Stroke: Impact on Life and Daily Function

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Background/Nature of Illness

Although there are many resources to help us understand stroke, the experience of having a stroke involves changes to many activities in social, leisure, and work life, and the way we interact with the world. The purpose of this chapter is to describe what happens to people who have experienced a stroke, and are living with a change in daily life circumstances. This serious medical event is the fifth leading cause of death in the United States, and an American dies of stroke every 4 min (Centers for Disease Control and Prevention, 2015). However, many more people in the US survive their stroke, but live with a persistent **mind-body problem** which affects movement, sensation, thinking, and emotional aspects of their lives, and limits their activity and participation at work, at play, in the family, and as members of society. A stroke is a health "wake up call": 25 % of people who have one stroke will have another stroke within the following 5 years (National Institute of Neurological

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N.D. Chiaravalloti, Y. Goverover (eds.), *Changes in the Brain*,
DOI 10.1007/978-0-387-98188-8_5

Disorders and Stroke, 2015). However, even if stroke survivors remain healthy, their lives after stroke may be radically changed. We will approach the daily life impact of stroke by outlining the fundamental impact of stroke on our brains, bodies, and the **mind-body problems** caused by this condition.

Stroke's most characteristic effect is to disrupt the connection between what we intend to do and what we can do, separating the mind and the body. In healthy people, intentions and actions are perfectly coordinated, and performing the tasks we need in daily life seems effortless. However, with a stroke, the brain sustains damage as a result of interruption of the flow of oxygen and other nutrients to the brain. This interruption is caused by a disruption of blood flow, since it is blood that carries oxygen and nutrients to the brain tissue, and also carries away waste products. When brain cells die or are damaged as a result of this interruption in blood flow, the result is a stroke. The concept of blood flow is crucial to understanding what happens to the brain during a stroke event. An interruption of orderly blood flow can either be caused by blood bursting through the wall of a vessel (a hemorrhage), or blood vessel blockage, by a clot or piece of fatty tissue (ischemic stroke). The treatment for stroke can be viewed in three phases: health strategies to prevent stroke, emergency/immediate medical attention after stroke, and activities to improve the ability to function in daily tasks, work, and social roles after stroke, which continue indefinitely.

The concept of stroke as a mind-body disorder captures the essential nature of the interruption between the person's mind, which wants to act and interact with the world, and the body, which is suddenly limited. Communication signals between the mind and body are distorted and abnormal, and the mind's signals may get lost or go unanswered. Stroke survivors then may say that their memory, speech, or arm "is no longer doing what it is supposed to do."

There is an intricate and close relationship between the body's cardiovascular health (the integrity and well-being of the heart and blood vessels) and the health of the brain. Thus, there is overlap between positive actions we can do to prevent stroke, and those that help us to prevent heart attack and cancer. Making lifestyle changes to lower stroke risk can thus also lead to better general health. Excellent information can be found through the website of the American Stroke Association (www.strokeassociation.org) and the American Heart Association (www.americanheart.org). Unfortunately, only about a third of stroke survivors make changes in their level of activity (exercising for health) or diet ("heart and brain healthy"; Teo et al., 2013). This study also indicated that although personal factors can limit the ability to make lifestyle changes (willingness to change, concern about risk), external factors like the financial resources available to the person, or even to public health in that country, can also limit access to exercise resources and food options. It is beyond the scope of this chapter to discuss in detail the medical health strategies to prevent a stroke, but it is worth mentioning the factors which can make it much more likely that one person has a stroke than another person. Some of these are beyond a person's control, such as being older than 55, or having a close blood relation who has had a stroke. However, we have the power to modify some aspects of our health and lifestyle that increase risk (risk factors). These include smoking (quitting lowers stroke risk), high blood pressure and high cholesterol (taking medication and making other changes to lower these, reduces stroke risk), certain abnormal heart rhythms, diabetes, and artery disease (treatment lowers stroke risk), obesity (losing weight lowers stroke risk), and excessive use of alcohol and some street drugs such as cocaine (reducing use lowers stroke risk). Once a person has had a stroke, he or she also has a higher risk of having a second stroke. If a person has had the kind of stroke that results from a blockage of blood flow, it is particularly important for that person to be on a medication which helps to optimize blood flow or even thin the blood, to reduce the risk of another stroke. There are several appropriate choices of medication to achieve this goal (Furie et al., 2011).

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It is important to understand that health strategies have a direct impact on daily life, which may feel quite negative. Making lifestyle changes can be difficult for both stroke survivors and their families with respect to their available time and financial resources. One stroke survivor's husband told us that "Since the stroke, we have no evenings free for recreation—I take her straight to therapy or to her exercise classes after work, we eat a late dinner, and then we are so tired that we go straight to bed." Unfortunately, formal research on how the process of making lifestyle changes affects emotional stress, daily life and function is limited. Future studies are needed to specifically identify easier ways of incorporating lifestyle changes into the flow of daily life activities, reducing burden on the person with stroke and on caregivers.

The Experience: Mind-Body Problems

This section will consider and describe the symptoms, or specific impairments of body structure and function experienced as part of a stroke: the mind-body problems which people who have had a stroke deal with at the time of the event, and during recovery. These include mind-body movement problems such as paralysis, difficulty walking, stiffness which increases with movement (spasticity), phantom movement (the body perceives movement in a limb that is not actually moving), disruption in executing skilled purposeful movement (apraxia) and difficulty in accurately aiming one's movement in certain directions or into certain parts of space. We use the term "mind-body movement" problems because the mind sends a command to the body to move, but the body's response is altered. The body part no longer does what it is supposed to do. This is because the signals, electrical energy generated in the brain, which normally coordinate body movements with mental commands, are distorted and altered.

Mind-body problems can also affect the senses, and result in pain, and disruptions of one's sense of body position. For example, it can feel as if a part of the body is positioned in one way (as if one's legs are crossed), when, in reality, that body part is positioned differently (legs are actually uncrossed). As strange as it sounds, one's feeling of familiarity with one's own body can actually change—it can feel like the stroke-affected arm, hand, foot or leg "belongs to someone else." Mind-body problems can also distort the way we put together complex information our senses relate about the environment around us, so that the world appears two-dimensional instead of three-dimensional, and the position of objects is altered. As odd as this may sound, our experience of the external environment may change—for example, people or events happening on the left side may seem unimportant, or may "disappear." Pain can also result from a mind-body mismatch, and after stroke, pain problems are associated with limitations on daily life activity and participation (Miller et al., 2013).

How do these kinds of mind-body problems affect daily life? Unfortunately, there is not much research directly examining how distorted body feelings affect daily activities. It is likely that they create unwanted emotional distance between the stroke survivor and family or professional caregivers, however. When the stroke survivor describes sensations that are not consistent with reality (commenting, "a cat is sitting on my arm!" when nothing is there), family caregivers can feel alienated from the stroke survivor, isolated and helpless. Other mind-body emotional problems after stroke also present challenges. These include depression, as well as abnormal awareness. Before the stroke, the stroke survivor, like all of us, has an alarm system that keeps a running record of how well he or she is performing at the challenges of everyday life. This alarm system lets us know when we make mistakes. After a stroke, however, the alarm system in the brain can stop functioning properly, because the alarm is itself supported by the proper function of brain cells. When this happens, the survivor may think he or she is able to do things that are actually dangerous or impossible. When a stroke survivor who has not been out of bed in weeks says "I'm able to walk," it may seem like s/he does not *want* to face the truth about the stroke. However, studies have shown that this unawareness is not a choice or an act of denial—survivors are telling the truth, and simply are not aware of the limitations because their brain alarm system is not functioning: it is not signaling them that anything is wrong. In the same way, mind-body problems after stroke can cause indifference to one's situation, and a disruption of socially appropriate interactions. This happens because the brain damage that occurred during a stroke can actually affect the parts of the brain that support emotional and social function.

