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Aging and the Behavioral Problems of Brain Injury

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Case Study

Aging and the Behavioral Problems of Brain Injury

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Educational Objectives

1. List the various classes of brain injury.
2. Identify cognitive and emotional problems as among the most common and disabling complications of brain injury.
3. Assess challenges to successful aging with a brain injury.
4. Examine the consequences of inadequate systems of care for the challenging behaviors produced by brain injury.

Background

Within the global aging phenomenon there is a dramatic expansion of persons aging with disabilities, many of whom will live well past the age of 65. Unfortunately, the care of persons with disabilities often focuses on the disability itself, without an emphasis on other

factors that promote successful aging, such as adequate social supports, environmental enrichment, wellness programs, and chronic disease screening (Aravich and McDonnell, 2005; Surgeon General, 2005). Consequently, the Surgeon General (2005) has sounded a call to action to address this unmet need for continuity of care, health disparities, and wellness programs. This call stresses replacing the “illness” model of disability with a more holistic person-centered approach that goes well beyond the disability and embraces a broader biopsychosocial view of the individual. This includes accommodations related to housing, transportation, assistive technologies, social supports, and more. Clearly, there are significant challenges in promoting successful aging in persons with disabilities. Just as clearly, there are significant consequences for failing to do so. Adults with brain injuries would greatly benefit from this more holistic approach.

Classes of Brain Injury

There are typically three main classes of brain injuries: developmental, acquired, and degenerative.

Developmental brain injuries include cerebral palsy, Fragile X syndrome, and trisomy 21 (Down syndrome). Acquired brain injuries (ABI) include injuries secondary to, among other things, oxygen deficiency (e.g., cardiac arrest), metabolic insult (e.g., liver failure), infections (e.g., meningitis), and brain tumors. However, stroke and traumatic brain injury (TBI) are the most common causes of ABI, with more than 250,000 Virginians over the age of 18 living with their consequences. The third class of brain injuries is degenerative brain injuries, which include Alzheimer’s disease and Parkinson’s disease. Increasingly, two additional classes of brain injury are defined because of underlying biological pathologies: mental illness and substance-related disorders. Collectively these various classes of brain injury are a major cause of disability in non-institutionalized Americans over the age of 18.

Cognitive and Emotional Problems

Cognitive and emotional problems are among the most prevalent and disabling complications of any

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form of brain injury. Individuals who lack cognitive capacity require surrogate decision-makers. In Virginia, court-appointed public guardians are the guardians of last resort and serve over 600 incapacitated adults who are both indigent and have no one to take care of them; an estimated 1400 additional people are in need of public guardians. Most of the adults in the program (about 2/3) are under the age of 60 and diagnosed with developmental brain injuries. Many of these individuals will live well past the age of 65.

Challenging behaviors are the most problematic complications of the cognitive and emotional consequences of brain injury. While extremely challenging behaviors occur in a minority of persons, they are an immense source of suffering, caregiver stress, and institutional difficulties. One cannot overstate the implications for geriatrics and gerontology of the rapid expansion of persons aging with the behavioral complications of the various forms of brain injury. The issue of TBI provides a case in point. Because of advances in emergency medicine and surgical care, countless individuals are alive today who would have otherwise died. These include children who suffered accidents, as well as veterans returning from the war on terrorism. Indeed, the signature injuries from this war are TBI and post-traumatic stress disorder (PTSD). Mild TBI (also known as concussion) greatly increases the risk of PTSD, which can become a lifelong disability, impairing cognitive and emotional function. Contrary to popular belief, the problems of persons with TBI do not go away when dis-

charged from the hospital; in many ways their problems are just beginning. A statewide survey of individuals living with an acquired brain injury (ABI) in Virginia found that their principal concern was the failure of health professionals to appreciate this fact.

Traumatic brain injury can produce a variety of physical complications, including those related to mobility problems and risk of falling. But TBI can produce a variety of “hidden” cognitive and emotional complications, which are called neurobehavioral problems in the ABI field (a term that we think should be replaced with the more empirical description of “behavioral complications”). A recent position paper for the Virginia Brain Injury Council concluded that there is effectively no system of care for the cognitive and emotional consequences of ABI. Individuals with these problems are often shuffled between neurologists who believe these problems are best treated by psychiatrists, and psychiatrists who believe these problems have an organic basis and are best treated by neurologists. This brain-behavior dualism relates to what others have called “a mindless neurology and a brainless psychiatry,” resulting in a tragic array: treatment providers who are not properly trained in the unique issues of ABI; institutional settings that are not designed to treat these problems and may exacerbate them; and overly restrictive pharmacological or physical environments. Persons with challenging behaviors due to the other kinds of brain injury, including Alzheimer’s disease, suffer from the same lack of expertise and care. Virginia has a number of dedicated neurobehav-

ioral facilities with nationally recognized experts and vacant beds. However, there is no Virginia Medicaid waiver to follow indigent people into these facilities. Instead, the person must first be rejected from all of the several hundred long-term care facilities in the Commonwealth before Medicaid will support treatment in an out-of-state neurobehavioral facility.

