury, in which he examined the clinical outcomes of patients with severe head injuries who had been admitted to Birmingham Accident Hospital in the United Kingdom between 1957 and 1961. The study examined the relationship between the duration of loss of consciousness and the level of disability based on the ability to return to work, which was categorized as “normal,” “easier,” “home care,” and “special care.” Based on the admission rates at the hospital, London was also able
to estimate the national disability rate. The study found that every year approximately 1,000 individuals suffered a severe head injury, and about 50% of them would “never work again” (p. 473). London also reported on the problems these individuals had finding appropriate rehabilitation services. He found that a certain stigma was associated with receiving services with other categories of patients, noting that they may be “understandably reluctant to seem to be classed with, say, spastic or mentally defective persons” (p. 476). He also found that some rehabilitation centers were reluctant to admit patients who had a poor prognosis.

These results suggest a cultural bias against patients with severe head injuries in obtaining rehabilitation services. In addition, the patients feel they are being discriminated against because they are treated the same as individuals with mental disabilities. It is interesting to note that neurorehabilitation facilities and programs have faced very similar dilemmas in attempting to deliver culturally relevant services.

Cultural variables other than gender have not been widely addressed in the early neuroepidemiological literature in the United States. The earliest epidemiological study of traumatic brain injury in the United States was conducted in Olmsted County, Minnesota, by the Mayo Clinic. It involved 3,587 cases of injury that occurred between 1935 and 1974 (Annegers, Grabow, Kurland, & Laws, 1980). This was likely the first report involving the well-known high rate of incidence in the age 15 to 24 cohort in males. No studies involving race or other common cultural categories (e.g., socioeconomic status) were conducted.

In 1974, the National Institute of Neurological and Communication Disorders and Stroke (NINCDS) initiated the National Head and Spinal Cord Injury Survey, which sampled those who were hospitalized for head injury (excluding those with mild traumatic brain injury) between 1970 and 1974. The survey used a sophisticated sampling strategy that included a stratified random sampling of U.S. counties with a review of hospital discharge records for making final determinations of case inclusion based on discharge diagnoses (see Levin, Benton, & Grossman, 1982, for the data generated by the survey). No mention of incidence rates broken down by race appears in summary articles of the major findings of this survey (e.g., see Anderson, Miller, & Kalsbeek, 1983), but rates of injuries, age at injury, gender, and day of the week the injury most commonly occurred were all examined. Kraus and Nourjah (1989) also did not include race and ethnicity variables in their chapter on the epidemiology of mild traumatic brain injury. Levin, Benton, and Grossman (1982) found a high occurrence
of traumatic brain injury in lower socioeconomic groups. In these groups, the injuries were most often the result of assaults, whereas in higher socioeconomic groups, the injuries were usually sports related. These findings clearly demonstrate the complex interactions between demographic and injury-related variables when examining cultural differences in neuroepidemiology.

Klauber, Barrett-Connor, Marshall, and Bowers (1981) conducted a large epidemiological study of traumatic brain injury in San Diego County, California, which is very ethnically diversified. It is not surprising, however, that neither racial nor ethnic variables were included in their study. Although they examined all deaths due to head injury and all individuals admitted to San Diego County hospitals with a diagnosis of head injury in 1978, it was not common to include race in such studies. Indeed, in 1970, U.S. Census data (U.S. Census Bureau, 1973) defined “race” only as “all persons” versus “Negro and other races.”

Kraus et al. (1984) conducted a follow-up study in which they examined new cases of traumatic brain injury in San Diego County in 1981. They pointed out shortcomings in the previous study’s case identification protocols, and they included a comprehensive profile of injury mechanisms, age distribution, and disposition after acute hospitalization. Unlike Klauber et al.’s study, they presented data on race and ethnicity. Hospital records showed that the vast majority of individuals who had sustained a traumatic brain injury were White, 12% were Hispanic, 6% were Black, and 2% were Asian. Because 1,198 of the 3,358 cases of traumatic brain injury did not indicate the race of the patient, no further analyses of race were conducted. Today, this information is always included in a patient’s records.

