WHY RESEARCH

MATTERS 2022

13 authors







SPINAL RESEARCH INSTITUTE



A COLLECTION OF SPINAL CORD RESEARCH FROM AROUND THE WORLD

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The Spinal Research Institute acknowledges the Traditional Owners of the land on which we work, the Wurundjeri People of the Kulin Nation.

We pay our respects to Elders past and present.

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Afterwords

A word from the International Spinal Cord Society Why Research Matters - Previous Editions The Spinal Research Institute's Programs

Welcome to the third edition of 'Why Research Matters', a compilation of the winning entries from the Spinal Research Institute's (SRI) Spinal Cord Injury Research Writing Prize 2022.

We're very pleased to bring you this edition, featuring a wide range of research interest areas, from gene therapy to exercise therapy, to caregiving for children with spinal cord injury. Thank you to all the researchers who submitted a piece to this year's Writing Prize and congratulations to the winning entries. I would also like to acknowledge and thank our judging panel, who volunteered their time and expertise to assess the Writing Prize submissions.

The objective of 'Why Research Matters' is to demystify and share the important and diverse work happening around the world in the field of spinal cord injury research. We understand that writing in English may be challenging for those whose first language is not English, and this year we were pleased to offer special consideration and language support to authors for whom English is an additional language, and particularly those from countries with low to very-low English language proficiency.

'Why Research Matters' is a vehicle for research communication, an important step in the knowledge translation process. Research communication – explaining research in an easy-tounderstand manner – helps bring research into the public domain. It moves it into the hands of the people who will use it, such as clinicians, policy makers, and the public, to support advocacy efforts and changes to health care policy and practice. Research communication makes research accessible and enables all stakeholders to engage in discussion, debate and decision making about the application of research outcomes. Most importantly, it puts research into the hands of the people who will benefit from its impact, in our case, people with spinal cord injury.

We're excited to provide this opportunity to researchers to share their work with peers, clinicians, the spinal cord injury community and the broader public.

Happy reading!

Kristine Hendry CEO, Spinal Research Institute

Spinal cord injury facts

Every year, around the world, 250,000 to 500,000 people experience a spinal cord injury.

People with a spinal cord injury are two to five times more likely to die prematurely than people without a spinal cord injury. Survival rates are lower in low-and-middle-income countries.

Spinal cord injury is associated with lower rates of school enrolment and economic participation, and it carries substantial individual and societal costs.

The majority of spinal cord injuries are due to accidental or preventable causes such as road traffic crashes, falls and violence.

Spinal cord injuries can also occur due to medical reasons such as tumours, bleeding into the spinal canal and infections.

Secondary health conditions

Spinal cord injury affects much more than a person's ability to walk; there are many secondary health conditions that can impact a person's life.

This publication illustrates the importance of diverse research in improving quality of life for people with a spinal cord injury.

Mental health issues such as

- depression
- anxiety

Social issues such as

- marginalisation
- pressure on relationships
- barriers to education and employment

Physical conditions such as

- recurrent bronchitis and pneumonia
- sleep apnoea
- blood pressure fluctuation
- recurrent urinary tract infections
- muscle wasting
- osteoporosis
- impotence and infertility
- pressure sores
- bowel dysfunction

2022 SCI Research Writing Prize

We asked spinal cord injury researchers and clinicians to write up to 800 words about their research in a creative way that would appeal to a broad-ranging, non-scientific audience.

The entries had to be easy-to-understand and compelling pieces about published or in-progress spinal cord injury research for a non-scientific readership.

The written pieces had to answer the following questions:

- Why is the research important?
- Why does it interest you (the author)?
- Why should it interest the reader?

The Spinal Research Institute is committed to supporting researchers and clinicians from diverse backgrounds. For the first time, in 2022, we were able to offer special consideration and additional language support to authors from countries with low to very-low English language proficiency based on the EF English Proficiency Index.

We asked the judges to indicate whether they thought these entries would merit publication with additional language support. This publication includes three such entries.

Prize details

All shortlisted entrants receive a place in a workshop that explores research translation and impact, facilitated by Australian course provider Research Impact Academy.

All shortlisted entrants have their writing featured in this publication. Their work will be shared and promoted through the SRI's networks.

Assessment criteria

Entries were subject to a blind judging, where the writers' names were not known to the judging panel.

The judging panel considered the following questions.

- Does the written piece convincingly explain why the research matters?
- Is the research explained in a way that is easy to understand?
- Is the piece compelling to read?

About the Spinal Research Institute

The vision of the Spinal Research Institute is to improve health outcomes and quality of life for people with spinal cord injury.

People with a spinal cord injury face many challenging secondary health complications that diminish their quality of life and capacity for independence. By building global collaboration in spinal cord injury research and clinical trials we aim to reduce the length of time it takes to achieve significant and translatable research outcomes.

Our work supports research collaboration and knowledge sharing, and actively involving people with lived experience of spinal cord injury in the resarch process to improve research relevance.

Reduced research timeframes

> Increased research collaboration

Judging panel

Dr Ali Otom

Director, The Royal Jordanian Rehab Center - King Hussein Medical Center, Jordan

Dr Otom started his career in 1986 as a Phusical and Rehabilitation Medicine (PRM) resident at the **Royal Medical Services which** include the only rehabilitation center in the country named the **Royal Rehabilitation Center. Upon** finishing his training program, he obtained a scholarship for specialized training in PRM in the United Kingdom, University of London where he obtained his Diploma in medical rehabilitation.

Dr Otom was appointed as a registrar at Stoke-Mandeville where he worked with Dr. H. Frankel focusing on spinal cord injuries management and rehabilitation. In 1994 he returned to Jordan where he worked as a PRM specialist and launched the theme of multidisciplinary team approach in rehabilitation unit particularly for spinal cord injuries.

Australia

Emily Quattrocchi is a 29-year-old paraplegic who since being injured in 2018 runs a YouTube channel 'Em Quattrocchi' with videos to help others with SCI's and raise awareness about disability.

Through striving for her goal to be a filmmaker, she has made a festival screened short documentary 'Emily, you never give up' and worked with the ABC to present a news report on Peer support after a spinal cord injury. In addition to her film projects, she has contributed with volunteer roles that help and impact the spinal cord injury community.

Emily Quattrocchi Film maker,

Dr Faroog Rathore Consultant in Rehabilitation Medicine, Armed Forces Institute of **Rehabilitation Medicine, Pakistan**

Farooq Azam Rathore is a consultant and Associate Professor in Rehabilitation Medicine at the Armed Forces Institute of Rehabilitation Medicine, Pakistan. He describes himself as a rehabilitation physician, teacher, researcher, and mentor. He has been an invited and plenary speaker in national and international conferences and chaired and cochaired scientific sessions.

Dr Rathore has won multiple national and international awards, travel grants and scholarships. He is an editorial board member of several Journals. He is the national representative of Pakistan for the International Society of Physical Medicine and Rehabilitation (ISPRM) and Asia-Oceanian Society of PMR and Advisory Board Member of Cochrane Rehabilitation.