The alarm-system problem with awareness that a person experiences after stroke is different from psychological denial, because we can see that different problems after stroke are affected differently by unawareness. Psychological denial would be expected to affect all of the disabilities a stroke survivor feels affect his or her self-esteem and competence, but in a recent study, we demonstrated (Barrett, Galletta, Zhang, Masmela, & Adler, 2014) that stroke survivors who were unaware of their very significant difficulties managing medications, and who underestimated the amount of help they needed in this area, nonetheless were able to report their mistakes when they attempted to name pictures, and were able to report weakness caused by the stroke, very accurately. This is consistent with a brain-related alarm system problem, because alarm systems for a particular function are often maintained in brain areas closely connected to that function. Thus, a stroke survivor can have inaccurate awareness of some stroke-related problems, while being fully aware of others. In one study of people who had had a right brain stroke (affecting the left side of the body), the ability of a stroke survivor to identify his or her own errors was the most important factor predicting how well the survivor could do daily life tasks such as self-care (activities of daily living; Vossel, Weiss, Eschenbeck, & Fink, 2013).

In the following sections, we discuss the relationship between brain dysfunction resulting from stroke and its effect on (Sect. 5.2.1) movement, (Sect. 5.2.2) sensation, and (Sect. 5.2.3) emotion.

Mind-Body Problems in Movement and Mobility

Paralysis

It is commonly known that a stroke can affect the mind-body relationship governing arm and leg movements, causing paralysis. Stroke survivors may be partly or completely unable to move one arm, one leg, or both the arm and the leg, and the face may also be partly paralyzed. As stroke survivors endeavor to resume life as they once knew it, they find that the way their body carries out their mental commands has changed. Paralysis, loss of muscle and movement function in one part of the body, is a common stroke outcome. In a person who has had a stroke and who has paralysis after the stroke, the most common area of paralysis is on the side of the body opposite the stroke damage in the brain. The person's face, arm, or leg may be weak in isolation, or all of these areas may be affected together. The anatomic reason that the stroke affects the opposite side of the body is related to the way in which our body is controlled by the brain. When a person wants to move a part of the body, that desire is translated from the brain, through wiring in other areas such as the brain stem, spinal cord, peripheral nerves, and finally into the muscles, which execute the mind's commands via motion. Movement signals can be interrupted at any one of the points of transmission mentioned above, but after a stroke, the most common level of interruption is at the brain level. As a result, the mental command to move is not transmitted correctly, and the desired movements cannot be produced. The ability to use a paralyzed hand and arm, and to improve function in a paralyzed leg to stand, and to walk, is frequently a high priority to stroke survivors and their families. Recovery of paralysis can be viewed by some as the main benchmark for recovery. Rehabilitation specialists emphasize that what is critically important is the return of function (for example, driving), even if adaptations for limited movement are needed (for example, left-foot controls).

Two Methods of Rehabilitation

There are two main ways to approach the return of body movement. Both are legitimate and valuable approaches. The first approach involves an attempt to restore movement to the paralyzed part of the body by reinstating movement. This usually entails intensive practice of activities designed to maximize mobility of the paralyzed limb. Think of a musician, practicing scales over and over: basic movements or tasks are practiced intensively, in order to build the ability to move effortlessly. A very different, but no less valid strategy is compensation. In this approach, the person focuses less on restoring the movement of a paralyzed limb, and more on learning strategies or using adaptations to "work around" the weakness, for example, by using assistive devices, or by using the unaffected, "good" limbs to do what the weak body part previously was able to do. These two approaches can be used together to produce maximum recovery of function. Stroke survivors and their families may not agree on when it is the right time to abandon efforts to restore or return function. This may become a source of conflict if one party is ready to accept limitation of movement and embark on using assistive devices, or the unaffected, "good" hand to compensate, and the other party feels that this is "giving up."

Continued work toward the return of movement is not an index of internal fortitude or a measure of character. Although the integration of personal strength and determination into illness recovery is invaluable, it is a medical fact that a profound interruption in the mind-body connection, such as the one that occurs after stroke, cannot be conquered by sheer force of will (Gillen, 2015). There is a better prospect of recovery of movement when some movement is already present: a small amount of movement can be strengthened and built through guided practice. Recovery of movement after stroke in both the arms and legs begins in the large muscle groups, closest to the center of the body. Therefore, ability to shrug the shoulders and move the arm at the shoulder joint typically occurs before recovery of hand movement. Return of hand or foot movement, when it does occur, typically follows the return of movement in the shoulder or knee.

Hand movement is a particularly prized milestone of recovery, as it is so integral to daily activities. When hand movement is a problem, it may even become more prized: Jack London describes the way problems with hand movement feel in "To Build a Fire" when the main character realizes his hands are not cooperating with the commands sent by his mind (in this case due to extreme cold, not stroke). "He discovered an appreciation of his own body which he had never felt before…It fascinated him, and he grew suddenly fond of this subtle flesh of his that worked so beautifully and smoothly and delicately (London, 2007)." Hand paralysis can create huge amounts of frustration, and it limits functional abilities: intensive therapies to improve movement in the hand and arm, in turn, are associated with reports of improved participation in spiritual and religious activities, crafts, reading, work, and activities with family and friends (social participation; Wolf et al., 2008). Problems with eating, dressing, and other self-care activities encountered by a person with a paralyzed hand are not usually caused by weakness in isolation. For example, daily life problems may result from frustration experienced by the stroke survivor, who can experience very negative feelings about the body that, in turn, adversely affect self-esteem (body image; Keppel & Crowe, 2000). It is good to discuss this, very normal, frustration with therapists and others: the more this normal becomes shared among the survivor, family and rehabilitation team, the less isolated any one person will be with these feelings.

Gait (Walking)

Difficulties in walking are common as a result of the mind-body disruption after stroke. "Gait"—the effortless pattern of movements of the arms, and especially the legs, in walking—can be significantly affected by stroke. Both arm and leg movement can be altered. Observation of most people with gait dysfunction after stroke reveals some common gait patterns. A person who walks after stroke may have difficulty in producing the desired movements that make walking effortless, and may also have difficulty in balance. The specific type of difficulty a person has in walking is determined largely by which area of the brain was affected by the stroke. The most common type of walking disturbance after stroke results in a pattern of walking movements in which the person's arm bends (flexes) more than usual at the shoulder, elbow, wrist, and fingers. At the same time, the person's leg extends more than usual during walking, so that the knee stays abnormally straight and the toe points down while walking. Clenching of the fist, bending at wrist and elbow, stiffening of the knee, and pointing down of the toe are exacerbated by walking quickly. This is a direct result of yet another mind-body disruption, namely *spasticity* (see below).

Balance problems and leg coordination are both definitely an obstacle to social participation in the community (Desrosiers et al., 2006; Hamzat & Kobiri, 2008), but stroke survivors may also feel embarrassed by the need for an assistive device such as a cane, brace, or walker. These devices can seem to be an impediment to normalcy or a marker of disability to stroke survivors, and this may inhibit their participation in formerly enjoyed activities. The experience of stigma that a stroke survivor experiences based on using a mobility device may differ depending on his or her cultural background: we discuss this in more detail at the end of the chapter.

Spasticity

As noted above, walking recovery may involve both physical therapy and also the use of assistive devices such as braces, walkers, and canes. From the perspective of the treatment team of physicians and therapists, these devices are akin to eyeglasses, in that they are external devices, and they allow a person to function in a way that would not otherwise be possible. It can be useful to make a comparison to eyeglasses in discussion, because eyeglasses are an artificial, obviously external device, usually viewed as allowing function in a non-intrusive manner. Further, most people think of eyeglasses as typical, and not particularly stigmatizing. The use of walkers, canes, and braces may be temporary for some stroke survivors, and may be permanent for others. Canes, walkers, and braces do not impair recovery and are important fall-prevention tools. Although they are frequently misperceived as "slowing down" recovery, they can prevent injury that would create a very serious setback. It is not true that a leg brace "slows down" return of foot movement.