**RECENT INVESTIGATIONS OF TRAUMATIC BRAIN INJURY EPIDEMIOLOGY**

Today, racial breakdowns on all medical and health care topics are readily available on the Internet. For example, one can easily look up statistics on motor vehicle and motorcycle accident injury and death rates by race/ethnicity in San Diego County during a certain time period. The Health and Human Services Agency’s 2010 report (County of San Diego, Health and Human Services Agency, Emergency Medical Services, 2012) shows that motor vehicle accident injury and death rates were highest among
Blacks, followed by Hispanics, Whites, and Asians/Other, in that order. The highest injury rate from motorcycle accidents, however, was among Whites, followed, in order, by Blacks, Asians/Other, and Hispanics (rates for death were not calculated due to fewer than five occurrences in the non-White population). These data can help brain injury prevention campaigns to target information to certain sectors of the population. National surveillance data and statistics on traumatic brain injury, categorized by race and ethnicity, can be found on the Centers for Disease Control and Prevention (CDC) website (www.cdc.gov) in its *Morbidity and Mortality Weekly Report* (CDC, 2015).

More recent epidemiological evidence routinely includes race as a key categorical variable in understanding incidence rates of traumatic brain injury in a given population. Fletcher, Khalid, and Mallonee (2007) studied brain injuries sustained by Oklahoma individuals age 65 and older from 1992 to 2003. Race was parsed into White, African American, and Native American categories, appropriately reflecting some of the racial demographics of that state. Overall, incidence rates among Whites exceeded those of African Americans and Native Americans, as did the rates of intentionality, except in cases of assaults, where the rate among African Americans was three times greater than both Whites and Native Americans. The mean length of stay for hospitalizations due to traumatic brain injury was greater for African Americans than for Whites and Native Americans. These findings offer valuable information for determining why these rates vary so widely among races. It is also important to explore the different methodologies, measurement approaches, source data, and calculations of incidence and prevalence rates. According to Corrigan, Selassie, and Orman (2010), “Surveillance comes in many shapes and sizes, and the informed user must know the differences” (p. 78).

Statistics about disabilities that result from traumatic brain injury can facilitate the implementation of needed and appropriate neurorehabilitation services in general. Detailed analyses of the interactions among race, age, gender, and other socioeconomic variables can help the development of culturally relevant and effective services. The U.S. Department of Education’s National Institute on Disability and Rehabilitation Research (NIDRR) Traumatic Brain Injury Model Systems (TBIMS) research program provides a rich database (TBIMS-NDB) from which to examine such interactions on a large scale. As discussed by Corrigan et al. (2014), although a race/ethnic breakdown is included, as with many large-scale
studies of this type, representing and recruiting non-Whites can be challenging. Their database from 2001 to 2007 included 78.5% White, 9.3% African American, 7.0% Hispanic, and 5.1% Other. Since 2014, with continued enrollment in the TBIMS-NDB, however, the database consists of 19% African American, 9% Hispanic Origin, 3% Asian, 0.5% Native American, and 1% other ethnic groups (TBIMS, National Data and Statistical Center, 2014). Researchers with the TBIMS have cited some racial/ethnic disparities in outcomes, which we discuss later in this chapter.

In addition to data on incidence and prevalence rates of traumatic brain injury, information on functional outcomes based on race and ethnicity can prove important in developing strategies for resolving racial/ethnic disparities in health care. Staudenmayer, Diaz-Arrastia, de Oliveira, Gentilello, and Shafi (2007) found significant deficits in long-term functional outcomes after traumatic brain injury in minority (non-White) patients. This multicenter study through the Traumatic Brain Injury (TBI) Clinical Trials Network tracked 211 patients on the Functional Status Examination (FSE) for 6 months after they were discharged from the hospital. Grouped into categories of ethnic minority and non-Hispanic Whites, these investigators found poorer functional outcomes in the minority group in terms of being dependent on others for care across the FSE domains of standard of living, leisure, and work or school. The data gathered did not allow for a more in-depth understanding of the reasons for poorer social reintegration and lower standard of living compared to the non-Hispanic White group, and they concluded that further study was needed to “determine causes of these disparities, and to identify potential remedies to minimize this ethnic divide” (p. 1369). Also, it is important to consider that variables such as insurance coverage, local access to services, and availability of family and community supports can influence these outcomes. This has been found to be the case in examining racial disparities in health outcomes in those with spinal cord injury (Krause, Broderick, Saladin, & Broyles, 2006), where education (in years) and household income mediated the relationship between race and health. Rath (2014) summed up this point well when he stated that disparities in health care outcomes in those with cognitive disabilities occur also within the context of “patients and families from low SES [socioeconomic status] backgrounds [who are] already less likely to have insurance, stable housing, and transportation, and are at risk for poor outcomes following cognitive disability.”
NEUROEPIDEMIOLOGY OF STROKE