Shivjeet Singh Raghav President, Spinal Cord Society Consumer Committee, India

Shivjeet Singh Raghav, is a Patient Education Coordinator and Peer Counsellor at the prestigious rehabilitation centre, Indian Spinal Injuries Centre, New Delhi, India. He is also Vice President of The Spinal Foundation of India. Shivjeet has been a pioneer in forming many associations and societies in his endeavour to facilitate the rehabilitation of people with disabilities; his work has brought him several prestigious awards, national and international.

Shivjeet's work, particularly in the areas of accessibility and sexuality in persons with spinal cord injury have been commendable. His presentations span horizons across several areas of spinal cord injury. Shivjeet has co-authored a chapter entitled "Family, Relationships and Community Life," in the WHO published book "International Perspective on Spinal Cord Injury."

Dr Christine Migliorini Research and Evaluation Coordinator, The University of Melbourne, Australia

Christine is a Social Worker with 20 years of psychosocial research experience. A key focus of her research has been exploring factors that influence mental health, wellbeing and living with spinal cord injury. Dr Migliorini has authored over 25 publications in peerreviewed journals. She has also supported several clinicians with related research.

Christine was chief investigator in two beyondblue Victorian Centre of Excellence grants that funded the development and randomised control trial of ePACT: a flexible (online) treatment for depression and anxiety in adults living with chronic spinal cord injury. She is currently collaborating with Spinal Cord Injuries Australia (SCIA) to enable ePACT to become part of their suite of services.

Destabilizing barriers to regeneration using gene therapy to reduce scarring after spinal cord injury

Martyna Stasiewicz

Imagine yourself in a car on a long multilane highway driving away from a metropolitan city. As with all highways there are several exits along it, each branching off into smaller roads allowing cars to reach different destinations. Some will drive further along the highway and leave at the next exit, or the one after. The brain is like a city, housing billions of neurons that send cellular processes called axons (like the different lanes on the road) out of the brain and through the spinal cord (the highway), with numerous branches that allow signals to travel (the cars) to their target, such as the muscles. Essentially, the spinal cord is a superhighway between the brain and the rest of the body.

It is because of this intricate and vital role as a conduit that injuries to the spinal cord, often sustained in road traffic accidents, result in such debilitating loss of function. Using our analogy above, if the road collapses, the cars become stuck on the highway, unable to reach their destinations from either side. Similarly, after injury broken axon pathways cannot send signals to their targets.

As when a road is damaged where workers quickly arrive on site to clean up the rubble, the body also rushes many different cells to the site of injury to help clear up the tissue debris. But unlike any type of highway rebuilding, where the clean-up crews are subsequently replaced by builders with a plan for repair, the damaged nervous system is not able to do so, and the clean-up crew hangs around. Unfortunately, the crew in this case are immune cells, which are superb at cleaning up injury sites, but they also release factors that keep the injury site inflamed. At the same time these immune cells also tell others to migrate and help seal off the injury site, like traffic cones and barriers used to surround a collapsed road to isolate the damaged area. In the spinal cord, star-shaped

astrocyte and connective tissue cells infiltrate the damaged area and work together to form a dense scar tissue. In doing so the injury site is isolated to prevent further damage,

but also creates a barrier that stops axons from regrowing through the lesion site.

Can we not just remove the scar tissue? Unlike scars that form elsewhere in the body, the spinal cord scar tissue does not resolve over time and chronically "blocks" regrowth. Through experimentation researchers discovered that removing it was not possible as inflammatory immune cells were free to migrate into healthy tissue, damaging it and increasing the size of injury. Therefore, a new way of dealing with the scar tissue is needed. I was intrigued by this problem and thought that if there was some way of gently disrupting the tightly packed scar so that cells separate, forming "gaps", regrowing axons might be able to pass through and cross the injury site, opening the communication highway.

But how does one go about studying cord scar tissue? Most scar research is carried out in animal models, which is very slow, expensive and time-consuming. So, with the help of Prof O'Brien and the Spinal Cord Injury team at the Department of Anatomy and Regenerative medicine in RCSI, I used latest tissue engineering methods to recreate a threedimensional model of the scar tissue in a dish in the laboratory. Composed of scar-forming astrocytes and connective tissue cells, this three-dimensional scar can be easily replicated and used for fast, high-throughput screening of potential therapeutics.

My next task was to devise a strategy for disrupting the closely packed scar cells. I have a particular interest in "junctional proteins" that sit on the surface of cell and like a zipper, link cells together, creating channels that allow passage of nutrients. Recently, by delivering very small pieces of 'blocking' ribonucleic acid (RNA), a method that stops cells making particular proteins, I was able to tell scar-forming cells to stop making a specific junctional protein, known to play a role in holding the scar cells together. When I did so, "gaps" appeared between the scar cells, suggesting that there were less connections between cells after the treatment. This exciting result confirms that I am on the right track and this approach could be an effective method for reducing scar barrier function and aid axon regrowth.

More work needs to be done and the next step is to see if axons can grow through the scar using the treatment I have devised. Looking longer term, I hope this new approach will form a part of a multifactorial treatment for spinal cord injury being developed at RCSI to maximise the chances of successful repair. After all, it is not enough to remove the rubble after damage, you also must lay down new asphalt and jumpstart a few cars.

Martyna Stasiewicz is a final year PhD researcher in the Tissue Engineering and Regenerative Medicine Group (TERG) in the Royal College of Surgeons in Ireland (RCSI) led by Professor Fergal O'Brien, working on developing a gene therapy approach for destabilising the impermeable central nervous system scar that impairs regeneration following injury, such as spinal cord injury, using 3D scaffold models. Her background in neuroscience and human anatomy has equipped her with the right expertise to succeed in the spinal cord injury research field. Martyna is passionate about anatomy and takes great pleasure in helping others understand how their bodies work.

Adaptive rowing exercise for people with spinal cord injury

Dr Rasmus Kopp Hansen

Wheelchair users with a spinal cord injury (SCI) are less physically active than the ablebodied population, which, together with a loss of muscle mass and accumulation of fat tissue, put these individuals at a higher risk of cardiovascular and metabolic diseases (collectively referred to as 'cardiometabolic diseases').

Most, if not all, of you have probably heard seated in their own chair, while they perform rowing exercise with the upper-body. that being physically active is important for maintaining health throughout the Importantly, the Adapt2Row unit can easily be disconnected after each workout, and lifespan. In fact, physical activity and exercise represent a cornerstone in the prevention of the sliding rail reattached, which provides a cardiometabolic diseases, and higher levels of universal design by permitting both wheelchair physical fitness is associated with a reduced users and able-bodied to use the same rowing machine. For those participants with a high risk of death of all causes. This information has resulted in specific guidelines recommending thoracic or cervical injury, who did not have that individuals with SCI should engage in at sufficient trunk control to resist the pull-back force of the handle required to remain seated least 30-min of moderate-to-vigorous intensity aerobic exercise, three times a week, in order to during rowing, we further adapted the exercise improve cardiometabolic health. To meet this using assistive equipment for stabilization of recommendation, people with SCI typically rely the trunk (trunk vest or Velcro chest strap). on exercise equipment that can be performed using their upper-body due to paralysis of the We found that the rowing exercise was legs. However, such upper-body/arm exercise perceived as feasible and enjoyable, and even is limited to a few exercise modalities such though the participants exercised with vigorous intensity three times a week for 6 weeks, they as handcycling, wheelchair propulsion, or arm-cranking exercise. Unfortunately, such did not experience increases in shoulder pain. In fact, in those participants with the most exercise equipment is not commonly available shoulder pain at baseline, pain reduced over the at community fitness centers, which thus may prevent many individuals from participating. training period.

