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by Rolf B. Gainer, PhD



The Greying of Brain Injury: The realities of aging with a brain injury

Introduction

In one aspect of my work with people living with a brain injury I have the opportunity to interact and follow a group of six people for approximately 20 years. We are all in the same age group somewhere between 60 and 70 and we are all growing older together. Recently, in July, we lost Ray a few days before his 68th birthday, following a massive heart attack. Ray has been a in power chair, which he called his “Vette” ever since I met him and he had a host of long-standing medical problems which became more difficult to manage as he aged. He had diabetes, circulatory and respiratory problems, skin breakdown, digestive issues and about 5 years ago experienced problems with swallowing which required, much to disappointment, a major change in his preferred foods. Throughout the years I’ve known Ray he was always a keen observer of everything which happened around him involving his peers and staff. He was known to take the younger patients aside after a particularly upsetting episode and exert an unusual calming effect through his whispered discussion with them. We were never privy to the actual content of Ray’s counseling, but it always seemed to work. At Ray’s memorial service more

than a few of us spoke to his role in our community and continued to wonder what he actually said in his version of counseling.

Through Ray, Mary, Jonathan, Sean, Tom and Bob I’ve been assisted in my understanding of brain injury and its lifetime effects. All were injured in their late teens or by their early thirties. They had careers or were in school, a few were married or in relationships at the time of their injury. They all experienced severe brain injuries and had cognitive, physical and psychological disabilities which required extensive rehabilitation and ongoing supports. Over the course of the 20 years we’ve been together the members of this group have aged, experienced a variety of physical and cognitive problems which decreased some of their functional abilities and have gone through life changes with family relationships, including getting divorced and the death of parents. On balance, we all have needed new eyeglasses routinely and developed our share of aches and pains which we didn’t have 20 years ago. With one exception, all have had periodic hospitalizations for medical crisis events increasing in frequency over time and struggle with maintaining their health. Their paid

caregivers from our staff fill the need to provide greater physical supports, help more frequently with memory and decision making and communicating with their families. Family visits, too have changed. I know that Bob is the younger brother, yet when Bob's wife, Ginger and his older brother Gary visit, Bob looks and acts like he's at least ten years older than Gary. And recently, Bob asked Ginger in their nightly call to remind him if they spoke yesterday. They have spoken every night since I've known Bob. He still closes each conversation with "goodnight, Honey."



What do we know about brain injury and aging?

For individuals living with the effects of a brain injury we see the convergence between the disabilities acquired in their brain injury and the normal consequences associated with aging with an earlier onset of needs for more physical assistance and specialized care. Specifically, as individuals with a brain injury age they may experience: more problems with mobility due to a decrease in function; increased memory and cognitive problems; the onset of other health issues; experience a greater likelihood for depression and experience an earlier decline in independence due to increased assistance needs. Of the individuals living with the long-term effects of brain injury, 84% report a co-occurring disability. We also know that individuals who are older than 65 prior to their brain injury have a greater chance of a severe disability than a younger person. As people age the ability of person's brain to adapt to the changes created by a brain injury decline. This enhances the risk for second injuries due to falls or other mobility problems. It also means that the person's ability to successfully adjust to life changes post-injury may diminish and their needs for support may increase.

Considering brain injury as a process of changes throughout a person's life

Our optimism can prevent us from considering that brain injury has more in common with the a chronic disease than a sickness. The World Health Organization (2002) defined a chronic disease as: a permanent condition which leaves a residual disability causing a non-reversible pathological alteration and requires the special training of the person which may involve a long period of supervision, observation and care. Certainly, that fits our understanding of brain injury as opposed to the definition of a sickness which defines a time limited event from which the person returns to the prior status with minimal ongoing care following the initial intervention. So, as we look upon the issues related to aging with a brain injury we need to consider the realities associated with the process of living with a chronic set of problems in addition to the "normal" processes that are associated with growing older.

The true cost of a lifetime of disability

In a 2007 report from the Harvard Kennedy School of Public Health, Dr. Linda Blimes noted that the lifetime costs associated with a young adult with disabilities arising from a severe brain injury could exceed \$15 million. Following the initial high cost of medical rehabilitation, the study looked at the realities of the high cost of care in terms of paid caregivers, specialized equipment, housing accommodations, caregiver supports and increased costs as the person aged. The study indicates that the scope of the needs of the person increases significantly as they age with a brain injury disability. What the study did not include was the value and importance of family caregivers who make a commitment to care for a loved one. With these families I don't think we could ever accurately identify the true financial value of the services they provide or the quality of life that they create for the injured family member. Dr. Blimes study alerts us to the cost of future care and the complexity of services which will be required.

Family Caregivers and the Greying of Brain Injury

Family caregivers are a vital aspect of aging with a brain injury. The caregiver may be a parent, or a spouse, a sibling or a grandparent. The person they are caring for may be of any age from childhood to beyond the age of their caregiver. What we do know about caregivers in general is that 75% are women and 80% are not employed outside of the home. Their household incomes tend to be below the national average and, as a group; they have a higher incidence of health problems than their age-peers. In a study conducted through the Rosalyn Carter Institute, National Quality of Care Coalition (2006) caregivers rated the following challenges in terms of a family response to disability: finding information and access to financial help 36%; finding time for themselves 35%; managing challenging behaviours 31% and needing information on activities to do 27%. In terms of the psychological issues faced by caregivers, they reported that the behavioural, social, emotional and cognitive changes had a greater effect on them than the physical care needs. Similar to the studies of individuals living with the long-term effects of a brain injury, the family caregivers reported decreased personal activity outside of the

home, the impact of their loved one's physical dependence on family function and experiencing feelings of "burnout" due to increased responsibilities. In a 2003 study of family function by A. Sanders, PhD at Baylor University, families who reported a low number of unmet needs and engaged in fewer escape or avoidance activities were able to sustain their caregiver functions over a longer period of time. Also, the study identified that the family coping style and satisfaction with their social support network was a more important factor than injury severity in assessing a positive family response to disability.