Shortage of Expertise

It is clear that we need more experts and facilities specifically dedicated to the cognitive and emotional complications of all forms of brain injury, including the behavioral complications of Alzheimer’s disease. Needs include more physicians trained in the new field of neuropsychiatry; more experts in so-called positive behavioral controls to identify the environmental triggers for challenging behaviors; better training in the unique pharmacotherapeutic approaches necessary to deal with challenging behaviors produced by the classically defined forms of brain injuries; and specialized treatment facilities, which differ significantly from skilled-nursing facilities and psychiatric hospitals.

Implications for Successful Aging

The lack of training in the post-acute complications of TBI, in particular, has a number of implications for successful aging. For instance, the single largest cause of TBI across all age groups is falls, with the number one cause of TBI deaths in older people also being falls. Older frail people as well as younger persons with disabilities are at increased risk of falls and,

therefore, at increased risk for TBI. Consequently, fall risk assessment and fall prevention strategies go well beyond the issue of fractures and are a major concern for the promotion of brain fitness and successful aging. Furthermore, it is not infrequent that an older person with cognitive impairment secondary to an undiagnosed TBI is misdiagnosed as having Alzheimer's disease. Finally, the lack of a behavioral system of care for challenging behaviors frequently results in overly restrictive interventions, the lack of transitional care, and significant caregiver and institutional stress.

Based on these considerations, it would be expected that there is a major research emphasis on the promotion of successful aging in persons with TBI and in the long-term outcomes for this population. Surprisingly, the literature shows a paucity of truly long-term studies. Those that do exist frequently define long-term as five or 10 years post-injury despite the fact that many people live multiple decades with these injuries. The issues of seizure disorders and choking hazards are clearly important in this population, but so, too, are the issues of heart disease, diabetes, Alzheimer's disease, Parkinson's disease, and depression (see Aravich and McDonnell, 2005).

For instance, a focus on the TBI at the expense of healthy eating or regular physical examinations increases the risk of various chronic diseases. There is a substantial increased risk for Parkinson's disease and Alzheimer's disease in younger people who age with moderate to severe TBI. Repeated mild

TBI in younger people is correlated with cognitive impairment in later life. Nearly half of all TBI is associated with alcohol abuse, either by the person who is injured or by the person who caused the injury. Alcohol abuse and depression are risk factors for Alzheimer's disease, as well as for TBI. Traumatic brain injury secondary to a failed suicide is highly correlated with depression. And, nearly half of all persons with Parkinson's disease suffer significant cognitive and emotional problems. The interrelationships and co-morbidities among these various forms of brain injuries demonstrate the complexity of promoting successful aging in this population and the need for multidisciplinary biopsychosocial approaches.

Case Study #1

Mr. Z, a frail, 84 year-old man living with his wife of 58 years, had mild cognitive impairment, unipolar depression, and end-stage congestive heart failure. He was diagnosed with emphysema five years ago and has PTSD related to his service in World War II. On the day before he was scheduled to have cataract surgery, he fell down the stairs. His wife did not remember how seriously he was injured but no 911 call was placed. Shortly thereafter, he began exhibiting cognitive problems and challenging behaviors, at which time he was misdiagnosed with Alzheimer's disease. The diagnosing physician did not refer the couple to the support services of the local Alzheimer's Association and of the Area Agency of Aging. Mr. Z. eventually tried to kill his wife, who called local law enforcement officials. He was

handcuffed and detained in a local mental health facility for a few weeks, after which time he was returned back to his wife. Tragically, two days later he killed her.

Case Study #2

Mr. M. is a 63 year-old Caucasian. At the age of 18 he fell asleep while driving home from his prom, suffered a severe TBI, and was in a coma for three weeks. Currently, he has a right-sided stiff knee with foot drop (commonly called a right-sided spastic gait), severe short-term memory problems, and challenging behaviors. Until six months ago, he lived with his parents, smoking two packs of cigarettes daily and sitting in front of the television. They died tragically in an automobile accident, leaving him indigent and un-befriended. He now has a court-appointed public guardian who has placed him in a long-term-care facility. Unfortunately, his challenging behaviors are so disruptive that the facility can no longer handle him. The guardianship program sought treatment in one of several specialized "neurobehavioral" treatment facilities in Virginia where there are numerous vacant beds. Unfortunately, Medicaid does not support such in-state "neurobehavioral" treatment. Following current Medicaid guidelines, the public guardian then documented that none of the nearly 300 long-term care facilities in the Commonwealth will accept him, at which time Medicaid supported his placement in a dedicated "neurobehavioral" facility in Massachusetts. That facility's neuropsychiatrist reviewed and then significantly altered his medications, for some

were actually exacerbating his problems; a psychologist specializing in the behavioral complications of ABI instituted positive behavioral controls, including a systematic identification of underlying environmental triggers. Mr. M's behavior has improved dramatically.