Spasticity is a velocity-dependent change in tone (Malhotra, Pandyan, Day, Jones, & Hermens, 2009; O'Dell, Lin, & Harrison, 2009). This means that the faster a joint is moved, the more resistance is encountered: the stiffer it becomes. Spasticity contributes to the mind-body disruption after stroke by impeding the movement commands that are sent from the brain to the muscles. It increases with increasing speed of movement, and frequently creates increasing problems with walking as a person recovers and walking speed increases. Spasticity can sometimes be briefly reduced by stretching the muscle, and sometimes can be treated by medications. Injection therapy can improve spasticity, but these injections need to be repeated regularly while the spasticity persists. Since spasticity is often persistent, injections may need to be scheduled every few months. It is very important that the stroke survivor undergo proper treatment of spasticity, as management can help prevent activity restriction. If a muscle is constantly contracted, the actual muscle length shortens and the limb can no longer be stretched back to a normal position, limiting walking, hand movement, bladder function, and can result in both decreased movement and pain for stroke survivors (Satkunam, 2003).

It is unfortunate that very little information is available about the emotional or personal experience of living with spasticity, and how it affects daily life. Our informal observations suggest that stroke survivors with spasticity can feel profoundly isolated, and ashamed. They may ask healthcare providers, "Have you ever seen a hand like this?" with evident self-disgust, or ask what they have done incorrectly, to cause this problem to develop. This suggests that they feel personally responsible for the symptom, which is not justified; there is no evidence suggesting that people who experience spasticity after stroke have not done the right things for themselves, or are in any way marginal compared to other stroke survivors.

Skilled, Learned, Purposeful Movement (Praxis)

Daily life is always affected when stroke causes a mind-body disturbance in executing learned, skilled, purposeful movement. People with this problem, known as ***limb apraxia*** (Barrett & Foundas, 2004), may have paralysis, but they may also have good strength and endurance. They have a specific problem with completing skilled movements that coordinate several joints and different motions over time, like those we make when we effortlessly scoop ice cream into a bowl. Limb apraxia is different from paralysis in the same way that the strength and speed of a movement is different from skill using a tool—no amount of strength or speed will make a person who has never used a paintbrush, able to create a beautiful portrait, as a trained artist can create. Losing our ability to use everyday tools, like a comb, a fork, or a baseball bat, creates challenges in daily life and in the activities we enjoy. There are subtypes of limb apraxia: slowed or clumsy movements can occur that disrupt the delicacy and accuracy of movements. There may also be difficulty in sequencing movement steps during tasks if a person has ***ideational apraxia***. For example, to brush one's teeth, one must complete several seemingly simple actions in the correct order. One must open the toothpaste, pick up the toothbrush, put toothpaste on the toothbrush, open one's mouth, and then proceed to brush each major surface of the teeth in turn, while refraining from biting down on the brush, retaining the toothpaste and saliva in the mouth, and without swallowing the toothpaste. A stroke survivor might lose this sequence, or unwanted steps could intrude: the stroke survivor might put the toothbrush in the mouth dry, bite down on it, and then let go of the toothbrush handle, retaining the brush in the mouth. Because learning skilled movements is associated with childhood, others sometimes assume the difficulties indicate a general problem with intelligence, or lost ability to make intellectual decisions. However, even a survivor with excellent thinking and memory abilities can make this kind of error if he or she has ideational apraxia. Limb apraxia is not caused by a childish emotional state, loss of impulse control or personality changes: it is the brain's inability to plan the movement that is responsible than underlying weakness, or desire to do well. When people have this problem, scientists identify disturbed function and flow of movement information in the left brain (Mohr et al., 2011).

Because skilled learned movements are so important to daily life, limb apraxia is strongly and consistently associated with disability. After stroke, the presence of limb apraxia is associated with increased caregiver burden, poorer performance of activities of daily living, increased dependency in the home setting, and problems returning to work (Barrett & Foundas, 2004). Using tools, and making skilled sequences of movements, is central to our ability to function adaptively and competently in both new and familiar environments. Limb apraxia thus presents a major obstacle to function and freedom. Of even more concern, most people with limb apraxia are unaware that they are making errors, and cannot request help and support. We will further discuss problems with unawareness, and their impact on daily life, in the sections on Mind-Body Emotional Problems, below.

Mind-Body Problems Related to Moving in Our Three-Dimensional World

Our Bodies and Space

One of the most amazing aspects of our mind-body connection is the system that automatically manages information about where our body is, and where everything in the environment around us is located, so that all of our movements are adaptive and correctly directed. We can continuously and effortlessly adjust the way we move, as we navigate a crowded, moving train to find a seat; as we exit a huge theater with a crowd while looking for a loved one we are supposed to meet; as we play sports, drive, as we play with a fast-moving toddler, protecting her from falling as she climbs the monkey bars; as we hit a line drive in a weekend game with friends; as we drive to a niece's party in a town we have never visited before. The intricate ballet of coordinated perception, memories, and action is our spatial system: the mind-body problem that makes spatial function difficult is called **spatial neglect**. In this disorder, part of the three-dimensional world becomes useless to the stroke survivor. It is as if that part of the world does not even exist. Usually, there is an obvious difference between the way the stroke survivor understands the left and the right side of the world.

The stroke survivor may completely ignore someone speaking if that person is on the "bad" side—usually the left, because right brain injury is more often the cause of this problem. We will describe, below, two different forms of spatial neglect that affect different functions. When people have trouble with *spatial-motor aiming*, their movement system is tuned lopsidedly; like a grocery cart with a stuck wheel, they keep moving in one direction, even though they want to make movements in another direction. Usually, people with spatial-motor Aiming neglect are "stuck" moving too far rightward, but sometimes after stroke people may have trouble veering leftward, as well. We describe this mind-body problem below.

Spatial neglect may also affect visual-spatial perception of the environment, or knowledge of where important landmarks are located. Visual-perceptual *spatial Where neglect* is a mind-body sensory problem that affects awareness of one side of space. Again, spatial Where neglect usually affects the left side of the world, from the perspective of the stroke survivor. Visual-spatial Where neglect is described below, under (Sect. 5.2.2) Mind-Body Sensory Problems.

Spatial-Motor "*Aiming*"*:* When stroke survivors make errors in spatial-motor "aiming," which is a form of spatial neglect (Na et al., 1998; Riestra & Barrett, 2013), they make errors because their ability to "map" and automatically compute the direction of our movements, and the "destination" to which they move the eyes, arms, legs, trunk, or whole body, is distorted. The internal gauge of the forces needed to move the body in one direction or another, can be out of balance. People with this problem may have weakness, but weakness after stroke does not cause this problem. Rather, the spatial system is giving the movement system incorrect "aiming" information, so that movements in one direction, or toward one part of space, are problematic. As we noted above, this problem is more common after a right brain stroke, which affects the left side of the body. When a stroke survivor has spatial-motor, "aiming" neglect, the survivor will have trouble turning his or her eyes and head to the left (to the side opposite the stroke). The survivor's posture will be lopsided, and s/he may lean too far to the right when sitting in a chair, work her/his way into a crooked position when lying in bed, with one foot or even leg off the bed. When that survivor moves parts of the body that are not paralyzed, like the neck or back or the unaffected, right arm, movements aimed to a particular point in space will fall too far to the right. Stroke survivors may try to put their eyeglasses on with the glasses positioned too far to the right, so that the left arm of the eyeglass frame hits the face, and when they attempt to dress or bathe, they may not move their good hand over to groom the left side of the body. The problem is not a visual input problem—aiming movements consistently swerve toward the "good" side, even with the eyes closed. Thus, when the survivor tries to stand, and is leaning too far to the right, he or she might realize that the body is not standing straight, but since he or she can only make rightward movements effectively, every attempt to correct posture is ineffective, moving the body in the wrong direction, and even eventually toppling the survivor over. These errors, which can appear clumsy or thoughtless, are the result of incorrectly aimed movements of the trunk, arm, leg, or hand. Even when people with stroke and spatial neglect can walk, they may not be able to walk straight—they may lean too far to one side even when corrected by a therapist—or they may collide with obstacles when moving in a wheelchair or while walking. This can be embarrassing for the stroke survivor and caregivers alike.

