# Neurological Rehabilitation: Promises and Challenges for Canada

*UTMJ* Interview Team (Rahel Zewude, Bonnie Cheung, Tina Felfeli, Kimia Sorouri)

*Dr. Mark Bayley*

**Biography**

Dr. Mark Bayley is a leading clinician scientist in the field of neurological rehabilitation. He completed his undergraduate degree and medical degree in Queen's University. He then completed a residency training in physical medicine and rehabilitation at the University of Toronto. Following his residency, he completed a fellowship on brain injury at McMaster University. His research focuses on rehabilitation of stroke, traumatic brain injury and multiple sclerosis. Dr. Bayley has also been involved in developing nationwide diagnosis and clinical practice guidelines for stroke as well as traumatic brain injury. Currently, he is serving as an associate professor at the Department of Physiatry at University of Toronto and a medical director of the Brain and Spinal Cord Rehabilitation Program at the Toronto Rehabilitation Institute.

**UTMJ:** Tell us about yourself and the scope of your work.

**MB:** I am a specialist in physical medicine and rehabilitation. I did my training in undergraduate medicine at Queen's University and then I studied rehabilitation and physical medicine at the University of Toronto. I have always been interested in neurorehabilitation. I did a fellowship in Hamilton on brain injury and worked there for a few years at McMaster University. I then returned to Toronto and have been the medical director of the neurorehabilitation program at Toronto Rehab Institute for a number of years. My clinical interest is in recovery and the things that we can do to enhance recovery after any kind of injury to the brain, including stroke, brain injury, and multiple sclerosis. I also do some work with individuals who have cerebral palsy and those who are born with brain injuries.

**UTMJ:** What initially made you interested in neurological rehabilitation?

**MB:** There are a few things. One of the things I realized is that everybody is different, depending on where in our brain they were injured. I found that was really fascinating - how the different parts of the brain that can be injured resulted in different kinds of recovery. The second thing I realized was that we do not really understand the brain. Neuroscience is such an emerging area, so what attracted it to me was helping people who had serious injuries to get better. A lot of medical complications of these injuries are really interesting because there are certainly some things we can do to enhance the brain recovery with medications. The third thing I really liked, which is something that was always part of what I like to do, is that I really enjoy working with a team. We have a very inter-professional team in rehabilitation, including physical therapists, occupational therapists, speech therapists, behavioral psychologists, social workers - what I found really interesting in my role was to provide a role of coordination.

**UTMJ:** You authored a recent article that was published in July 2015 in Stroke. This article revealed the increasing number of Canadians that will be living with the effects of stroke such as long-term disability. Why do you think such a trend exists in Canada?

**MB:** The trend is probably true around the Western world in particular, due to the aging of the population. There are a few things going on with stroke. We are doing a better job with reducing the number of smokers and controlling high blood pressure, but what's happening in stroke is that the average age is getting older. The population of Canada who are aging into their 70s and 80s is the time when a lot of people have strokes We are really concerned that as people survive and live longer, we are going to have a huge number of people who are not going to be living in good health, they are going to be living with the effects of stroke. We are concerned that we need to be prepared for this sudden increase of about 40-50% in the number of people living with stroke.

**UTMJ:** In the article, there are different recommended lifestyle changes for the increasing stroke burden that we are going to see. What can be done at a policy level in implementing the suggested changes so that Canada will not experience this predicted increase in the number of Canadians living with the effects of stroke?

**MB:** At a policy level, what we are striving for is that people are aware of the signs of stroke so that we can get them into treatment earlier. An example is the FAST mnemonic, which stands for Face, Arms, Speech, and Time, helps people recognize the symptoms of stroke

and come in to the hospital as soon as possible to reduce the disability. So from a policy level, we have actually built an integrated system in Ontario where people call 911 and get taken into the hospital. However, this is not enough though, because a lot of people are not eligible for thrombolysis. So we are looking to try to enhance secondary prevention and rehabilitation. Secondary prevention means that we need to find out why they had the stroke - the cause. A less known cause of stroke that we need to prevent a bit more aggressively is sleep apnea, which a lot of people would not think to be a cause of stroke. It is related to heart disease, and puts stress on your brain when you stop breathing at night.