In the first part of my PhD, I tested the feasibility of 6 weeks of upper-body exercise performed on a commercially available rowing machine (Concept2 Indoor Rower) adapted to wheelchair users with SCI using an adaptive unit. In addition to being an underutilized exercise modality both in research and clinical practice, upper-body rowing could potentially be beneficial for shoulder health, as it involves the large, relatively weaker, posterior (rear) shoulder muscles important for balancing the heavily involved anterior (front) shoulder

muscles used for daily activities. We adapted the rowing machine by removing the seat and sliding rail of the rowing machine (used by able-bodied to push off with their legs), and replacing it by an adaptive unit (Adapt2Row) consisting of a small stand and knee pad that one can wheel up to. This modification, which can be made within seconds, allows wheelchair users to remain

In the final part of my PhD, I examined the effects of 12-weeks of upper-body rowing exercise, complying with the SCI specific exercise guidelines, on cardiometabolic and vascular health in 17 participants with SCI. In this study, we found that, compared with the control group (who maintained usual living), the people in the rowing group had an approximately 17% elevation in their cardiorespiratory fitness (reflecting the ability of the body to take in, transport, and use oxygen for physical work), as well as a clinically relevant 5cm reduction in waist circumference (a marker of abdominal obesity). As a novel contribution, we also measured the resting diameter of the participants brachial artery (a large blood vessel of the upper arm) using highresolution ultrasound and found that the artery of the participants in the rowing group was enlarged after the 12 weeks.

Taken together, the results from my studies are relevant for the SCI community, as they provide evidence that adaptive rowing exercise is a useful exercise modality that allows individuals with SCI to exercise with vigorous intensity without exacerbating shoulder pain. As the rowing exercise can be performed on a commercially available rowing machine, in combination with a single adaptive unit, it is possible to implement rowing exercise in most training facilities, thereby offering an extra exercise option to wheelchair users who currently are limited by the availability of exercise equipment. Finally, the results show that rowing exercise, even when performed only with the upper-body, elicits favorable changes to the cardiovascular system that increases physical fitness, with potential implications for longer-term improvements in cardiometabolic health.

After completing an MSc investigating cerebral blood flow responses to highintensity exercise in a collaboration between Aalborg University (DK) and the Copenhagen Muscle Research Centre, Rasmus Kopp Hansen went on to pursue a PhD. During this project, he investigated physical activity barriers in wheelchair users, and the cardiometabolic health effects of upperbody rowing exercise in people with SCI. Rasmus obtained his PhD in 2022 and is currently working as a Postdoctoral researcher at Aalborg University. Outside the laboratory, Rasmus is an enthusiastic cyclist, and in true Scandinavian manner, he also enjoys winter bathing, just like a real Viking.

Image provided by author

Exploring ageing in spinal cord injury for promising holistic rehabilitation care and services in Sabah, Borneo

Associate Professor Fatimah Ahmedy

The earliest documented spinal cord injury cardiorespiratory health ranked top of the list. (SCI) history was from Egypt in 3000 BC. For the former, overused joint pain, reduced muscle strength, nerve impingement and bone During the early age of spinal cord medicine, the primary aim was to prolong the life of those density loss causing early osteoporosis, are with paraplegia by managing life-threatening common due to constant use of upper limbs conditions, including pressure injuries and for wheelchair mobilisation and performance upper urinary tract complications. Then, we of daily activities and the non-use of lower see a better survival rate for individuals with limbs. Physical inactivities from the non-use of tetraplegia by optimising their pulmonary lower limbs increase the probability of being functions. With time, the advancement overweight and the development of coronary of rehabilitation care and evolution in heart disease at an earlier age compared to regenerative medicine have increased the life able-bodied counterparts. expectations and the excellent quality of life of These complications are expected to occur at some point in the lives of people with SCI. must be emphasised as part of holistic care so that they may cherish a better quality of life (QoL). For such care to be delivered, one must have reasonable access to rehabilitation care, but how many ageing people with SCI do receive this accessibility? In many underdeveloped countries, even granting

SCI survivors. These are materialised through effective pain and spasticity management, Nevertheless, prevention and early treatment an interdisciplinary approach, technologyassisted rehabilitation interventions, and, most importantly, a paradigm shift towards patient-centred care. Many of the healthcare professionals are from diverse expertise backgrounds and work closely toward shared goals based on the resultant impairment, functional limitations and participation restrictions together with SCI survivors and access to healthcare facilities for basic medical their caregivers' expectations. care is considered 'luxurious', and rehabilitation care is mainly confined to capital centres in these regions. In the state of Sabah, located As we are celebrating many success stories in the field of spinal cord medicine in the northern part of Borneo Island, our and rehabilitation research, for instance, rehabilitation physicians here treat and follow up between 400-450 people with SCI annually, neuroprosthesis for walking in paraplegia, stem cell therapy for spinal cord modulation, both traumatic and non-traumatic causes. They neurostimulation therapy for upper limb are followed up across the state by providing weakness in tetraplegia, our focus must also outreach specialist care services due to vast be directed to the issues revolving on ageing in geographical distributions and remotely located areas in this state, instigating limited SCI. With improved life expectancy, whereby access to tertiary health centres and district we are anticipating a 20-year-old SCI survivor with low level paraplegia to live up to the age hospitals. More information on barriers and of 70, the right question to ponder is, are we challenges to health accessibility and social inclusiveness among this population must be providing adequate care and access to people explored. With this knowledge, stakeholders with SCI as they age? Several works have been can highlight initiatives towards materialising reported concerning premature ageing for SCI one of the principle values in the Agenda 2030; survivors, and such prematurity involves almost every single system in our human body. Studies Leaving No One Behind. have shown that musculoskeletal system and

With this impetus, our research group is driving works to evaluate clinical and rehabilitation outcomes among ageing people with SCI, compare these with younger individuals with SCI, and explore perceived barriers and challenges among ageing people with SCI for holistic rehabilitation care and services as well as their current state of quality of life. Our initial survey conducted in 2021 has shown that out of 380 patients with SCI that have attended our rehabilitation specialist clinic in the tertiary centre, 22.6% were those aged 60 years and above, with a mean age of 67.3. Compared to those below 60, older people had an incomplete injury type, more complications with neurogenic bladder, urinary tract infection, and a higher proportion of musculoskeletal disorders. Mobility functions, whether categorised as walking (with or without aids), ambulant wheelchair users, independent wheelchair and assisted wheelchair mobilisation, were more affected in the older SCI patients. More data are coming in from other districts of Sabah for a more comprehensive picture of common issues among ageing in SCI. At the time of writing, we are formulating a qualitative study methodology on identifying perceived challenges and barriers to receiving holistic rehabilitation care and services here in Sabah. With these findings, we aim to provide solid evidence to the stakeholders for more allocation of healthcare and rehabilitation resources beyond the urban areas and to advocate more opportunities for ageing SCI survivors with social inclusiveness.