Like limb apraxia, spatial-motor "aiming" neglect is especially challenging for stroke survivors, who may be completely unaware of their movement errors. Because the body-space interaction controlling movement in our brain is designed to be effortless, our conscious minds are not easily able to monitor our spatial performance (Heilman, Watson, & Valenstein, 2011).

Social interactions also require the ability to make accurate movements in a room, behind a desk, at a dinner table, or in similar settings. If someone speaks on the left side, a stroke survivor with left-sided paralysis who has spatial-motor “aiming” neglect may turn the head and eyes in the wrong direction (toward the good side of the body). The survivor may repeatedly collide with environmental obstacles when walking or using a wheelchair; the survivor may veer or have trouble controlling steering when driving, and could lose the ability to drive safely. Family or care givers may find it very upsetting when stroke survivors fail to acknowledge they are making errors; they can feel quite isolated. Since schools and society do not emphasize non-verbal intelligence, and body-space skills, caregivers may find themselves needing to explain over and over why the stroke survivor behaves differently. Friends and family may not understand even after multiple explanations.

In fact, what the person with spatial neglect experiences may be very hard for a neurologically typical person to imagine. Again, because moving accurately and safely in the environment is something we learn to do very early in life, people around the stroke survivor may incorrectly think that the stroke survivor has lost the ability to think in an adult way, or may think that intellectual function is globally impaired.

At our rehabilitation center, we sometimes ask nurses in training, or family members of stroke survivors, to go through an exercise so that they can understand the experience of having a spatial problem. We give caregivers goggles that contain optical wedge prisms. These prisms displace and distort what they see, by displacing everything in the world to one side. We then ask them to maneuver a wheelchair or walk. When caregivers wear these prisms, they find themselves making incorrect movements; they may even feel off-balance. They can then more easily understand why people with visual-spatial problems are vulnerable to being overwhelmed by a spatially crowded environment—these survivors can have trouble seeing many things at once, or creating a visual “whole” out of “parts,” even if the environment is well organized (Kimchi, 1992; Navon, 1977). Stroke survivors with spatial “aiming” neglect may make movements that seem bizarre or immature—for example, the stroke survivor with spatial neglect may reach out to touch something that is too far away. This can affect stroke survivors even when they are capable of very sophisticated thinking and have excellent memory—aiming spatial neglect causes a disruption in the mind-body systems that match the control of movements to our three-dimensional world.

People with spatial neglect after stroke always improve as the stroke improves, but its effects on life participation may be long-lasting. When a stroke survivor has had spatial neglect in the weeks after stroke, 6 months later that survivor will report moving around in a smaller area (reduced community mobility or smaller “life-space,” (Oh-Park, Hung, Chen, & Barrett, 2014). This suggests that waiting for spatial-motor “aiming” symptoms to recover on their own, without specific treatment, is likely to put the stroke survivor at risk of social and community participation problems.

Mind-Body Problems in Perception and Sensation

Visual-Spatial, "Where" Neglect

Recovering from a stroke is rife with challenges. Just as the errors people make when they have spatial-motor "aiming" neglect can affect the way the stroke survivor moves to the left and right, spatial "where" neglect affects the ability to perceive the left and right side of the world we live in, and to be aware of new and relevant events. Spatial "where" neglect, unlike spatial-motor aiming, is especially noticeable in the way the stroke survivor deals with visual information. Spatial Where neglect is not vision loss—the survivor can usually see, hear and feel on the affected side of space at least a little, and the areas of the brain where the sensation comes in register the information, but the information is not processed normally. Like spatial-motor aiming neglect, visual-spatial where neglect is most common in stroke survivors who suffer a stroke on the right side of their brain, with left-sided paralysis. Unfortunately, most clinicians do not look for this hidden disability, and its assessment is frequently left out of the examination and clinical care documentation (Chen, McKenna, Kutlik, & Frisina, 2013). Hidden disabilities can definitely alter life social context, and others may confuse these mind-body problems with limited intelligence or motivation. Stroke survivors and their families may feel poorly prepared to deal with these reactions of others as they return to work and community (Stone, 2005).

People who have "where" neglect, even after a mild stroke, are in a sense experiencing a kind of blindness. However, people with this type of neglect can see objects; they can recognize them and identify colors, shapes and letters, even small ones, as they did before the stroke. The problems occur depending on *the location of the event in the space around the body*—people with "where" neglect do not notice important things on the side of their body opposite the stroke. So, for example, if a new person comes into the room from their left side, a person with visual-spatial "where" neglect may not see that person at all. Left-sided objects may be ignored: a stroke survivor might complain that there is nothing to drink with her meal, when a glass of water stands just to the left of her plate. This can be frustrating; caregivers can feel that the survivor is "demanding" or "careless" because further cues were needed: the caregiver might not realize that the water glass is simply not there, from the stroke survivor's perspective. Objects can also appear displaced to the right; people with "where" neglect might search over to the right side for objects, people, or landmarks that are actually on the left side. This can, again, look to other people as if the stroke survivor is confused, or distracted. We have observed "where" neglect to be very dangerous, because safety problems on the left side—a hot water tap left on, for example—may not be noticeable, and the stroke survivor could put his hand right under the stream of water, burning himself. Other common dangers include wheelchair, walking, or driving collisions with left-sided obstacles. Falls (more than six times more common in people with spatial neglect; Chen, Hreha, Kong, & Barrett, 2015), cooking-related injuries, oncoming traffic, and safety issues may occur in people with "where" neglect, because these stroke survivors may make errors when circumstances require rapid responses during childcare or work.

The visual problems of where spatial neglect affect visual information we keep in our minds for reference, as well as new, incoming visual information. These survivors might not be able to use spatial cues to remember the location of their personal belongings, or to interpret a map, and they may get lost easily even in their own house, driveway, or neighborhood. As we noted previously, survivors with spatial problems have a restricted “life space”—a smaller area outside the house and in the community where they move on a daily basis—compared with stroke survivors who have typical spatial function (Oh-Park et al., 2014). Stroke survivors may feel very discouraged by new limits on their community mobility, but may be too embarrassed to share their feelings with their caregivers or articulate the difficulty.

Some people with right brain stroke and spatial neglect may not be able to read, because they do not scan to the beginning of each line. Because they do not look far enough leftward, these stroke survivors do not see the left side, of a page or even of a word. The stroke survivor, looking at the word “backpack,” might read “pack.” One caregiver shared with us that since her husband’s stroke, when they go out to dinner or are in a public building, she has to accompany him to the restroom. If he goes alone, he may misread the sign “WOMEN” as “MEN,” and enter the wrong restroom—since he may only see and read the right side of the word. This need for assistance is difficult for both her and her husband to accept, since “being walked to the bathroom” is not consistent with their standard for personal autonomy and dignity.

Because visual-spatial function is normally automatic and effortless, and most people are not even aware of how and when they are exercising visual-spatial skills, spatial neglect is under-diagnosed and commonly misidentified as apathy, obstinacy or near-sightedness, which increases the burden of the mind-body disruption. Caregivers can find it very upsetting when the stroke survivor fails to greet them or respond to events in the “bad space,” usually the left space, and when the stroke survivor does not notice gestures or emotional facial expressions that happen in the “bad side” of space, because the survivor has lost the ability to focus and concentrate on that part of the external world. As we stated above, stroke survivors may not notice the things they need to see when they are eating, getting dressed, or moving around at home, and they may appear lost, confused or careless, when actually their visual-spatial system is just not giving them access to the same reality the rest of us take for granted. People with spatial neglect after stroke simply do not have the right information needed to solve many everyday problems. The visual-spatial system is intended to work without any feedback or conscious control, and so stroke survivors are usually unable to recognize their own visual-spatial errors. Thus, stroke survivors with visual-spatial difficulties usually do not know why they are making mistakes, and they will not ask for help.