High blood pressure is another concern that we think policy could have an impact on. This is through regulation of salt content in food and decreasing the amount of salt we intake. For example, about 80-90% of our salt intake is not from added salt, but from salt that is already embedded in the food. When we go to the supermarket, and you buy the low-salt foods, you are avoiding a lot of that salt. However, a lot of people just buy the regular food brands. In some jurisdictions around the world they are starting to regulate the salt. This would be a big major help in reducing the burden of stroke.

I think the other thing is that we need to be prepared to help reduce disability in people who have suffered from stroke. What does that look like? Everybody should have access to at least a course of rehabilitation. Everybody should have access to ongoing exercise programs in the community. We have built a partnership with some of the community centers and we have trained a community center fitness instructor how to manage people with stroke and include this in their classes. The initiative was called "Together in Movement and Exercise". I think policy-wise if we were to offer these kinds of exercise programs to maximize people's function, then we have a lot less people living with disability.

I think we also have to be ready for the fact that stroke also is a disease of small vessels, which means that about 50% of what we see as dementia and what was previously thought to be Alzheimer's is actually a combination of Alzheimer's with mini-strokes. We can help people with cognitive impairment through exercise, better control of risk factors, as well as cognitive interventions, such as what we are doing currently at Toronto Rehab. We are currently developing smart homes where the home can be interactive with the individual. I know that the neurologists are trying to use new techniques but that probably only applies to 12-15% of people with stroke, but we will have many more people who will be living with the effects of stroke.

**UTMJ:** What are some of the challenges you faced in reinforcing this strategy to minimize the number of patients who will be living with the effects of stroke?

**MB:** First of all, we need to raise awareness amongst physicians as well as the general population about the risk factors for stroke. We also need to believe that when a person has a stroke, it is not the end of the road and that we do not give up on them. Yet we know that the person can get progressively worse through multiple strokes, so we need to be very aggressive about chasing down their risk factors.

I think that one of the barriers is that we do not have easy access to sleep studies and we need better access to secondary intervention clinics. We might need to create what are called vascular prevention clinics. There is a huge overlap between people who have had heart disease and people who have stroke, kidney disease, peripheral vascular disease, and so forth. So what if we had clinics that were experts in trying to get these people moving? The barriers are awareness and resources. There is also the belief that we cannot do anything – and this is really wrong in 2016.

**UTMJ:** As you mentioned, sometimes once people have a stroke, they might give up on caring for other related health issues and even stroke-related issues. Is this related to the effectiveness of post-stroke rehabilitation services? In general, what is the effectiveness of post-stroke rehab services in Canada?

**MB:** Our stroke rehab services are quite effective in reducing disability. We know that rehabilitation results in a 40 to 45% reduction in death and disability after strokes. It is important to get people into rehab early, mobilizing them, taking them through the rehabilitation in-patient programs for a while.

What we do not know is if everyone gets adequate access to the necessary intensity of rehabilitation. They might go into rehab but they do not receive enough therapy to maximize their brain recovery. With respect to policies, we are working with the ministry to try to set standards around expectations in care.

The access to outpatient rehab is not as effective as we would like it to be currently. In-patient rehab is typically about 25-45 days, which is very effective at increasing their disability by 25 points on the functional independence measure. This can reduce the number of hours of care they need by about 2 to 4 hours per day. Even once they go out into the community, they can still benefit from another few weeks or months of care. We know the window of rehab is open for quite a while after their discharge. Therefore, the problem is likely bigger than access to in-patient rehab and is actually problems with access to out-patient rehab.

One of the things we are looking at in our research is the notion that recovery of the patient plateaus. We studied motor recovery for a number of years and found that within 12-18 weeks, people tend to level off. We are trying to do a RCT to see if we can keep the window of recovery open longer. Some people think that the brain gets gelled in one spot and if we can

keep the connections continuing to grow for another few weeks or months, we might actually allow people a longer chance to recover.