Fatimah Ahmedy is a rehabilitation medicine specialist and Associate Professor at Universiti Malaysia Sabah. She received an MBBCh from Cardiff University in 2006, and Master of Rehabilitation Medicine (MRehabMed) from Universiti Malaya in 2018. Fatimah has worked in the field of rehabilitation since 2013 with a special interest in spinal cord medicine. She is a member of the National Project for Medical Curriculum Review for MRehabMed and the Conjoint Board for the same specialty. She has dozens of publications and received the Young Researcher Award in 2020 from Universiti Malaysia Sabah. It is her dream to have an attachment at the Swiss Paraplegic Centre.

Image provided by author

Al-based electrical stimulation for locomotion rehabilitation after SCI

Ahnsei Shon

Interestingly, people can walk while they are activities can be observed several decades texting or reading a book without much effort. of milliseconds earlier via a microcontroller unit than actual muscle movements. In our However, this simple task can be arduous for the people for those who are diagnosed with preliminary research, reduced sensory a spinal cord injury (SCI). Each year around feedback from peripheral nerves to the spinal 400,000 people, globally, are diagnosed with cord was observed after SCI. Also, CPG in the a SCI, mainly because of car accidents, falls, spinal cord can modulate rhythmic locomotor violence and sports injuries. Spinal cord injuries patterns with sensory inputs without the are one of the most debilitating injuries while involvement of higher brain areas. Although significantly affecting daily motor functions like the amplitude of electrical muscle activities locomotion due to primarily physical effects is weak after SCI, the small amplitude of muscle activities can be amplified to extract such as paralysis. meaningful data by electronic amplifiers and There is a secret of autonomous locomotion filters. Also, these data can be used to trigger closed-loop electrical stimulation. Based which is crucial for smooth and coordinated movement. The lumbar section of the spinal on these phenomena, we hypothesized that compensating for the reduced sensory inputs cord features a central pattern generator (CPG), that organizes and generates rhythmic to the CPG through the PNS would augment locomotor patterns by itself. motor outputs and improve locomotion after SCI. To evaluate our hypothesis, we developed a fully implantable neural interface system that In recent years, electrical stimulation directly accessing and utilizing the central nervous can record muscle activities from the extensor system (CNS), which consists of the brain muscle and stimulate the cutaneous nerve in the PNS at the stance phase. In our research, and spinal cord, has received much attention due to its almost immediate effectiveness in the fully implantable device greatly improved the range of ankle movement and the duration regaining locomotion, which was not previously of the stance phase. Also, a strong carryover achievable after SCI. However, extracting effect was observed in overall gait kinematics. intention through CNS requires huge

computing power with large and inconvenient devices. Additionally, CNS electrical stimulation turning on a precise set of neurons relevant to the locomotor can be a challenging task without activating neighboring unnecessary axons and cells because various types of neurons are densely packed in the CNS. Thus, undesirable stimulation can occur and lead to disorganized motor output, generating unexpected and unnatural movements, which can cause injury from unstable and imbalanced locomotion.

Contrary to CNS, peripheral nervous system (PNS) can be an alternative method for extracting intention by simply monitoring the electrical muscle activities from the targeting muscle because strong electrical muscle

It is rare that one fixed universal stimulation parameter for neural rehabilitation exists. Currently, the stimulation parameters, including intensity, frequency, and duration, should be readjusted manually by a clinician with the progress of rehabilitation because the therapeutic efficacy of electrical stimulation changes with time. Adjusting these various stimulation parameters at adequate times is hard to achieve every single time. However, Al algorithm can be one of the most suitable solutions for generating optimal stimulation parameters by allowing automatic and continuous updates at various circumstances without a clinician's involvement.

In our previous study, the fully implantable device showed the efficacy of activitydependent sensory nerve stimulation generated by real-time muscle activity recording. Now we are working on developing an Al algorithm which can be combined with the fully implantable device. Among various AI algorithms, reinforcement learning algorithm can be one of the most suitable solutions for generating optimal stimulation parameters for neural interface devices. Unlike traditional control theory, reinforcement learning algorithm does not require a detailed mathematical description of the relevant neural circuitry in order to extract an optimized stimulation strategy. In addition, reinforcement learning algorithm can generate stimulation parameters in real-time based on the incoming muscle activities recorded by our developed fully implantable device. By using a newly designed AI-based closed-loop sensory stimulation system, the weakened sensory feedback after SCI will be compensated by the timely generated stimulation pulses mimicking natural sensory feedback via the peripheral sensory pathway. We hope that our new approach and system can expedite recovery of locomotor function after a spinal cord injury.

Ahnsei Shon is a PhD candidate in multidisciplinary engineering at Texas A&M University, USA. Since 2008 he has been designing various biomedical circuits and devices, including neural recording/stimulation electrode, SpO2, EMG, ECG, EEG, ENG, fully implantable neural interface systems. Also, he has work experience within various government-funded research institutes including Korea Institute of Science and Technology (KIST), National Rehabilitation Center (NRC), and Korea Institute of Machinery and Materials (KIMM). His current research focuses on neural interface systems for gait rehabilitation after spinal cord injury by using sensory electrical stimulation.

Activity-based therapy after spinal cord injury

Rija Kamran

Spinal cord injury is a lifelong illness that Secondly, to build a partnership including results in loss of movement and sensation in people with SCI and providers involved in various parts of the body. People living with activity-based therapy to implement a research Spinal cord Injury usually require lifelong study to understand the perspectives and rehabilitation. Most of this rehabilitation and experiences of people receiving and providing treatment is focused on teaching compensatory activity-based therapy. approaches, utilizing the remaining functions of the body. My research is on a therapy The potential results of this project will contribute to connecting all these services and approach, activity-based therapy, that focuses on the neuro-recovery approach instead forming a partnership that builds a community of practice of activity-based therapy in the of the compensatory approach. Activityfuture. I consider this research as a first step based therapy focuses on training the body towards forming a global community of practice parts below the level of injury. This therapy for activity-based therapy and neuro-recovery is repetitive and aims to retrain the body for approaches for Spinal cord injury. specific movements. Activity-based therapy is beneficial to improve motor, sensory, bowel, and bladder functions.

Despite the research backed value of activitybased therapy, there is a lack of awareness and access to activity-based therapy in Canada. Activity-based therapy has most potential when started immediately after the injury, however lack of a formal mechanism and integration of ABT in regular rehabilitation protocols leads to a delay in access.

The goal of my research is twofold. First, is to understand the experiences around activitybased therapy by talking to people who are providing and receiving activity-based therapy after Spinal cord injury, in a series of interviews. The information gathered will help us better understand the potential and perspectives about activity-based therapy after a spinal cord injury. The whole process will be guided by a research team, which will include two patient advisors. The outcomes of this project will include a set of themes explaining patient and therapist perspectives on ABT after SCI, patient's perspectives on why activity-based therapy was sought and how it compares to previous therapies as well as recommendations for improving activity-based therapy provision.

Image from disabilityimages.com

Rija Kamran is a physiotherapist from Pakistan and a Graduate student in the Faculty of Rehabilitation Medicine at the University of Alberta, Canada. Her research is in the area of spinal cord injury, and her current projects focus on community-based and patient-oriented research, and activity-based therapy.