According to the American Heart Association, stroke was the fifth leading cause of death in the United States in 2009 (Kochaneck, Murphy, Xu, & Arias, 2011) and a leading cause of long-term disability (Go et al., 2014). In 2010, the total cost of treatment for cardiovascular disease and stroke was estimated to be around $315.4 billion in the United States alone (Go et al., 2014). Potential risk factors for stroke identified in the literature include those related to lifestyle, medical history, and social factors, such as older age, hypertension, diabetes, hypercholesterolemia, atrial fibrillation, diet, obesity, smoking, amount of physical activity, region of residence in the United States, and lower socioeconomic status (Addo et al., 2012; Go et al., 2014; Obisesan, Vargas, & Gillum, 2000). Additionally, membership of certain ethnic groups has also been associated with greater risk for stroke, which we discuss later in this chapter.

Much like early studies of traumatic brain injury, race was seldom included or only categorized participants as African American/non-White or White. In a Nationwide Cerebrovascular Disease Mortality Study of stroke incidence, mortality, and clinical data, only White male and White female subjects were included (Kuller et al., 1970). As the stroke epidemiology literature grew, it became more apparent that there were stark differences in stroke incidence by race. Wylie (1970) described differences in age-adjusted incidence for Whites and non-Whites from 1949 to 1967 in his review of mortality statistics from cerebrovascular disease. He found that the rate of death was higher for non-Whites and speculated that this was due to higher hypertension rates and other factors, such as lower socioeconomic status, limited access to medical care, and “life stresses.”

Ahmed et al. (1988) examined stroke mortality between 1971 and 1980 in two hospitals in Allegheny County, Pennsylvania. This included incidence data by race, which was grouped by White, Black, or “unknown” membership. They found that after adjusting for age, African American patients had a higher rate of mortality from stroke compared to White patients. Sacco (1995) and Sacco et al. (1998) also found greater prevalence of stroke in minority groups compared to Whites for those living in New York City. African Americans and Hispanics were found to have 2.4 and 2 times greater risk, respectively, compared to Whites (Sacco et al., 1998). In their review of the literature on stroke incidence published between 1995 and 2003, Stansbury, Jia, Williams, Vogel, and Duncan (2005) found...
higher rates of mortality, severity of stroke, and disease burden for African Americans compared to Whites. Japanese Americans, Chinese Americans, and Filipino Americans were all found to have higher rates of hemorrhagic stroke compared to Whites (Palaniappan et al., 2010).

More recent studies have also found a higher incidence of stroke among certain minority groups. For example, the CDC (2012) reported that the age-adjusted prevalence from strokes between 2006 and 2010 was 5.5% for American Indian/Alaska Natives, 3.7% for African Americans, 2.5% for Hispanics, 2.4% for Whites, and 2.3% for Asians/Pacific Islanders.

In addition to the rates of stroke in White versus minority populations, rates among ethnic minority subgroups have also been examined. For example, Daviglus et al. (2012) found that among the more than 15,000 individuals studied in the Hispanic Community Health Study/Study of Latinos (e.g., Cuban, Dominican, Mexican, Puerto Rican, Central American, and South American), those from a Puerto Rican heritage had a higher rate of cardiovascular disease risk factors. Additionally, lower income groups and individuals who had been living in the United States for a long time also had more risk factors. This study is significant in that data on ethnic subgroups were included, which is rarely the case in larger neuroepidemiological studies.