Life focus changes and shifts due to disability

We all have a life plan for ourselves consisting of a career, education, personal relationships, social and recreational activities and family life which can be disrupted by a life changing event such as a brain injury. For people who have experienced a severe injury their primary social roles in the family may dramatically shift from caregiver to care recipient. They may have difficulty maintaining friendships and social activities in the community that they enjoyed prior to their injury. Some of the barriers related to aging with a brain injury include: the emergence or earlier onset of medical problems, a greater chance for depression and substance abuse; problems in maintaining appropriate and accessible housing, finding the specialized services they need in the years following rehabilitation and the stresses of living with their brain injury related disabilities.

Social Isolation and Loneliness

Two Canadian researchers, Dawson and Chipman (1994), studied the social experiences of people living with a moderate or severe brain injury in the years after their original injury. They studied the level of life satisfaction experienced by the

person; their personal care assistance requirements; the long-term likelihood of remaining employed and restrictions on socialization activities with others, including telephone contact and in-person visitation. Their research points to some of the long-term problems in living with a brain injury disability as related to the onset of social isolation and loneliness. While the proliferation of cell phone use, internet accessibility and the role of social media to maintain involvement has advanced since the early 1990's, we cannot discount the significance of social contact in helping people living with a disability to maintain a quality lifestyle. We do know from Olver's study (1996) that the likelihood of the person sustaining employment diminishes approximately 5 years post-injury and that point-in-time coincides with higher incidence rates for cognitive, emotional and behavioral changes. Work, family and social engagement are important aspects of measuring the quality of life for adults. We know that through the normal process of aging a person will experience change in these critical areas and that the advent of these changes occurs earlier for the person living with a brain injury disability.

Brain Injury, Health Disparity Issues and Wellness

Living with the long-term effects of a brain injury can have some significant health consequences for the person in the form of poorer personal health maintenance practices due to their cognitive problems and the difficulty in finding and accessing physicians and specialists with the knowledge of the age and health-related aspects of brain injury which is needed to maintain wellness. Another component of health disparity associated with brain injury is reduced health literacy or the ability of the person to respond actively to their health problems and participate in treatment by following a prescribed regime or program of care. Increased physical health issues will have a negative impact on family caregivers



and may eventually require that the person find care and housing in a long-term care facility. The long-term health problems relate to increased “vulnerability” of the person to chronic health problems and the decrease in the ability of the person to access the care they need in community settings. In a 1997 study of this problem, Gerben DeJong, PhD spoke of the person needing longer, more complicated treatment for health problems, developing new problems and requiring more specialized treatment or equipment to address their health needs with a high likelihood of poorer outcomes.

Mental health issues cannot be discounted as we look at aging with a brain injury. In a 30-year study of individuals living with brain injury which was conducted by Kaponen, et al (2002) in Finland, 61.7% of the individuals in the study experienced an Axis I (mental health) diagnosis in their lifetime and 40% had a current Axis I diagnosis at the time of the study. The most common Axis I diagnosis was Major Depressive Disorder with no difference observed over injury severity from mild to severe. 23.3% had Personality Disorders and another 18.3% had what was defined as sub-threshold disorders which involved aspects of personality and behavior change but did not fully fit the criteria for a Personality Disorder. The long term Finish results speak to the increased vulnerability to psychiatric disturbances, including substance abuse and the results resemble the studies conducted in the U.S. and Canada which noted similar mental health problems. When the studies are compared to the mental health statistics of individuals without a brain injury, the rate of mental health problems is substantially higher among people with brain injuries. Mental health is an important component of maintaining wellness.

Addressing the realities

Advances in emergency medical technology allow more people survive severe brain injuries and with that increase in survivability the population of individuals living with disabilities will increase. We are better able to treat and manage a number of age-related diseases and conditions which also has improved the lifespan expectations for people with brain injury related disabilities. What has not been fully realized is that people who are aging with a brain injury have enhanced needs for financial resources and for services and supports that will flex and increase as they grow older with their disabilities. In consideration of the required resources are basic needs like: housing; medical care; home and community-based supports and specialized caregiver resources to extend the abilities of family members to provide home-focused care. For many individuals the long-term aspect of their disability will be underfunded and the options that become available to them may be more restrictive than needed as they age.

People living with a brain injury can lead full and satisfying lives. As they age they will require more services and supports to remain independent, healthy and happy with their quality of life. We need to look at the existing portfolio of resources which are available as ask ourselves if they are adequate to meet the challenges faced by the person aging with a brain injury. Similarly, we need to consider the role of advocacy organizations like OBIA who provide education and support to caregivers and consumers and take on a leadership role with defining new initiatives needed by people with a brain injury. ♦♦♦

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