An emotional rift can grow between stroke survivors and their family and caregivers because of a lack of self-awareness (also called “anosognosia,” or lack of knowledge of disease), because survivors may insist that they are functioning normally, while the family works hard to keep the environment and activities safe. Spatial “where” systems help us with information that come in through other senses, as well as visual information—the ability to hear noises on the left, and feel sensations on the left side of the body (for example, feeling pain) can be distorted and abnormal. Everyone can become frustrated, and emotional tensions and misunderstandings can interfere further with relationships. If Where neglect is mistaken for a different problem (for example, an eye problem or a hearing problem), the stroke survivor might receive unnecessary testing, treatment, medication, and equipment. Spatial neglect is extremely costly. When spatial neglect goes undetected, survivors and their families may experience unexplained complications and setbacks during recovery. "Where" spatial disability increases the risk of acute and chronic complications associated with stroke, such as hip fractures, and can result in longer hospital stays.

Identifying either "where" or "aiming," spatial-motor neglect can be challenging. However, it is very important to identify them; otherwise, the survivor might receive treatment for memory problems, concentration, or some other problem that is not the real source of errors. If the wrong treatment is received, the stroke survivor is unlikely to improve and gain independence in daily life. Be wary of the following warning signs of a possible hidden disability of spatial function: (1) Bumping into one side of the body while walking through doorways (2) Staring off in one direction (particularly toward the unaffected side of the body), or poor eye contact (3) A driving accident since the stroke. Stroke survivors might report that they feel the car is running off the road when it is moving straight, either while driving or riding as a passenger, or the survivor may show a new tendency to veer to one side when steering. (4) Trouble finding things on one side or in one place (5) Incomplete self-dressing, especially if glasses miss the ear on the side affected by stroke. (6) The survivor's body or head is turned to one side most of the time (usually toward the unaffected side of the body).

Phantom Limb and Phantom Movement

In normal mind-body communication, messages move up from the skin through nerves, spinal cord, brainstem, and into the brain where the information is analyzed and a response strategy is sent to the limb. Sometimes, this pathway generates "phantom sensations," or false signals. Many people have heard about phantom sensations occurring in an arm or leg after amputation; this symptom can also occur after stroke, affecting a paralyzed limb. Under normal conditions, body awareness is continuously updated by all of our senses working together with the signals generated when we try to make a movement (Schwoebel & Coslett, 2005). A phantom movement can be felt, if the sensory and movement signals are poorly coordinated, or the movement signals are not properly controlled. Essentially, the stroke survivor can have the strong sensation that the paralyzed or affected limb is moving, when it is not (Melzack, 1990). The survivor may insist that he or she can move a paralyzed limb; even though caregivers and family might not see any movement, the stroke survivor might feel the "phantom" movement clearly, just as movements were felt before the stroke event. The perception of a phantom movement, or a phantom limb, replaces the perception of the actual limb. Even more strange to family and caregivers, some stroke survivors may feel that they have an "extra" limb—for example, they may feel that both a paralyzed arm, and an arm that can move, are attached to the same shoulder (Bakheit & Roundhill, 2005; McGonigle et al., 2002).

Body Ownership

Another mind-body problem that can happen after stroke is the aptly named "alien hand syndrome"—one hand seems to have a "will of its own" or is "not under my control." Persons with this experience have lost function in the part of the brain that allows perception of control over actions. This is different from paralysis, and the experience can be alarming or distressing. People with stroke can be reluctant to discuss the feeling of phantom movements, or a feeling of loss of limb control, because they may not realize that these problems are part of the mind-body disruptions in movement that can happen after stroke. Stroke survivors may worry that, if they report these sensations, other people will think they are hallucinating, or delirious. Of course, phantom movements are an experience something like a kind of hallucination, but these illusions usually do not affect judgment or understanding. When we discuss these problems with survivors, we mention that these sensations are like the sensations some people experience after limb amputation. Discussing these problems with physicians, loved ones or other health care providers can often relieve anxiety and could open a path for physical therapy, reassurance, and, validation that these experiences are part of their stroke recovery. Distortion of body ownership and phantom limb movement can be thought to be a psychiatric illness by stroke survivors and family members. Screening for these problems, and educating survivors and their families that they are caused by new patterns of activity in the brain after stroke, can be very reassuring.

Pain

Pain after stroke is common, especially shoulder pain, which provides a prism through which the mind-body disruption that results in pain after stroke may be viewed. Shoulder pain affects up to 84 % of stroke survivors (Turner-Stokes & Jackson, 2002), yet it usually has a different cause than shoulder injuries due to muscle, bone and joint problems, and requires different treatments.

In the initial post-stroke period, the muscles on the side of the body affected by the stroke are loose and weak. Over time, the muscles on the side of the body affected by the stroke become tighter, and, as we discussed above, *spasticity* or abnormal tightness and contraction can occur. There are sources of pain in both of these states. Both flaccid (loose) and spastic muscle tone fails to do the muscle's job of holding the shoulder into its joint in a natural manner. The shoulder, a ball-in-socket joint, normally has a remarkable range of three hundred and sixty degrees of motion. After a stroke, the shoulder may have significantly reduced range of motion. This reduced range may become permanent if good therapy does not move the shoulder through a wide range frequently. Sticky places in the joint capsule—adhesions—will eventually restrict shoulder movement and cause pain. This condition, known as "frozen shoulder" (adhesive capsulitis) is treatable with a combination of therapy and medication, but can be prevented by therapy that moves the shoulder in a proper range.

Changes in muscle tone (both flaccid and spastic) may contribute to an incomplete dislocation (subluxation), of the upper arm bone (the humerus) from its socket in the scapula. There may be pain due to the alteration of bone position, and sensory nerve fibers translate this change in position as pain. Pain may also be due to a more central origin that is a mind-body source. A solution that frequently seems to suggest itself to family and stroke survivors is to wear a sling. It might seem that wearing a sling would prevent or improve shoulder dislocation, but this is not supported by research studies (Page & Lockwood, 2003)—we do not recommend it. The sling might actually create harm by accelerating the process of adhesive capsulitis and impeding attempts to strengthen the arm, and sensory deprivation can result from reducing the input the arm sends to the brain when it is restrained in a sling.

Another cause of pain as a result of disruption in mind-body pain pathways after stroke is complex regional pain syndrome (CRPS; Chae, 2010) In CRPS, everyday sensations such as those of clothing or something in the environment lightly touching the affected limb, suddenly become intensely painful (dysesthesia). The distorted sensations can be unbearable. Wearing clothing, or having a blanket or sheet on the area, can become intolerable. Other changes in blood flow to the limb and eventually bone changes occur in CRPS. Since CRPS becomes more difficult to treat the longer it persists, early diagnosis and treatment by a pain management specialist is essential to prevent and reduce suffering.

Post-stroke pain syndromes can have a profound effect on daily life. For example, studies indicate that pain after stroke is strongly associated with mobility limitation (O'Donnell et al., 2013; Sommerfeld & Welmer, 2012), dependence, and cognitive decline (O'Donnell et al., 2013).

Mind-Body Problems in Mood and Emotion

Depression

Stroke produces profound mind-body disruptions. Although it is a part of stroke recovery to grieve for lost abilities and expectations, 30–40 % of stroke survivors experience serious and disabling mood changes. Depression is most evident within the first 2 years after stroke (Hackett, Yapa, Parag, & Anderson, 2005), and prompt treatment is associated with better recovery of everyday abilities (Mead et al., 2012) and faster improvement in strength and movement (Chollet et al., 2011). Early treatment of stroke-related depression was actually associated with better stroke survival in one study (Mortensen, Johnsen, Larsson, & Andersen, 2015). Well-known symptoms of depression include overwhelming feelings of hopelessness, emptiness, worthlessness, social isolation, and helplessness. This is distinct from emotions stemming from adjustment to disability. The change in brain chemistry is a medical condition, adversely affects the immune system and general health, and requires treatment. Less well-recognized but significant symptoms of depression include loss of interest in activities that were once enjoyable, disruption in sleep patterns (either insomnia or oversleeping), change in appetite with weight loss (or gain), and physical symptoms such as overwhelming fatigue, decrease in energy, irritability, or other physical concerns resistant to treatment (such as gastrointestinal difficulties, headache, or generalized aching), overwhelming sense of guilt for issues beyond one's control (such as feeling personally responsible for the state of world affairs). The structural damage that occurs in the brain after stroke seems to trigger depression as a physical reaction to the stroke event, or as a reaction to neurochemical changes produced by the brain condition. More unfortunate, many stroke survivors with depression are unaware that their mood is abnormal, and even while depression is obviously limiting their ability to engage in life activities, they will deny that they are experiencing any emotional changes.