**Moderators of Ethnic Disparities in Stroke**

As a result of this new information about the differences in the rates of cardiovascular disease and stroke between ethnic minority groups and Whites, research is now focusing on identifying factors that may moderate this relationship to inform the development of public health interventions. This is an important step, given the potential for erroneous assumptions that might arise if ethnicity is used as an epidemiological variable to the exclusion of other, potentially more salient factors. Fustinoni and Biller (2000) reported on the rates of coronary heart disease and stroke among Japanese males and Japanese American males. Although all of these men were of the same ethnic background, a significantly higher stroke rate was found among the Japanese men. The rate of coronary heart disease, however, was higher among the Japanese American men. It was believed that this was due to differences in lifestyle between Japan and the United States, such as diet (Takeya et al., 1984). Other authors, however,
have argued that using ethnicity as a variable in public health research serves a practical role. Although acknowledging the presence of confounding factors, Saposnik (2000) argues that ethnicity should be included as a variable in studies and in fact may provide important information in finding ways to reduce disease incidence in specific populations.

Potential moderating factors that have been identified in the literature include both common health conditions that may contribute to stroke (e.g., diabetes mellitus, hypertension, atrial fibrillation) and non-medical influences. Among minority groups, these include lack of education about strokes (e.g., signs of stroke, benefit of urgent care as soon as possible), lack of participation in research, cultural differences (e.g., acculturation, attitudes or beliefs), and access to health care (Cruz-Flores et al., 2011). Chong and Sacco (2005) also discuss “novel risk factors” that may contribute to stroke in young minority group members, such as illicit drug use.

Disparities in Access to Health Care in Stroke

In addition to disparities in the rate of stroke, differences in access to health care following a stroke have also been identified in minority groups versus Whites, although these findings are less robust (Stansbury et al., 2005). This is especially true of African American stroke survivors. Zweifler, Lyden, Taft, Kelly, and Rothrock (1995) found that while most Whites and Mexican Americans got medical care within 24 hours of stroke onset, only about half of African Americans did. In addition, African Americans had significantly longer emergency department wait times compared to White and Hispanic patients (Karve, Balkrishnan, Mohammad, & Levine, 2011).

The results of research on acute length of stay, use of diagnostic imaging procedures, and use of postacute rehabilitation have been variable (Stansbury et al., 2005). For example, in an analysis of 10 large studies, Ellis, Breland, and Egede (2008) found that minority group members were more likely to participate in rehabilitation and to stay longer in rehabilitation facilities. The results were more variable, however, when the use of specific rehabilitation therapies was examined, with some studies demonstrating less outpatient services for minority group members and others greater use of these postacute services (Cruz-Flores et al., 2011). Additionally, Ng, Brotmas, Lau, and Young (2012) found that ethnicity
was not related to increased mortality from a myocardial infarction and coronary artery event. Instead, insurance status (privately insured versus underinsured) and socioeconomic status were significant factors in their prospective cohort study of patients who suffered a cardiovascular event in the Maryland hospitals included in their database.

**Disparities in Functional Outcomes in Stroke**

Studies examining disparities in functional outcomes after stroke have also been variable. Roth et al. (2011) interviewed and evaluated stroke patients and their family caregivers for 1 year after the stroke. They found that even after controlling for age, education, and whether the patient resided with the caregiver, African American patients had greater deficits in activities of daily living and in instrumental activities of daily living, including mobility, hand functioning, social participation, memory, and Mini Mental State Examination scores compared to Whites. However, with regard to return to work after the stroke, a study that covered the years 1968 to 1973 found that Whites returned to work sooner than African Americans, but more recent studies found no significant difference (Stansbury et al., 2005). In their examination of the influence of stroke location on return to work following ischemic stroke, Wozniak et al. (1999) did not find that race, among other factors, predicted return to work within 1 year for those who were working full time at the time of their stroke. It should be noted, however, that in this study, race consisted of only White and non-White, with the latter group mostly African Americans.

Overall, the neuroepidemiologies of traumatic brain injury and stroke are quite similar, and the scientific literature has reported similar findings in terms of racial and ethnic disparities. Of particular concern is the variability in mortality rates by race/ethnicity after stroke, which highlights the need for addressing disparities in neurorehabilitation care.