COMMUNITY OF PRACTICE FOR ACTIVITY-BASED THERAPY FOR NEURORECOVERY

Image provided by the Spinal Research Institute

From autoantibodies that combat the SILENCE in traumatic spinal cord injury treatment

Annika Guntermann

Probably everyone knows someone who has a spinal cord injury (SCI), or at least someone who knows somebody. For me, it was my neighbour of almost the same age who suffered an SCI due to a motorcycle accident. Then he fell into a coma. Now, he is paralysed from the abdomen downwards. However, he has fallen in love with his physical therapist and hopefully will be able to drive an adapted car at some point. This is one reason why SCI research matters: Despite this stroke of fate, it is worthwhile to continue living one's life as much as possible; to use it as a new chance, while SCI research moves forward.

Only a few are aware that such a fate does not always lead directly to a standstill. Indeed, to date no curative treatment is possible and despite medical advances, the rate of recovery has also not changed over the last twenty years (Bourguignon et al., BMC Medicine, 2022). But how do we finally combat the silence of traumatic SCI?

SILENCE is the name given to Spinal Cord Injury-induced Systemic Maladaptive Immune Response and Autoimmunity to Central Nervous System Antigens - European Network Approach. It may sound a bit complicated at first glance so, I will explain to you why this project matters and what it means to me. My PhD project is part of this transnational ERA-NET NEURON project and comprises two research groups from Germany (of which one is now in Ohio, USA) as well as one group each from Austria, Italy and Switzerland. When my supervisor gave me the offer to work on this project in 2019, it immediately grabbed me in a way I had never experienced before: curiosity, awe, researcher tingle, responsibility to contribute with a tiny piece to the advancement of SCI research. Thus, effective

treatment options may be discovered and patients' quality of life improved.

Oh well, to get back down to earth: paralysis or loss of sensation is just the tip of the iceberg. Besides other secondary complications and comorbidities, SCI also disrupts the control of the immune system. On the one hand, this makes SCI patients more vulnerable to infections. On the other hand, they may paradoxically have elevated levels of so-called autoantibodies. These are formed against antigens, meaning tiny small substances or structures, of the injured spinal cord tissue. Briefly explained, those now becoming autoantigens trigger a maladaptive immune response. This results in autoantibodies recognizing and attacking the body's own injured spinal cord tissue or associated substances as "foreign", rather than attacking only true foreign particles from influenza viruses, for instance, as under normal circumstances of an immune response.

My aim is to ascertain more about the impact of the immune response following a traumatic SCI on patients' neurological as well as functional rehabilitation outcome, because that is at present still an enigma.

To this end, I am investigating autoantibodies, found in the blood sera, of traumatic SCI patients over a course of time. Their blood was drawn at both 1 and 12 weeks after injury, covering an early as well as a subacute stage. Subsequently, each blood serum sample was separately incubated with a so-called protein microarray chip. It is a small glass slide, coated with a membrane of nitrocellulose. This membrane contains more than 9,000 different human proteins, here representing all the different autoantigens to which potential autoantibodies from the blood serum could bind. Using additional fluorescence labelling, it is then possible to detect with a scanner where an autoantibody from the blood has bound to an autoantigen on the microarray chip. The stronger the autoantibodyautoantigen binding, the more intense the fluorescence signal and the more significant the autoantibody probably is in the SCI context.

Now, in 2022, I can say that with SILENCE we have contributed a little more in combating the research silence in SCI treatment. In future, some of the significant autoantibodies with their corresponding autoantigens might provide a meaningful, patient-specific prognosis and become suitable targets for an immunomodulatory treatment of SCI. I am proud to be part of this project, enabling an international exchange from "bed to benchside" and beyond.

Independent of my research, I joined the Wings for Life World Run this year already for the third time. I was one of more than one hundred thousand runners and wheelchair users side by side, whether in Munich or Melbourne. All donations and participation fees contribute to SCI research. Because of the COVID-19 pandemic, running against a virtual "catcher car" is possible. Thereby, I was even more motivated when it said to me something like "you go off like a rocket, thank you for your dedication!"

Summarizing from my perspective, curing SCI is a global task that most likely cannot be solved by a single researcher or in silence, only together and that is the matter.

Annika Guntermann is a biological PhD candidate at the Medical Proteome Center of the Ruhr University Bochum in Germany. After completion of her PhD, Annika would like to continue in the field of spinal cord research related to neuro-immune interaction. She would like to collaborate with other (inter)national researchers. During her masters studies, Annika spent a semester in Sweden and in 2020, she completed a research placement in Austria, where she experienced other methods in spinal cord injury research. Since spinal cord injury can happen to anyone, Annika realises the importance of her research every day.

When research isn't sexy but still matters the impact of oral health after spinal cord injury

Dr Jennifer Coker

In February of 2019, the SCI 2020: Launching a Decade of Disruption in Spinal Cord Injury (SCI) Research meeting was held that brought together a broad range of stakeholders involved in SCI research and treatment. One of the sessions focused on the needs of people living with SCI and the key takeaways were that, "the SCI community is overwhelmingly" tired of media hype about research results that have not yet been translated to treatments that are not clinically available," that "research is driven so much by innovation that studies needed for translation are considered not innovative and rarely get funded," and that "treatments leading to small improvements in daily life are highly desirable."

Now, let's replace the word "innovative" with "sexy." If research that is not sexy does not get funded, then results from these studies are not translated into treatments to improve the lives of people living with SCI. But just because research isn't sexy and doesn't promise a huge BREAKTHROUGH! or CURE! doesn't mean the research isn't important and can't lead to improvements in quality of life and health for people with SCI.

One such understudied area in SCI research is after SCI, including spasticity and neurogenic bladder, can lead to dry mouth that increases the importance of oral health to physical health and well-being after SCI. It is very well studied the risk of cavities. Pain and tooth loss may in the general population, with good oral health make using mouth-held adaptive devices more known to be integral to our general health. Oral difficult; similarly, devices such as mouthsticks can damage the teeth and cause oral injuries. diseases are among the most common noncommunicable diseases and can have persistent negative effects on the health and well-being Oral health education for people with SCI and their caregivers is generally lacking in the of a person throughout his or her lifetime. rehabilitation curriculum. Anecdotal evidence In fact, the World Health Organization even has elevated oral health as a global concern suggests that rehabilitation educators typically address oral health care simply by advising to overall health and well-being. Poor oral patients to brush, floss, and see a dentist health is associated with bacterial infections, regularly..."just keep doing what you were respiratory disease, and pneumonia – all doing before." Dental providers and office staff common secondary conditions after SCI – as

well as diabetes, heart disease, and stroke. Poor oral health can directly impact psychosocial well-being as well. Dissatisfaction with one's oral health can decrease social functioning as people tend to avoid conversation, smiling, and laughing, decrease quality of life and employment outcomes, and be a barrier to social participation.