Depression after stroke results in feelings such as sadness, hopelessness, and helplessness (Brodaty, Withall, Altendorf, & Sachdev, 2007; Jaillard, Grand, Le Bas, & Hommel, 2010). Experiencing these feelings is clearly associated with worse health, social and economic problems and social isolation (Sienkiewicz-Jarosz et al., 2010). This is likely to happen because of a vicious cycle of life participation problems and adjustment issues. Depression impairs confidence, self-efficacy, and can reduce the survivors' willingness and ability to self-advocate and solve new problems creatively, accelerating losses. It can result in a reduced desire to participate in previously enjoyed social activities. Because being able to be independent, free and socially active is highly important in the US culture, loss of these abilities can further adversely affect self-esteem, adjustment, and recovery.

Initial adaptation to stroke can affect the risk of depressive symptoms that affect social participation chronically (Rochette, Bravo, Desrosiers, St-Cyr Tribble, & Bourget, 2007). Losing the ability to drive is an example of this phenomenon. Driving disability as a life problem may initially result from physical (e.g., hemiplegia) or cognitive problems (e.g., visual-spatial or concentration deficits). Many stroke survivors cannot return to driving (although some can). In people who cannot return safely to driving, disability may persist because changes in social role (dependency) and loss of initiation due to depression prevents the stroke survivor from pursuing rehabilitation, discussing return to driving with healthcare providers, or following through with driving assessment and adaptive driving recommendations. Depression, as well as the stroke itself, may directly impair cognitive functions required for safe driving including focused attention, normal processing speed, ability to plan routes, and ability to follow the plan to the destination (De las Cuevas & Sanz, 2008; Fisk, Owsley, & Mennemeier, 2002).

Survivors who cannot drive because of stroke-related impairments are dependent on others for daily errands, community gatherings, and leisure travel. This increases their risk of adjustment disorders with depressed mood. Chronically, some survivors experiencing depressed mood unfortunately choose to reduce their social activities, becoming grounded and isolated. Stroke-related problems that limit driving ability can thus become mood problems, or social participation problems.

Apathy and Motivation Problems

Living with a stroke survivor can place a strain on family, friends, and coworkers. Stroke survivors may be unaware that they have disorders such as spatial neglect, or depression, and therefore are not able to acknowledge what the family has lost, or express concern for their caregivers. In particular, a stroke affecting the right brain (left body) can make it hard to express emotion in the face and voices, and can cause a stroke survivor to lose the ability to respond automatically to others' emotions, which could make them appear insensitive or uncaring. Apathy (decreased expressed concern or self-generated reaction to people or events) and motivation problems (decreased urgency, energy or drive devoted to task completion) can occur after any kind of stroke, and may be frustrating for family members who are trying to help loved ones in the battle to recover. When the person who has suffered the stroke does not seem to want to put the best effort into rehabilitation, or continually fails to participate in the process of rehabilitation, family members can feel alienated from him or her, and immensely unhappy, resentful, and angry. Stroke survivors who have apathy or loss of motivation may also stop going to therapy or taking appropriate medications, actions that adversely affect their well-being. At times, apathy and motivation problems co-occur with problems with self-awareness. Survivors may be ***unaware*** of their problems, may appear indifferent to their illness, and may even express that they do not think they are disabled or limited (Adair & Barrett, 2011). This unawareness, or anosognosia, as we discussed above, may even cause survivors to question whether they have had a stroke or whether they have been ill. This unawareness is part of the change in their thinking and brain function caused by stroke. One of the ways that it is distinct from psychological denial is that it almost always gets better, rather than worse, as time passes and survivors are more confronted with the impact of their stroke on their life in the outside world. When a survivor has unawareness, confronting the stroke survivor with the facts he or she seems not to understand can be confusing to the stroke survivor and is probably not productive.

Many stroke survivors will not be able to participate in a conversation about whether their beliefs are logical or reasonable; a profound mind-body disconnection is responsible for their distorted self-awareness, and discussion cannot usually alter this process. Family members and caregivers do not need to pretend to accept the stroke survivor's beliefs. In a neutral way, family members can simply continue with necessary activities and routine. For example, when the caregiver says "We're going to the physical therapy gym," and the survivor responds, "I don't need physical therapy," it may be helpful if the caregiver does not specifically respond to the statement, but simply helps the survivor put on her jacket, while describing the trip, how they will get there, and what will happen afterward: "We'll get some lunch after therapy at the deli: they will probably have the chicken soup you like." It is possible that the survivor will then be able to join and participate.

As previously noted, unawareness definitely affects daily life: survivors with unawareness do less for themselves, and recover more slowly, increasing the burden of their care (Gialanella, Monguzzi, Santoro, & Rocchi, 2005; Vossel et al., 2013). Even if stroke survivors with unawareness report that they are satisfied with their lives, they may have more falls and may be at high risk of accidents because of balance problems (Dai et al., 2014).

Emotional Lability

Emotional lability refers to rapid fluctuation to emotional extremes such as laughing or crying but with little provocation (Morris, 2009). This can happen after stroke affecting either side of the brain, but may be more common after right brain (left body) events. Affected stroke survivors have a mind-body dissociation that disrupts the expressions of emotion (such as laughing or crying) from their internal state. This is called pseudobulbar affect, or sometimes may be labeled “emotional incontinence.” A sudden, surprising burst of emotional expression (laughter, bursting into tears) may happen when the stroke survivor does not feel particularly emotional. It can sometimes happen after a minimal stimulus, such as hearing the word “mother,” or seeing a Hallmark commercial, and can be quite embarrassing to the stroke survivor, and to loved ones. Medications can address this problem, and can be quite effective, but frequently stroke survivors and their families do not ask healthcare providers about this.

Social Interaction and Personality Changes

Stroke can change the way the survivor interacts with others. Our personality and individual style influences the way we assess and respond to others emotionally, and in communication, negotiation, and interaction. Stroke can change these behaviors and even create problems with accurately assessing and responding to the emotions of others. In that way, it can disrupt communication, because emotional exchange is an important part of human interaction. Stroke can also affect how much the survivor discloses: how private, or open, he or she becomes in expressing negative feelings such as anger, and expressing private thoughts or feelings, especially sexual, or physically intimate information. After stroke, about a third of stroke survivors may have difficulty censoring anger (Kim, Choi, Kwon, & Seo, 2002)—the parts of the brain that help us to “filter” what we say to others may be damaged, and this can adversely affect social participation. Personality changes after stroke are associated with reduced independence, and with caregiver depression (Stone et al., 2004). The stroke survivor who has experienced social behavior change may find it difficult to navigate working relationships of many kinds, and may experience conflicts limiting return to work and other aspects of social independence (Gehl & Paulsen, 2012).

At times, stroke survivors may touch themselves or others in a manner that is not socially acceptable. This problem may be more common after the right frontal region of the brain is damaged. For these individuals, an individualized approach led by a physician, nurse, or rehabilitation professional experienced with this problem can be very helpful (see reference (Joller et al., 2013) for a review); both behavioral learning and medication interventions are useful to re-establish boundaries on appropriate behavior. Psychological counseling for the family and caregivers may also assist in adjustment and open communication about challenges during recovery.