There are a number of things that are implicated in this. One of which may be what is called perineuronal nets. These are collagen and proteins that lock into the matrix around the nerves. We think that this might stop the brain from spreading the new connections that it needs to make. If we can just keep the nets from forming too tightly or too closely, we might be able to extend the window of recovery. We are hoping to take individuals who we thought were limited by 12 to 18 weeks and keep them rehabilitating potentially for months afterwards and continuing to enhance their recovery.

**UTMJ:** You have also worked on developing the update for the Canadian Stroke Best Practice Recommendation Guidelines. This update focused on post-stroke depression, vascular cognitive impairment and fatigue. What are some of the challenges Canada might face in integrating the screening of these three stroke outcomes under standard clinical practice for stroke patients?

**MB:** We know that post-stroke depression occurs in 30-40% of patients, maybe even higher. It is possible to see symptoms of depression a few weeks after the stroke when patients are still recovering. We believe that this results from decreasing levels of brain neurotransmitters like serotonin and norepinephrine.

The barriers to screening have been lack of awareness, again, but also people are not using tools for screening, such as the assessment scales that have been included in the best practice guidelines. If people were to use them regularly, I think we would have more appropriate and frequent treatment for depression.

I think there is also a stigma that prevails around mental health; even the words "mental health" make a statement. I think we should be thinking about "brain health". I have learned from neuronal rehab that you cannot really separate psychiatric problems from brain injury-related or stroke-related problems – they are all to do with the same brain and the same organ. That organ works just like your liver does. Sometimes the neurotransmitters are off and sometimes the nerve cells are not connecting well. When the brain does not work properly, the symptoms that we get are things like depression. One of the things that we found in our study is that we need to focus on screening for depression more frequently but we also need to have a conversation with our patients to say:

"You know, this is about brain health. It is not that I think you are weak or that you are not tough enough, this is because your brain chemicals (neurotransmitters) are low and your recovery depends on us helping your brain for a while to treat the negative effects of the stroke and improve outcomes."

The cognitive impairment is a very similar problem. Doctors are not looking for it so therefore, they are not finding it. I think we need to continue to encourage everybody to screen patients for cognitive impairment. The Montreal Cognitive Assessment (MoCA) is a very good tool and is the one we tend to use. I think the field of rehabilitation of cognitive impairment after stroke is just emerging and we are still learning whether evidence-based treatments are enough for those who do have cognitive rehab needs.

I think the big thing is awareness, screening and getting on with treatment. As far as post-stroke fatigue, it is very common, it is very organic in a person that when there is anything that we would think of as routine, such as sleeping, walking and talking, with a person with stroke, they have to exert so much cognitive energy just to walk, and if you look at their brain MRI, they are pulling from other areas of their brain to help them with walking. It is very clear these people are working extra hard to walk and the amount of brain resources they have available to them to walk is limited. This is why they have experiences of fatigue. There are many other reasons for their fatigue, such as medical, electrolytes and even depression. Fatigue is very common and in fact about 30-60% of people will have post-stroke fatigue. So I think that we must ask people about it and try to help them.

**UTMJ:** You mentioned the stigma associated with depression. How has the approach been received from the perspective of healthcare professionals?

**MB:** Part of the policy imperative is actually to get people to specialize stroke teams. Those specialized stroke teams will recognize these complications. Providers are faced with the reality that they have to talk about depression. I often will talk to my patients about the fact that because of your stroke your neurotransmitter levels are low and we know that if we treat that with medication, you will recover with both motor - and cognitive recovery. So while you may call that "depression" I will refer to it as the neurotransmitters being low. If you look at the books you will see that these drugs and these treatments are labeled as anti-depressants but I am using it because I believe that your neurotransmitter levels are low. I think we as professionals need to start talking about it in a different way.

**UTMJ:** Your research area also focuses on developing diagnosis and clinical practice guidelines for traumatic brain injury (TBI). How would you describe the intersectionality between stroke and TBI rehabilitation?