Case Study #3

Ms. K. is a 55 year-old African-American woman who was diagnosed with schizoaffective disorder when she was 25 years old. Two years later, she was beaten by her husband and sustained a moderate TBI. She is a highly social person who has lived alone since that time. Unfortunately, she has long struggled with serious mood swings and cognitive issues, which have put her at risk of losing her independence. Not long ago, while her out-of-state family members were considering placing her in an adult facility, Ms. K happened upon a notice in her local library announcing a meeting of a support group for brain injury survivors which was organized by the Brain Injury Association of Virginia. She reached out for help and obtained a case manager from the Association who now helps manage her life. The case manager also got her involved with a clubhouse program known as the Beacon House, which is part of the non-profit Mary Buckley Foundation and receives partial support from the Virginia Department of Rehabilitative Services. Clubhouses focus on abilities not disabilities and promote social support, skills building, and community re-integration. Virginia is a national leader in clubhouses for persons with ABI. The quality of Ms. D's life has improved dramatically. Her out-of-

state relatives are working closely with the case manager to build even more services to meet her needs. Recently, the case manager persuaded her to get her first physical examination in nearly 20 years. Breast examination revealed a lump, which was proven negative when biopsied. She was subsequently diagnosed with osteoporosis but is in otherwise excellent health and says that she is the happiest she has been in twenty years.

Conclusion

These three cases, all factual, reflect much about the current status of aging with a brain injury. While the third case is evolving positively because of appropriate case management and use of an available resource in the community, far too frequently older adults with brain injuries, whether they age with an earlier injury or suffer the injury later in life, are not so fortunate. Happy endings are few and far between. While the behavioral complications of brain injury are among its most prevalent and disabling features, there is no system of care for these complications. Because of the current healthcare reform debate and because of the Federal 2008 Mental Health Parity and Addiction Equity Act, the climate is now ripe for behavioral health reform. Neurological and psychiatric disorders account for "...more hospitalization, more long-term care, and more chronic suffering than nearly all other disorders combined" (Cowan and Kandel, 2001). Larger numbers of people aging with various forms of brain injuries will only exacerbate the complexity of these problems, posing ever more serious chal-

lenges for policy-makers, service- and health care- providers, families, and advocates.

As argued elsewhere, the lessons learned from the promotion of successful aging with one form of brain injury may be applicable to other forms of brain injury (Aravich and McDonnell, 2005). For instance, does the clubhouse model of psychosocial enrichment for persons with mental illness and ABI have applications for community dwelling persons with degenerative brain injuries? Are the lessons learned from PACE programs (Program of All Inclusive Care of the Elderly) for continuity of care in older people applicable to younger people aging with disabilities? Sadly, providers and advocacy groups for the various classes of brain injury frequently "travel in largely parallel, non-intersecting universes" and often compete with each other (Aravich and McDonnell, 2005). Successful aging of persons with brain injuries requires a genuine paradigm shift to promote more interdisciplinary training and cooperation, address the behavioral problems of brain injury, and look beyond the disability to see the whole person.

Study Questions

1. What are the various classes of brain injury that affect cognition and emotion?
2. How can successful aging be promoted in persons with brain injury?
3. Which behavioral problems are among the most common and disabling complications of brain injury and is there a system of care?

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Cowan, W.M. & Kandel, E.R. (2001). Prospects for neurology and psychiatry. *Journal of the American Medical Association*, 285(5), 594-600.

Surgeon General. (2005). The Surgeon General's call to action to improve the health and wellness of persons with disabilities. Accessed December 2009 at www.surgeongeneral.gov/library/disabilities.

Resources

Brain Injury Association of America: www.biausa.org.

HHS. Centers for Medicare and Medicaid Services. Program of All Inclusive Care for the Elderly (PACE): www.cms.hhs.gov/PACE.

IBICA. International Brain Injury Clubhouse Alliance: www.braininjuryclubhouses.net.

ICCD. International Center for Clubhouse Development: www.iccd.org.

National Alliance on Mental Illness: www.nami.org.

Office on Disability. Department of Health and Human Services: www.hhs.gov/od/topics/healthandhumanservices/healthandhumanservices.html.

About the Authors



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SGS Annual Meeting in Richmond

April 7-10, 2010

The Southern Gerontological Society (SGS) will hold its 31st Annual meeting at The Jefferson Hotel in Richmond from Wednesday, April 7th to Saturday, April 10th. The meeting theme is *Applied Gerontology as Community Engagement*.

SGS's annual meeting attracts staff from aging-related agencies, academics, policy makers, providers in health care, social services, and other direct services, and others committed to the quality of later life. The Society aims to build bridges and interconnect researchers, educators, and practitioners, with the annual meeting being a focal point for these bridges.



Dozens of sessions. Exceptional lodging rate of \$138/night for single or double. For more information about the conference visit www.southerngerontologicalsociety.org.

For more information about The Jefferson Hotel, one of the few hotels in all of North America with both Five Star and Five Diamond designation, visit www.jeffersonhotel.com.