**Racial Disparities in Neurorehabilitation Care**

Racial disparities exist across the health care spectrum and are not unique to the delivery of neurorehabilitation services. This is a serious problem in the U.S. health care system, and it has gained significant attention over
the past decade. The number of studies devoted to this issue has risen dramatically, and there is widespread debate on ways to reduce such disparities in health care delivery and outcomes. To better understand health risks in minority populations, the CDC initiated a large-scale annual survey called the Racial and Ethnic Approaches to Community Health Across the U.S. (REACH U.S.; Liao et al., 2011). In this survey, 28 racial/ethnic communities across 17 states used multiple evaluation methodologies (telephone calls, questionnaires, in-person interviews) to interview residents of different ethnicities about their experiences with the health care system. While the conclusions of the survey are beyond the scope of this book, it is worth noting that barriers to adequate health care, lower socioeconomic status, and greater health risks and disease burden, compared to the general population, were reported.

Racial and Ethnic Disparities in U.S. Health Care

As noted earlier, race or ethnicity variables alone do not explain racial/ethnic disparities in health care or neurorehabilitation care. However, a report by the Institute of Medicine (IOM; 2002) stated that even controlling for variables such as insurance coverage and ability to pay, disparities continue in health care for ethnic minorities. According to the report, “social stereotypes” (p. 4) regarding race and ethnicity (e.g., the quiet and compliant Japanese American) can not only influence the patient–provider interpersonal relationship (thus affecting clinical outcomes) but also can reinforce stereotypes that may persist across clinical encounters. This is an example of how epidemiological or research study information about cultural differences relating to a particular medical condition is not enough to guide clinical practice. For example, just because a certain group of Hispanics is found to have a higher risk of cerebrovascular disease, that may not be a sufficient reason to guide clinical practice based on this one group. Stereotypes can have the effect of erroneously simplifying one variable out of the vast array of complex demographic and economic variables that may play equal or significant roles in the genesis and treatment of a cerebrovascular condition. The IOM report also mentions “health care provider prejudice and bias” (p. 4), where medical personnel may have personal prejudices against certain ethnic groups. While this may not always be openly expressed, microaggressions (see Chapter 10)
may arise during the patient–provider relationship. The IOM report goes on to state:

While there is no direct evidence that provider biases affect the quality of care for minority patients, research suggests that health care providers’ diagnostic and treatment decisions, as well as their feelings about patients, are influenced by patients’ race or ethnicity. (p. 4)

Of further concern is the issue of “patient response” (p. 5), where a provider finds it difficult to offer care to a patient who expresses distrust and is uncooperative about treatment. If a patient had a bad experience with medical treatment in the past, it can influence his or her feelings about the current situation. The issue of prior racial discrimination resulting in distrust of the health care system was highlighted in a study by Armstrong et al. (2013). In their survey, African American and White adults were administered a questionnaire that measures health system distrust and prior experiences of discrimination where the two variables were strongly correlated, despite adjusting for sociodemographic and residential segregation. Using a mediational model, Armstrong et al. found that distrust of the health care system was lower in the African American group than in the White group. This underscores the importance of considering preformed attitudes toward the health care system when developing care for ethnic minorities.

The neuroepidemiological literature cannot address all such problems in patient–provider clinical encounters, although such information is clearly relevant when identifying particular health risk groups and planning interventions. It may be that at the intervention level, more work is needed to identify mechanisms in which racial and ethnic disparities impact the delivery and receipt of health care and, in this context, neurorehabilitation care at the patient–provider or patient–interdisciplinary team level.