This section described common issues facing stroke survivors by reviewing mind-body problems affecting movement, sensation, pain, and emotional and social function. Frequently, family members, friends, coworkers, and caregivers misinterpret these changes as being the result of changes in the individual’s values, intelligence, or desire to recover, instead of recognizing them as the result of damage to the brain. This misperception adversely affects the daily life of stroke survivors, who can become isolated from their loved ones. Spatial systems in the brain assist us in “thinking with our bodies” as we perceive the environment, and move around in it; spatial Where and Aiming abilities can be profoundly abnormal after stroke, limiting the survivor’s adaptive capacity. Spatial disorders can cause stroke survivors to encounter safety risks during the simplest aspects of mobility and self-care, and experience limited community mobility. Emotional changes, and apparent personality changes can also result from specific injury to parts of the brain that control these functions.

Other Issues in Life Participation

Physical as well as cognitive consequences of stroke may alter the survivor's ability to accomplish daily activities and fulfill social roles valued by the person or socio-cultural environment. Above, we discussed stroke-related issues that are frequent after moderate–severe stroke, but even when a stroke is mild, mind-body changes can create persistent limitations in life participation (Rochette, Desrosiers, Bravo, St-Cyr-Tribble, & Bourget, 2007).

A universal problem after stroke is in managing expectations and communicating about gradual progress. During the course of stroke recovery, the brain can re-connect with the body and with the world by re-forming its idea of relationships, as when we are children we learn to understand the relationship between the right hand and left shoulder, between our feet and the floor, between what we see and what others see. Stroke survivors may encounter similar learning situations. For the stroke survivor, the re-learning experience can be stressful or frustrating because they may expect themselves to adjust immediately. They may be profoundly disappointed about the time and effort that returning to an independent life and regaining social roles requires. Learning new movement patterns is not guaranteed, even when stroke survivors exert their best efforts and receive the most intensive rehabilitation. The amount of brain affected by the stroke, the areas of the brain affected, and other medical problems may affect how survivors recover. Every stroke survivor starts with a different set of physical resources in the brain, and it is important to recognize these organic differences, so that stroke survivors do not compare themselves inappropriately to other people who also have a stroke.

Hidden disabilities, as we discussed under mind-body problems, can affect thinking and emotion after stroke. In this section, we will discuss further the impact on meaningful life activities in how the stroke survivor is able to concentrate and remember. We will also discuss the stroke survivor's speech and language; and how fatigue after stroke affects daily life.

Life Problems Related to Concentration and Memory Deficits

Concentration and memory problems are very common after stroke. In one study, 90 % of a group of stroke survivors with good recovery reported that they had thinking and memory problems, including fatigue, cognitive slowing, memory difficulties, and poor concentration (Lamb, Anderson, Saling, & Dewey, 2013). Many stroke survivors express that they feel tired easily even though they are less active physically or mentally after stroke. This feeling can be related to a reduced capacity to concentrate in order to perform daily tasks such as remembering an appointment or following a conversation. Concentration is necessary for the broader definition of memory that includes not simply storing past events or knowledge, but also picking out the specific information to be learned, paying attention to its details, retaining the information, and retrieving it when it is needed. Stroke survivors may not have difficulty remembering their own personal history in general. However, when they are retrieving details of a past event, which requires focused attention to sort through the memory, they may find this effortful, or they may not be accurate.

Learning new, detailed information, keeping it in mind for a few minutes, and calling learned information up at the moment it is needed, can be difficult after a stroke. Holding information in mind is needed for many daily tasks: for example, the survivor may have trouble making a call immediately after reading a 7-digit telephone number, and may need to recite the number several times or dial it one number at a time, as he or she reads the number over and over again. Manipulating information while holding it in mind, for example while calculating change in a store, may take longer or fail. The ability to keep a to-do list in mind may also be impaired; for example, the intention to go to the post office before going home may be easily forgotten. Stroke survivors may miss doctors' appointments, forget new friends' names, or fail to concentrate on difficult tasks. They may also have trouble tracking whether they have taken their medications, leading to double or missed medication doses (Barrett et al., 2014). Most stroke survivors recognize their attention or memory problems. Because memory problems are associated in our culture with the loss of competence, autonomy, and dignity, survivors may find these problems very stressful, frustrating, and embarrassing. Even if they are able to do what they need to do in daily life, stroke survivors may find their errors embarrassing and lose confidence and self-esteem. This may be why survivors of a mild stroke, with good recovery, report less life satisfaction if they have problems with mental organization skills (Edwards, Hahn, Baum, & Dromerick, 2006). When stroke survivors do not ask for help from healthcare providers, changes in their memory performance can be associated with problems in their jobs and social roles (Vestling, Tufvesson, & Iwarsson, 2003). Coworkers, supervisors, and even friends and family members may conclude that their thinking is "slow" or not as attentive as before, and their jobs or social roles may be threatened. Stroke survivors may feel that they themselves are defective, not their memory performance, and might feel guilty or ask for forgiveness. Even when stroke survivors are studied who lack severe cognitive issues, cognitive functional problems are associated with a poorer sense of well-being and less purpose in life after stroke (Clarke, Marshall, Black, & Colantonio, 2002).

Life Problems Related to Communication Deficits: Aphasia

Problems with communication using oral or written language is common after stroke. Usually, this is the result of a stroke that damages areas devoted to language comprehension, production or language meaning in the left side of the brain, but some people have problems understanding and using both written and spoken language after a stroke affecting the *right* side of the brain (crossed aphasia), or they may have trouble with communication after having a "mini-stroke" with little effect on other abilities.

Aphasia is a **mind-body problem** in that the language apparatus can be damaged, without affecting the intelligence, will, capability, or feelings of the person. In the same way that the internet connection for a computer can be broken, preventing someone from communicating by email, the language apparatus can malfunction, causing problems understanding or distinguishing words, whether written or spoken. In this situation the computer itself is intact, but cut off from channels customarily used for expression and connection. Sometimes, it is easier for the person with aphasia to understand written words than spoken words. It is always easier for the person with aphasia to understand if the words are presented in written form at the same time as they are heard, so that information comes in from more than one channel. It is also helpful if other information (clues) are also available—a gesture, a picture, a facial expression, or even a little drawing the communication partner might make on the spot! (Galletta & Barrett, 2014).

In real life, aphasia causes many difficulties. Communication disorders after stroke are very strongly associated with community participation problems (Ostir, Smith, Smith, & Ottenbacher, 2005). We feel that this gives rise to the worst problem in daily life that is associated with aphasia, social isolation (Dalemans, de Witte, Wade, & van den Heuvel, 2010). People may not speak directly to the person with aphasia—even though the person is standing right there. It is devastating to the self-esteem of the person with aphasia when someone they wish to communicate with, turns away and speaks to the caregiver. If you are a caregiver being asked to “translate” or “speak for” the person with aphasia, it is appropriate to encourage people to talk to the stroke survivor directly. If they speak slowly, use gestures, written words, pictures, or other aids, and check frequently to make sure everyone understands, they will show respect for the maturity and autonomy of the person with aphasia. People with aphasia want to be engaged and involved, and it may take time to find the right environment, where others are willing to make the right communication efforts. Contributing meaningfully in one activity may address social isolation more effectively than a range of activities in which they feel stigmatized or assigned a “less than” status (Dalemans et al., 2010; Sarno, 1981).

Remember that the ability to speak and communicate effortlessly is often interpreted in our society as a sign of intelligence. As a result, a person with aphasia who can still carry out his or her job well might be interpreted as being less competent; many people with aphasia report problems with working cooperatively with their employers to adjust work conditions and accommodate their needs. Reading a menu in a restaurant, reading road signs when driving, communicating with people about needs at a store, when lost, or in a public building such as a hospital, post office, or bank can be difficult. At times, others may assume that the person with aphasia is under the influence of drugs or alcohol, or has a developmental disability, and this can be very embarrassing. The National Aphasia Association (National Aphasia Association, 2014) provides palm cards and other materials that can be helpful in advising strangers that the barrier is a communication problem, so that they will not assume that the stroke survivor is intoxicated, or has a problem with intelligence. A counselor in vocational rehabilitation, a speech-language pathologist, a psychologist or neuropsychologist experienced with stroke survivor self-advocacy and life adjustment issues, or a case manager or social worker with experience with communication disorders can be extremely helpful to the stroke survivor and his or her family in working out the best strategies for communication within the family, and also with the external world.