Yet, research on the impact of poor oral health on the lives of people with SCI is limited. In the few studies that have been done, people with SCI had poorer oral hygiene, more oral health problems, and higher levels of depression and anxiety than those without SCI. Numerous factors may serve as barriers for people with SCI in maintaining good oral health or accessing appropriate and timely oral health care. We all know the significant financial burden of a SCI – it makes sense that visits to the dentist become a lesser priority. Injury-related functional limitations, such as impaired finger movement and decreased strength can impair one's ability to brush and floss or can result in needing assistive mobility aids and devices (e.g., power wheelchairs), that may pose barriers to accessing care in the built environment. Medications to treat common complications

may not be aware of the special needs of people with SCI and may be wary of treating them, and people with SCI may avoid going to the dentist for this same reason.

I am currently conducting two recently funded studies on the impact of oral health on physical and psychosocial health in people with SCI. Both studies are in the early days, but already we are learning so much. Surprisingly, our participants with SCI are very well educated on the importance of maintaining good oral health to maintaining their health overall, and not just the one participant who happens to be married to a dentist! A prominent SCI researcher noted in a recent talk that "rehabilitation may not be seductive or sensational, but often the less sensational option is the most effective." If we are able to establish that oral health is related to secondary conditions after SCI and that providing restorative and preventative dental care after SCI is able to decrease secondary complications and increase quality of life, we will be able to do exactly what people living with SCI are asking of us as researchers - translating small findings into tangible improvements in health and quality of life!

What could be sexier than that?

Jennifer Coker has worked in the field of traumatic spinal cord injury since 1997. She obtained a Master of Public Health (MPH) in May 2001 and a PhD in Clinical Science from the University of Colorado-Anschutz Medical Campus in 2020. Dr Coker has won several awards for research presentations and publications, including the James W. Alley Award for Outstanding Service to Disadvantaged Populations and the **American Spinal Injury Association** MJ Mulcahey Award for rehabilitation outcomes measurement. She has been at Craig Hospital since April 2012 and is the Co-Project Director of the SCI Model Systems and PI for several other projects.

Image provided by author

Is depression just a psychological consequence of spinal cord injury?

Dr Shambhovi Mitra

Depression has been seen as a mind problem, but is it? In my doctoral work, I tried to investigate this query. Research on depression has indicated depression is associated with autonomic nervous system functions in an individual. The autonomic nervous system regulates the body functions like heartbeat, respiration, digestion, urination, defecation, and sexual arousal. Depression is inversely related to the autonomic nervous system function esp. that of the heart. The fluctuation observed between consecutive heartbeats is heart rate variability (HRV), and is associated with depression. The presence of high HRV lessens the chances of the person being at risk for developing depression.

The association of HRV with depression represents the concept of "mind-body interaction" for the regulation of emotion. Depression is an emotion-based disorder, thus the association. An individual with a high HRV can regulate their emotions better in response to a situation and reduce the risk of developing depression than one with low HRV.

In spinal cord injury, the autonomic nervous system function is impaired. Research into this aspect of depression in spinal cord injury was deficit. Depression is known to have both somatic i.e. body related symptoms like loss of appetite, insomnia, etc, and behavioural manifestations like bad mood, suicidal tendency, lack of interest in doing things, etc. Thus, through my doctoral work, I tried to

The spinal cord injury individuals with low HRV The observations were similar to those of the western population where the risk of depression has been documented highest in the first six to eight months post-injury. Depression being heavily influenced by coping, we observed that acceptance of injury and its consequences influence depression in a later phase of injury. The SCI individual who has accepted the injury has less risk of developing depression. Thus, the mind-body interaction in depression plays differently post-injury. Initially, the body functions represented by HRV influence depression, and later part of the injury, it is the mind as acceptance of injury influences depression. Thus, depression is a psychophysiological construct.

Depression post-injury is not just one time, it is a longitudinal problem. We further looked into how depression manifests longitudinally. We are the first to study depression longitudinally in India. It was observed that depression was reduced over a period of time contrary to the belief that once depressed will always be depressed. This phenomenon represents the idea of the "Disability Paradox" i.e. presence of well-being irrespective of disability. Compare to the western population, in the Indian population reduction in depression was observed. We further investigated to understand the possible reason for the reduction in depression. The interesting observation was that the HRV post-injury measured within one year was associated with cognitive adaptation to injury. High HRV is associated with better cognitive adaptation

of depression longitudinally. On the contrary, initial coping post-injury was not associated with depression longitudinally.

My work adds a new perspective to the understanding of depression in spinal cord injury. Just because you have an injury does not make you depressed. The autonomic nervous system function post injury is associated with depression and well-being. The take home message is that HRV-based screening of the patients with spinal cord injury can act as a risk screener for mental health issues.

Dr Shambhovi Mitra wishes to acknowledge her thesis supervisor, Dr Varsha Singh, for her support and insight into the research area of depression post spinal cord injury.

Shambhovi Mitra has been an Assistant Professor (Physiotherapy) at the Indian Spinal Injuries Centre since 2011. Her research includes the influence of cardiac autonomic regulation on depression post spinal cord injury. Shambhovi received her PhD from the Indian Institute of Technology in Delhi with a focus on understanding the role of the nervous system in depression in spinal cord injury.

Breathing life into SCI research

Dr Anne E Palermo

The COVID-19 pandemic cast a new spotlight Clinical interventions to treat poor respiratory on the importance of respiratory function. function are well established but assessments The world was shocked to see 'young and and interventions may not consistently healthy' individuals severely impacted by this translate to the clinical care of individuals disease, causing them to require a ventilator with SCI. People with SCI have many pressing to breathe. A similar shock is present when a clinical needs acutely and chronically and it 'young and healthy' individual experiences a appears that respiratory care may not always be top priority. Similarly, research investigates spinal cord injury (SCI). A SCI impacts more than the ability to walk, it alters the sensation regenerative medicine, implantable of touch, the ability to go to the bathroom, even neurostimulators, exoskeletons, and more, but for over 40 years we have not been able the ability to breathe. Changes in respiratory function after SCI may require an individual to find ways to prevent people with SCI from experiencing respiratory complications. to use a ventilator to breathe for the rest Curative research is very important and truly of their life, heavily impacting the ability to incredible but respiratory function needs to be participate in rehabilitation and quality of life. Other individuals with SCI may not have a topic of deeper exploration so that individuals visible signs and symptoms of pulmonary with SCI are healthy enough take full advantage of the advances in the field. issues but they may experience pneumonia or respiratory complications at a higher rate than Respiratory function research is an avenue I someone without SCI. The emphasis on lung function brought about by COVID-19 may have have great interest in as a physical therapist, secondarily improved awareness of respiratory researcher, and a family member of an impairments in people with SCI. individual with tetraplegia. When starting my

The goal of SCI research is to answer questions that are meaningful to people with lived experience of SCI to hopefully improve their quality of life. Poor breathing function has been a leading cause of death for people with SCI for over 40 years, which is why research into this area is of great importance. Some people living with SCI who breathe independently (without the use of a ventilator) may not realize they are at risk of a respiratory complication. However, there may be some subtle clues that your respiratory function could improve.

- Do you have a difficult time sneezing, coughing, speaking loudly or for a long time? - Do you find that you get short of breath when pushing your wheelchair even for short distances?

- Have you had COVID?

If you answered yes to any of these questions, you would likely benefit from improvements in respiratory function.

research into respiratory function after SCI I found it necessary to explore and expand upon assessments used to identify individuals with SCI at risk of impaired breathing and respiratory complications that lead to poor outcomes. Research findings now show that breathing assessments thought to be the "gold standard" measures of respiratory function should likely be accompanied by additional SCIspecific assessments. My future will investigate how well the new SCI-specific measures can identify people at risk of respiratory compromise before they start experiencing symptoms.