Emic and Etic Sources of Disparities in the Neurorehabilitation Setting

Recent literature has underscored racial and ethnic disparities in neurorehabilitation services for those with neurological disorders. Simpson, Mohr, and Redman (2000) conducted a study in which qualitative information was gathered through semistructured interviews of Italian,
Arabic, and Vietnamese patients and family members in a brain injury rehabilitation unit. Common themes among respondents included a variety of conceptualizations of the characteristics of brain injuries and praise for the health care staff. Common complaints included frequent staff turnover, limited access to doctors, and staff not being available during scheduled appointments. These responses are representative of etic (i.e., more universal experiences across cultures) elements of experiences with brain injury rehabilitation participation and do not represent unique cultural perceptions. These findings, however, also underscore more emic (i.e., the perspective of the individual within a specific cultural or social group) elements of their cultural experiences with rehabilitation. Many considered the social worker’s questions to be intrusive. Some cultures consider family or lifestyle information to be private and not open to public scrutiny. Although the stigma and social isolation an individual with a brain injury may feel are not emic aspects of neurorehabilitation care, some participants expressed discomfort with being labeled. In this study, one Arabic respondent objected to the term brain injury. A Vietnamese respondent felt that having a brain injury brought shame to his family, which is consistent with what many Asian cultures believe. Therefore, it is important to include both etic and emic aspects of neurorehabilitation care when it involves individuals of minority cultures.

These concerns also apply to cases where the brain injury causes other disabilities, such as physical disfigurement, amputation, dysarthria, or decreased social cognition. Such disabilities can also make both an individual and his or her family feel stigmatized. The following case study illustrates some emic and etic aspects of neurorehabilitation.

**Case Vignette:** Eric is a 19-year-old Chinese male who was born and raised in Hong Kong. He and his brother have been attending a U.S. university. One night, after Eric had been drinking during a party at his dorm, he and his brother were driving on the freeway when their car struck another vehicle. Eric sustained a severe traumatic brain injury and was in a coma for 3 days. He was eventually transferred to the neurological ICU, where he was placed on a ventilator. Eric’s brother sustained upper extremity fractures, but he was released after 2 days in the hospital. The boys’ parents flew to the United States and visited Eric in the ICU every day. Neither parent spoke English, but Eric’s father was highly involved in making decisions about Eric’s care. After emerging from the coma and being
weaned off the ventilator, Eric was transferred to the acute neurorehabilitation unit. A telephone translation service was offered, but Eric’s parents refused, preferring and expecting Eric to translate despite his severe brain injury. The rehabilitation staff expressed frustration with this situation, as well as with what they perceived as Eric’s mother’s “passive” attitude toward the rehabilitation. His mother often showed little interest in Eric’s physical therapy, and his father only seemed to be interested in how soon Eric would be able to go back to school to complete his studies.

This case highlights the many difficulties that can arise as a result of cultural attitudes. Having to use a translator meant that personal information would have to be revealed to a “stranger,” which may be an emic preference by the parents. Eric’s father’s reaction could be interpreted as one of a “typical” traditional Asian parent who had high expectations for his firstborn son. This could be considered emic as well. However, it is just as possible that Eric’s father was finding it difficult to accept that his son had sustained a serious cognitive disability. He may have found it too difficult to admit that Eric would possibly never be able to achieve his goal of getting a college degree. This would be an understandable etic (i.e., toward a more universal) perspective taken by a grieving and suffering father. Therefore, it is a mistake to look at this case strictly in terms of Asian emic aspects and/or etic elements of the experience of neurorehabilitation. Social stereotypes of Asians could make the rehabilitation staff misjudge the parents’ participation in the rehabilitation process and could lead to ongoing health care provider bias in the future. The patient’s or family’s response to these interactions might be a result of overgeneralizing what “mainstream” American rehabilitation is all about. The neuroepidemiological literature on racial and ethnic disparities in neurorehabilitation is still emerging, but some key findings should inform specific case conceptualizations.

**Disparities in Outcomes**

The question of racial and ethnic disparities in outcomes after traumatic brain injury has recently been well documented. Much of this information comes from the aforementioned NIDRR TBI Model Systems research (Arango-Lasprilla et al., 2007). Ethnic minorities (classified as self-identified African American and Hispanic) sustained traumatic brain injury from acts
of violence four times as often as Whites. Minority rating of functional status as measured by the Disability Rating Scale and the Functional Independence Measure was lower than Whites at discharge from inpatient rehabilitation, and this difference was sustained after 1 year. In another TBI Model Systems study, Perrin et al. (2014) found African Americans who sustained traumatic brain injury had elevated scores for depression at 1 and 2 year follow-ups compared to Whites. Depression among Asian/Pacific Islanders was also found to be elevated over the same time span whereas it decreased among Hispanics even more than among Whites. One year after the injury, it was found that African Americans had lower self-reported life satisfaction compared to Whites and Asian/Pacific Islanders (Arango-Lasprilla et al., 2009). In a review of the literature on racial and ethnic differences in traumatic brain injury outcomes, Gary, Arango-Lasprilla, and Stevens (2009) concluded that “after controlling for demographic and injury characteristics, discrepant postinjury outcomes are prevalent among African Americans and Hispanics with [traumatic brain injury] compared to Whites” (p. 787).