Fatigue

This, particularly frustrating, mind-body problem refers to the stroke survivor feeling chronically tired. It is described by stroke survivors as both a physical and a mental lack of energy. It is distinguished from a problem with endurance, because it can affect performance at the beginning of a task or immediately upon waking, just as much as it may affect performance at the end of a day.

It is not clear why some stroke survivors feel chronically tired, but the problem is common, affecting 10–30 % of stroke survivors (Glader, Stegmayr, & Asplund, 2002; Radman et al., 2012). Fatigue is an independent predictor of dependence, and predicts moving to an institutional setting after stroke (Glader et al., 2002). Of particular concern, fatigue does not resolve spontaneously over the first year after stroke, and in fact some stroke survivors report it as a new problem as late as 6 months after stroke or later, when they try to return to work. One study of stroke survivors with fatigue reported that half of them had to reduce work activities because of this symptom, and 23 % reported fatigue was the “worst” symptom of their stroke (Radman et al., 2012).

Many stroke survivors assume they need to deal with fatigue independently; in fact, occupational, or physical therapy, or speech-language pathology professionals, health psychologists, or rehabilitation physicians (physiatrist or neurologist) may be able to offer medication, cognitive-behavioral interventions, or compensatory strategies.

In summary, hidden disabilities such as concentration and memory problems, communication disorders (aphasia), and fatigue may affect the daily lives of stroke survivors just as much as visible disabilities (for example, paralysis). When stroke survivors have these problems, it may be helpful to understand that they are common, and that rehabilitation professionals have a toolbox of specific interventions and compensatory strategies.

Steps in Returning to the Community

Employment After Stroke

Returning to work obviously helps families financially, especially when the stroke survivor is younger, but returning to work may also aid re-integration into social role and general well-being; it is associated with better long-term outcomes (Daniel, Wolfe, Busch, & McKevitt, 2009). Most stroke survivors experience limitation on their ability to work due to stroke-related problems, based on comprehensive reviews of US and Canadian research (Graham, Pereira, & Teasell, 2011; Wolfenden & Grace, 2009). A very important factor in recovery is taking advantage of services that are available after the initial period of hospitalization (post-acute rehabilitation). These include vocational interventions. It is also important to use adaptive strategies, meaning specific changes in communication style, or equipment to assist in function, or other means of “working around” stroke-related problems. Lastly, a stable, secure work environment that engages the survivor as a partner is also helpful for successful work return (Wolfenden & Grace, 2009). We feel strongly that vocational rehabilitation services are underused by stroke survivors, as compared with working-age people with psychiatric issues or traumatic brain injury, and there is research to support this contention (Hofgren, Esbjornsson, & Sunnerhagen, 2010).

Even if stroke survivors return to work, they may need to change their hours or find a new job (Wolfenden & Grace, 2009). Only about 20–40 % of stroke survivors return to work (Graham et al., 2011; Hofgren et al., 2010; Wolfenden & Grace, 2009), and those who are younger, do not have communication disorders (Graham et al., 2011) and more independent (Hackett, Glozier, Jan, & Lindley, 2012) may find it easier to work. Changes in thinking, concentration, and memory (cognition) may also play an important role in return to work (Hofgren et al., 2010; Kauranen et al., 2013). Having trouble with several areas of thinking makes it more difficult to return to work successfully than having one or two areas of decreased thinking abilities (Kauranen et al., 2013).

Returning to Social Participation

As the survivor’s success in recovery builds on itself, step by step, new areas of challenge will emerge. Universally, stroke survivors can have difficulty resuming family relationships, sexual life, and leisure activities because of new daily life limitations of function. Marital separation and divorce can be a direct result of the event, but a review of 78 studies on social consequences of stroke (Daniel et al., 2009) reported that 38–54 % of couples report they experience conflict (38–54 %). Up to three-fourths of stroke survivors report new, unwanted limits on their ability to take part in a sexual relationship. We know that school-age children of stroke survivor require support, but it may be very difficult for families to find resources and services that support them in explaining what has happened. Lastly, participating in leisure activities, such as sports, religious participation, volunteerism, clubs and other social groups, is very commonly limited after stroke: in 79 % of stroke survivors according to a review of 78 studies. Stroke survivors and their families can seek family counseling, peer support, resources through advocacy organizations, and resources available through organizations focused on aging and brain injury. Exercise, alone or in combination with other interventions, may also improve social participation (Obembe & Eng, 2016). Many communities are building health and wellness centers that offer support, counseling and resources for mental health and resilience through life transitions and in relationships. We encourage stroke survivors and their families to take advantage of these resources so that organizers will be motivated to keep them stroke-relevant and -accessible.

Cultural Issues

People with different racial and ethnic backgrounds can have different inherited medical conditions that affect stroke and its recovery (Sacco, Kargman, Gu, & Zamanillo, 1995). Socioeconomically disadvantaged groups differ demographically from those that are more privileged; these healthcare disparities may lead to differences in stroke outcomes (Kleindorfer et al., 2012).

Differences in functional recovery may also be the result of cultural and ethnic practices (McNaughton et al., 2011). In medicine, we strive to improve the *cultural competence* of providers, so that doctors, nurses, and others can present information to people in a way that makes the most sense to their racial, ethnic, religious, and other cultural beliefs and practices. Some conventional beliefs and practices might help to support better stroke recovery in the community; other practices might diminish independence. Healthcare providers need to discuss this information with stroke survivors so that the survivors and their families can choose how to balance their cultural and recovery priorities. Our scientific understanding of how cultural factors interact with the impact of stroke on daily life is still actively growing. For example, people from racial or ethnic minority backgrounds report that they may be more hesitant about using mobility aids like a cane, walker, or wheelchair than their Caucasian counterparts (Resnik, Allen, Isenstadt, Wasserman, & Iezzoni, 2009). This means that they may be at a disadvantage in obtaining and using these devices optimally; visual aesthetics of the device, and physician recommendations, can improve the likelihood African-American or Hispanic stroke survivors will view mobility devices positively. Cultural, racial, and religious beliefs can also affect how caregivers view professional support and adjust to changes in the marital and sexual relationship (Lurbe-Puerto, Leandro, & Baumann, 2012). It is important for stroke survivors and their families to educate their health provider team about their cultural beliefs and how they affect the recovery process; if the team knows more about the family's priorities, they can more effectively advocate for them. Stroke survivors and families may prefer to discuss cultural, ethnic, or religious issues with a social worker or case manager, rather than discussing them with the healthcare providers. Many cultural, racial, and religious support groups are also good at helping their members interact with healthcare teams.

In summary, stroke recovery continues beyond physical aspects of self-care; as stroke survivors look to return to work, social activities, and relationships with marriage partners, children, and others in the community through participating in meaningful activities outside the home, they may encounter challenges. It is important to realize that support from professional and community organizations, as well as rehabilitation-based resources like vocational assistance, may not be offered automatically. Stroke survivors and their caregivers can approach advocacy organizations, hospitals, and even university departments of rehabilitation sciences, where inexpensive and helpful services may be available. Organizations primarily serving other disorders (for example, organizations specialized to assist people with Alzheimer's Disease, and their families, if memory problems are a challenge to return to work), may be able to make useful referrals, or help the stroke survivor and family plan next steps with specialized services. Because it is very common that cultural and ethnic practices affect the stroke recovery process, we hope that stroke survivors and their families will speak to their healthcare providers about these issues and their specific needs.

Acknowledgements The authors were funded in this work by the Kessler Foundation, the National Institutes of Health (PI: Barrett, K24 HD062647), and the Wallerstein Foundation for Geriatric Improvement. We are grateful to the many stroke survivors who shared their experiences of stroke recovery with us between 2004 and the present, helping us to include both personally and professionally relevant information in this chapter.

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