**MB:** There are many similarities but there are also differences. The difference actually comes from the difference in the pathologies. As you know, arterial occlusion, leakage or hemorrhage effects a distinct or focal area in the brain. Traumatic brain injury when you hit

your head there are two problems that go on; first, diffuse axonal injury which is when the axons of the brain are shaken. These areas of injury occur at junctions between two areas of the brain. The grey-white matter junction and the junction between the brain stem and the cerebral hemispheres in the connections between the cerebellum and the brain stem and then corpus callosum. While stroke is a very focal disease, brain injury is a little more perfuse.

The second thing that goes on with brain injury is focal contusions. You hit your head and the frontal-temporal aspects of the brain get bumped. Brain injury rehabilitation, if you think of motor recovery, the practices are very similar. We would do motor rehabilitation in a very similar way. We would see in brain injury more balanced difficulties because of cerebellar and inner ear involvement. In brain injury we have a much more different cognitive profile, people have trouble paying attention and there are behavioral changes due to frontal lobe injury. Where as the classical stroke has arteries involved which involve the motor strip and less involvement of cognitive, executive and planning functions. Therefore in brain injury, we have to be very aware of behavioral changes. Because of this, we do have a bit more of a comprehensive involvement with neuropsychology and cognitive and behavioral psychology because we have to deal with these very real issues because of the trauma.

**UTMJ:** As a clinician-scientist whose research focuses on rehabilitation medicine, how do you balance your approach to prevention as well as rehabilitation; especially if public policy tends to be focused on prevention strategies?

**MB:** I am not actively involved in the primary prevention in terms of understanding rules of the road and trauma. However, I do speak about it and raise awareness about things such as concussion. I believe one of the biggest things for concussion awareness and for traumatic brain injury/concussion, sports in particular, we can raise awareness. I think its about teaching coaches and referees in sports and teaching players that they need to be protecting themselves. They cannot go head-on into the boards. They need to be prepared to stop. If they are running into a player, they need to be looking that the other player is looking at them and that you do not hit them in the head. I am able to show them what happens when they do that thus I have been involved with raising awareness about concussion.

In stroke, I am very interested in the primary prevention of high blood pressure, salt levels and sleep apnea awareness and triggers associated with it. Thus I think that balancing awareness of what we see in rehabilitation and than preventing complications. Our prevention role is primarily secondary prevention. We see a person who has had a brain injury and we prevent them from getting all contracted up because their muscles are too tight. We prevent them from getting pneumonia because they are lying in bed. We prevent them from having swallowing complication by testing and treating them for their swallowing difficulties. In stroke we prevent them from getting mobility complications and preventing secondary complications that relate to the medications which I have talked about, including blood pressure and cholesterol. I think our role in rehabilitation is very much secondary prevention to the injury. But I think because we know what these people look like, we can look back and tell the public, this is what will happen to you if you don't take care of yourself. We can raise awareness about it. We have very eloquent spoke persons because our patients can be very eloquent in telling people what happens when you have a concussion. The general public believes those people better than they believe the doctors. Thus we often need to bring our patients in and have them be part of the future.

**UTMJ:** Even though the public has increasing awareness about prevention strategies such as low salt intake to reduce blood pressure, there is still not a significant decrease in stroke prevalence. What do you think some the challenges are in reinforcing this knowledge to the public?

**MB:** I think we need to continue reminding people that stroke is a bad disease and reminding them that your brain is part of what makes you human. If you lose some of your brain-power that can be incredibly problematic. We really need to raise awareness that it is not just about the big stroke. But what we know now is that for every very large, symptomatic stroke in a person there are nine times as many smaller strokes that can cause cognitive impairments. So I think it is imperative on us to make people aware that this is about their brain, their thinking skills, being healthy as a senior and it is about their quality of life. One of the things that is interesting is that we are actually being successful in reducing the incidence of stroke. But because the population is growing and people are aging, the prevalence of people living with stroke is higher. Every year, some of these secondary prevention efforts are actually having effects and we are seeing the level of stroke going down. But it is not fast enough. We need to see much faster declines in the level of stroke. Or else we are going to end up with 700,000-800,000 people, the equivalent of people in the city of Ottawa, all living with stroke.