Improvements in detection are important to identify individuals with lived experience of SCI at risk of respiratory compromise but, once risk is detected, evidence-based interventions must be readily available. Research shows that when individuals with SCI complete supervised inspiratory muscle training by breathing through resistive training devices, pulmonary function improves and

decreases the risk of developing a respiratory complication. However, the high rates of pulmonary complications gives evidence that people may not be performing these types of training protocols outside of research studies. The devices can be costly and barriers to healthcare access can limit clinical supervision. I have found that individuals with SCI do adhere to a home-based, app-led, inspiratory muscle training program with once-weekly virtual supervision in attempts to provide clinicians and individuals with SCI an alternative to constantly supervised sessions. I am also investigating the usefulness of straws as training devices to improve availability and limit the cost associated with other inspiratory training methods.

Through my research I will continue to increase the awareness of the respiratory impairments commonly experienced by individuals with SCI. I will continue this line of research to expand access to cost effective inspiratory muscle training solutions. My future projects will aim to empower individuals with SCI by providing them the tools and the knowledge to improve their health and quality of life.

Dr Anne E Palermo is a physical therapist and researcher completing a postdoctoral fellowship at Neuroscience Research Australia. Her research focuses on secondary complications of spinal cord injury, specifically respiratory and balance function. The Function in Sitting Test for individuals with spinal cord injury (FIST-SCI), a product of her dissertation work, is used clinically throughout the United States and is being translated into Portuguese, Chinese, Italian, and Spanish. She is currently investigating interventions to improve respiratory muscle function, including abdominal functional electrical stimulation, with the goal of improving the evidence base for clinical practice.

Image provided by author

Effects of dual task exercise training on balance in elderly population with spinal cord injury

Assistant Professor Kanchan Koul

Impaired balance is a serious problem associated with spinal cord injury (SCI). The ability to walk safely while concurrently conducting different types of dual tasks is crucial for daily life. The contribution of different walking types to dual task performance has not yet been determined, nor is there any agreement on the strategies that people with SCI used to divide their attention between two tasks (task prioritization).

As the subjects live longer with disability following SCI, they are more vulnerable to the effect of sedentary lifestyle and chronic disabilities such as balance and coordination impairment, and they are prone to physical deconditioning and decline in motor performance. These are common as people with SCI age and they often coexist causing mobility limitations. They are also prognostic of future adverse health events including falls. Balance exercise training increases the gait speed and increases a variety of spatial and temporal gait variables. It is established that physical activity improves cardiovascular outcome and reduces risk factors for heart diseases and stroke.

Dual task training has been used in this study, as it suggests that the sensory motor processing is essential for motor control that requires attention resources. Balance training can also improve the quality of life of subjects with SCI. The current protocol was not specifically designed to improve isometric strength in the participants, but improvement in isometric strength in our subjects was an additional benefit.

The objective of the study was to evaluate the effects of dual task exercise training in the SCI population to improve their balance and to improve their quality of life by improving

their functioning. We have studied 20 subjects ranging in age from 60 to 80 years. Both male and female ambulatory SCI patients with minimal gait deviations were selected on the basis of ASIS Scale with minimal motor and no sensory loss as an inclusive criteria. Pre and post evaluation was done using Berg Balance Scale. Subjects with SCI were given dual task balance exercise training for 24 weeks. Outcome measures were evaluated on the Berg Balance Scale. Impairment and disability levels were assessed on the basis of ASIA Scale. Our research study has shown significant improvement in balance among subjects with SCI following balance training.

Dual task training was found to be very effective in improving functioning, gait parameters and improving quality of life for patients with SCI. We suggest additional research should be done in this area to explore further possibilities to improve life for the SCI population.

> **PRIMARY TASK** (MOTOR SKILL)

Dual task training involves doing a primary task like maintaining postural control or walking speed while performing a secondary task such as counting backwards or naming objects.

Kanchan Koul is working as Assistant Professor at Rajiv Gandhi University of Health Sciences in Bangalore, India. She is also a senior neuro-rehabilitation consultant at Acharya Institute of Health Sciences in Bangalore, India. Kanchan has nine years experience in treating and assessing spinal cord injuries. She researches various difficulties performing activities of daily living among people with spinal cord injuries. Kanchan enjoys teaching students of different social and cultural backgrounds using constructive and effective teaching methods.

SECONDARY TASK (COGNITIVE ACTIVITY)

Lived experience of adult students with spinal cord injury returning to study in Bangladesh

Arifa Jahan Ema

"In late 2018, we saw a photo in a Bangladeshi Most students with SCI appeared for exams only without attending classes physically due newspaper where a mother was carrying her adult son with a disability to the exam to accessibility issues at the academic institute. hall during an examination. Instead of using Stairs everywhere and no ramps, classrooms in multi-storied buildings, inaccessible toilets, a wheelchair, as the mother was carrying and inaccessible public transport to commute him, the photo instantaneously went viral on different social media platforms in Bangladesh between home and educational institutes to portray the mother's love. The mother restricted their education participation. When later got included in BBC's list of influential they appeared for exams, most were carried and inspirational women. It was indeed very by someone else to the exam room upstairs. inspiring. However, while watching people Simply changing the classroom to downstairs applauding her, I wondered how much it hurt significantly increased some students' physical her physically and emotionally to carry her participation. adult son. How did she feel? How did her son Nonetheless, accessing class lectures or feel to be carried by his mother? Did it make educational material always remained him proud? Or was carrying him instead of challenging. The inaccessibility issues, stigma, using a mobility device her only option?" – shared Mr X when I interviewed him for my stereotypes, and prejudice around disability MPhil research work. Mr X was a student with made it harder for the students with SCI to spinal cord injury (SCI), studying in Grade fit in and resulted in bullying and isolation. 11 and living in a rural area of Bangladesh. I Mr C said, "everyone stares at me in school interviewed Mr X for a study where I explored like I am in a museum, and they have never the lived experience of adult students with SCI seen anything like me before, which is very discomforting". Female students with SCI were returning to study in Bangladesh, a low-andmiddle-income country. My first-hand working doubly discriminated against, first, as a woman and second, as a woman with a disability. For experience as an occupational therapy clinician with this group of people and minimal researchexample, Ms Y's family did not want to allow based evidence in this area convinced me to her to resume pre-injury education as they explore this topic through my research. prioritised their son to have a better education than their daughter with a disability. She was also labelled as "the crippled one" among her What did I find? classmates, and because of this, she cut ties with them. Although some students with SCI I interviewed 15 adult students with SCI in cut their relationships with their friends due Bangladesh. They had their SCI between 15-18 years of age and had completed their to negative attitudes, most of them referred rehabilitation at the country's only specialised to their friends "as the same friends they had in their pre-injury life". Some teachers also SCI rehabilitation hospital, widely known as the Centre for the Rehabilitation of the Paralysed showed negative attitudes primarily due to a (CRP), and returned to study after discharge. lack of knowledge about SCI-related issues, but in general, meaningful relationships with friends, classmates, and teachers played a crucial role in facilitating students with SCI.