In examining differential rates of discharge after traumatic brain injury care in an Oregon group, Kane, Wright, Fu, and Carlson (2014) found that Hispanics were sent to posthospital care at a significantly lower rate than African Americans, non-Hispanic others, and Whites, after controlling for a set of demographic, injury, and insurance variables. As might be expected, those without insurance were less likely to be discharged to posthospital care. Similarly, African American and Hispanic individuals with traumatic brain injury were shown (through examination of the National Trauma Data Bank) to be less likely to receive acute neurorehabilitation services compare to Whites (Meagher, Beadles, Doorey, & Charles, 2014). In summarizing the literature on racial and ethnic disparities in outcomes after brain injury, Arango-Lasprilla and Kreutzer (2010) find the preponderance of evidence quite sobering. Their review suggests poorer treatment outcomes of ethnic minorities compared to Whites, poorer neuropsychological outcomes, poorer employment outcomes, poorer everyday functioning outcomes, poorer community reintegration outcomes, more marital instability, more psychological and neurobehavioral problems, and poorer overall quality of life experienced by ethnic minorities compared to Whites. They point out that “researchers and clinicians need to understand the linguistic, economic, and social barriers that individuals from different cultures face, preventing their access to health care and rehabilitation services” (p. 134).
CONCLUSIONS

The neuroepidemiological evidence continues to mount with generally consistent findings regarding the racial and ethnic disparities that exist in accessing neurorehabilitation care and functional outcomes for those who have sustained neurological disorders such as traumatic brain injury and stroke. As large-scale epidemiological studies increasingly include and distinguish individuals of color and linguistic minorities together with religion, sexual orientation, physical disabilities, place of residence, and key socioeconomic variables that interact with race/ethnicity, more information will be available to make changes in policy, training, and clinical service delivery. As the field advances, more specific clinical practice guidelines will be developed. The following are some recommendations for what we can do now:

1. Awareness of racial and ethnic disparities in the context of neurorehabilitation care should alert researchers, health care organizations, policy makers, and clinicians that disparities in other cultural groups may be suspected. As noted earlier, many other cultural groups may also experience disparities in their attempts to get neurorehabilitation care and the quality of the care they receive.

2. Studies of racial/ethnic disparities in neurorehabilitation should delineate key interactive variables that may account for cultural disparities. Current research has come a long way in breaking down racial and ethnic variables, but these are clearly difficult studies to carry out, especially on a larger scale. Thus, a continued call for funding priorities that are inclusive of an array of cultural experiences would be beneficial to advance the science in this area.

3. Research has resulted in actionable health care administration policies and clinical guidelines. Caregivers must be aware that different racial/ethnic groups can have different risks (e.g., increased rate of depression after discharge from the hospital in African Americans) and that other dynamics may also impact a patient’s recovery (e.g., access to social support, additional medical conditions that may increase depression). There must be a balance between considering emic contributors and overgeneralizing research findings that may not be relevant to a cultural group, thus running the risk of a stereotyping.
4. Clinical researchers should be encouraged to use comparative effective research designs, as suggested by the Agency for Healthcare Research and Quality (2015). A more rapid deployment of tested clinical interventions to key stakeholders is a critical element in comparative effectiveness research. This also includes dissemination of findings and reaching out to stakeholders (an active outreach approach) to effect the implementation of findings.

5. According to Arango-Lasprilla and Kreutzer (2010), rehabilitation providers should seek out input and perspectives from diverse cultural groups. Listening to patient’s perspectives and their personal experiences with having a neurological disorder or caring for someone with a neurological disorder can help design individualized care. Surveys may not always provide this information, so it is important to give different cultural groups the opportunity to talk about their experiences.

REFERENCES