**UTMJ:** You work with an inter-professional team in neurorehabilitation. Can you tell us about your team?

**MB:** We have been working in the field of rehabilitation for a number of years. At Toronto Rehab, we have a big focus on re-integrating rehabilitation clinically with research. So in our team, many of us are very engaged in helping out with research and facilitating research.

We have a unique clinic called the Balance, Falls and Mobility clinic, where our physical therapist and some of our scientists work side by side. When the clinical team come into this very sophisticated lab, they know how to use it. So on every single patient, who can walk, we do our best to collect data about how they are recovering. I think what we are being successful at doing is bringing together people who are very interested in bed practice, research, and providing the best care. I am proud of the fact that, we believe now that the Toronto Rehabilitation Institute is the number one rehabilitation, research hospital in the world. And that is very exciting for us. I think it is partially because we have a culture in our team where people are not just interested in taking care of patients. They want to help us move the field forward and really get engaged in understanding the process.

**UTMJ:** What are the most common difficulties patients face when they are trying to access neurological rehabilitation services?

**MB:** One of the most common difficulties people have, particularly in brain injury, is that we have a waitlist. It is a 20-30 days waitlist unfortunately because there is not enough specialized, brain injury rehabilitation. In stroke, because of initiatives we have been involved in, there is better access to rehab. I think what we are seeing is that, unfortunately for the very severe strokes, the recovery curve is not as strong. And what we find is that if they are not lucky enough to have an able bodied family member or caregiver, their ability to recover is less. One of the sad things is if somebody lives to a quite old age and they do not have anybody to live with them and yet they are doing pretty well but they need somebody to be there in case they need a little bit of help. So we are finding that the major impediment is the lack of caregivers in the family and families not being around. We are seeing a lot of problems because we have families with all the kids working and it is not their fault.

When both the husband and wife are not well. Now that strokes, are occurring in older people, they both might have it. Maybe they both have arthritis. One of the things we are finding is that those people can help each other. If you think about it, once they have gone through an in-patient rehab, now we want them to come back for a rehab at the hospital. And they have to travel on real transit to get out of their house. Maybe their house is inaccessible, maybe their family member cannot help them down the stairs. There are some significant barriers with transportation being one of them. Having a healthy caregiver, having the knowledge and awareness are others. So I think what we are trying to do is make it accessible in their community and trying to figure out how to get the rehab out to people.

**UTMJ:** What advice will you give for young professionals such as medical students who are interested in neurological rehabilitation?

**MB:** For medical students and for people joining the field of medicine and all the individuals in the allied health professions as well, I just want to give them a message that this is a really exciting time for rehabilitation and our understanding of the brain. We are getting so much better in understanding how to image the brain, which neurotransmitters are important. I think this is an extremely exciting time to be in the filed of rehabilitation. I just have to say that as much as there is a great deal of promise in prevention and acute treatment of stroke and brain injury, it is the unfortunate reality that there will still be people who will fall and hit their head. There will still be people who get involved in accidents and some people who will still have strokes and do not remember to call 911. So unfortunately, with the aging population we do not perceive in the imminent future that we will be out of business. Even if we were very successful in eliminating the risks in society for injury and reducing the incidence of stroke, I still believe we will have a role in neuro recovery for the milder strokes, for people with Alzheimer's. We should be learning more about how to help people recover from any thing neurological.

My advice to medical students will be, and this is what I tell the students who come to my clinic, unfortunately neurology and musculoskeletal medicine are not really a focus in medical school. And if you come and join us, even if you end up not being interested in neuro rehabilitation, you will get an opportunity to practice your neurological exams, your musculoskeletal exams and you will get a better exposure to pathology because people do not come to rehab if their brain is fine. People do not come to rehab if they do not have any musculoskeletal problems. So I think from a training point of view, I will certainly encourage medical students, if they are going into family medicine or if they are going to any field, that this is an opportunity for them to get to see more neurological and musculoskeletal pathologies. We will be very excited to have them even do a couple of weeks of selectives with us, so they get a practice on their clinical skills on these areas. So I just want to leave people with the idea that this is a very exciting time for neuro rehabilitation.