The SCI was their most critical life event that brought drastic changes to their post-injury life regarding occupational role performances. Why does my research matter, and what's next?

My research is a stepping stone in this topic area in Bangladesh. The CRP provides SCI rehabilitation services to 300-350 people annually; and estimates have been made that among them, 20-25% are students with SCI. While education should have been a fundamental right for everyone, this study showed that it's more like a privilege for this considerable number of people with SCI in Bangladesh.

There was a rapid change in the field of disability and rehabilitation in Bangladesh, from enacting disability-related policies to promoting inclusive education. Yet stories like the one about the mother carrying her son to his exam made me pause and reflect. Did we really progress? Having policies does not guarantee practice. There is still a lot to work to be done removing barriers to ensure quality education participation despite disabilities. Obstacles do not come in the same shapes and sizes. They are unique but interconnected. So, removing one barrier does not ensure quality participation. Therefore, a collective effort is needed from the rehabilitation professionals, students with SCI, their families, friends and teachers, and policymakers to enable equitable participation alongside the non-SCI students. Diversity and inclusion go hand in hand. So, we need more such research work to hit the status quo and change the narrative because inclusion in education must be seen as a non-negotiable priority.

Arifa Jahan Ema is an Occupational Therapist experienced in working with people with spinal cord injury. She is currently working as a Lecturer at the Department of Occupational Therapy at the Bangladesh Health Professions Institute where she is involved in undergraduate teaching and is one of the founding team members starting the MSc in Occupational Therapy Program in Bangladesh. Her research interests include occupational participation, community reintegration, inclusion, accessibility, education, and employment. Arifa is working as a Governing Panel Member of the ISCoS **Occupational Therapy special interest** group to promote Occupational Therapy and spinal cord injury education, clinical practice, and research.

Image provided by author

Can we turn the upside down quality of life of individuals with spinal cord injury right side up?

Dr Bakhtawar Qureshi

Spinal cord injury (SCI) produces drastic effects access to all the needed facilities, were all on the life of an individual, bringing them from found to be factors affecting QOL post SCI. a level of independence and performance of simpler tasks with autonomy, to the level So, here is a question worth discussion. Are of complete or partial dependence for daily we seeing the life of an individual with SCI in life chores. Hence, the diminished quality of all these contexts individually? How many of the aforementioned factors are being openly life (QOL) people with SCI experience on the and clearly addressed for SCI individuals whole. beyond the cultural, social and environmental This QOL is more than merely scientific restrictions? When we talk about a free society with equal rights for all humans we somehow, terminology when it comes to the life of a person that has been shaken by an event that deep in our hearts, believe that this equality could be as small as stumbling on a step or means more for the persons with SCI. This slipping over on a lubricated surface. That's equality is what serves as their living potion. how in a millisecond a small strike to the core The feeling of being cherished as a human on whose entrance heads turn out of awe and pillar of one's body can turn the life of a person upside down. The feet he used to walk and inspiration, not pity. Someone who doesn't need to wear the sight of confusion while sitting run with become a pair of flesh and bones beside those stairs finding a walkway for his that remain stuck to the body but are merely wheelchair. Someone who doesn't shed a tear spectators. They can't help but witness the person they belong to, getting shattered over on the feeling of pain shooting out from or on sight of small discolored swollen patches of skin their sight. they would lie on.

The results of almost all 90 articles of varying study designs in our systematic review more or less reflected the negative effect of SCI pertaining to almost all the domains of QOL. The physical, psychological, social and environmental domains of QOL scales being the comparatively prominent ones in regards to the most affected and least affected aspects of QOL of an individual with SCI as per the findings of majority of included studies.

To name them, individual's age at time of injury, time since injury, completeness of injury, level and severity of injury, cause of injury, development of complications post SCI event, autonomy, extent of dependence, physical activity, ability to drive, social and community participation, perception about one's own injury, employment and marital status, family and social relationships, social equity, easy

Pertaining to our systematic review, it wasn't only epidemiological statistics that almost varied for all the countries but the QOL domains were what caught our eye. The major domains of QOL showed variations among various countries across the globe. This came as a surprising ray of hope because if one domain is less affected in one country it's obviously something achievable.

Besides, what caught our attention was the fact that the causative agent of SCI is at times in itself a traumatic event to recover from. The participants involved in the majority of studies included in our review reported traumatic causes of SCI, reflecting comparatively lower QOL scores specifically pertaining to the physical and mental health domains of QOL among those injured due to a gunshot as

compared to the ones suffering from SCI due to a non-gunshot event. Further, in light of the study's findings, etiology of SCI is a strong determinant of certain needs of a SCI individual post injury including the need to hospitalize and the self-perception of such a person regarding their own injury.

Another reason appeared. Global peace is not just something worth achieving but is essential in regards to matters of life and death, not death in just physical terms but in terms of the inner self as well. SCI is regarded as a global issue. Global issues need global attention and a subject of global attention requires global efforts.

This systematic review was able to reveal the aspects of QOL deemed as necessary for SCI individuals otherwise overlooked. Varying effects of SCI pertaining to different domains of QOL can light the way for future research studies. Evidence-based approaches in preventing or reducing the drastic effects of SCI regarding improving the QOL of SCI individuals will allow us to witness them wheeling around with heads held high while moving even faster than any man's limbs would make him run.

Dr Bakhtawar Wajeeha Qureshi is a Physical Therapist at Prime Foundation in Riphah International University, Pakistan. She completed her Masters degree in neurological physical therapy with a research project focusing on quality of life of persons with spinal cord injuries. Currently, she is undergoing training as part of a joint research development program between Oxford University, Nairobi, and Agha Khan University, Pakistan, while serving as a full-time research officer in Prime Foundation. With neurology being her specialty and research her passion, Bakhtawar strives to combine her interest and passion to implement positive change.

Can you hear a million voices?

Elin Salmiranta

In the song 'Voices', Sweden's contribution to The Eurovision Song Contest 2021, the singer Tusse asks, "Can you hear a million voices?" When listening to the song – by the way, it is a great song! – I thought about the million voices of caregivers of children with spinal cord injury (SCI).

I became one of these million voices eight years ago, when my then 7-year-old son got a SCI. It started one evening in November. My son had complained about pain in his back for some time, but the local doctor did not think it was anything serious. That evening my son's pain got worse and suddenly his right leg became numb. We went to the emergency room and waited for almost 24 hours for a magnetic resonance imaging (MRI) examination while my son lost function after function, from the ability to move his legs to the ability to empty his bladder. When the MRI finally was done, a neurologist told us our son had a cavernoma, a vascular malformation, high up in his spinal cord at the C4-6 level. He was moved to the intensive care unit and was surrounded by staff putting needles in him and connecting devices to him. My son was now completely paralyzed from his chest down and he could not feel or move anything below that level. He could not move his hands and had a hard time breathing. After a couple of days, we were taken to a room full of doctors and told our son had a permanent SCI. I left that meeting feeling as if I was falling into a big black hole.

experimental subjects and health professionals Since that horrific first time after my son got the injury, we have fought hard to get the are the only ones called experts. support he needs. We need help from many different healthcare settings and other support I cannot represent a million voices, but my systems, for example children's hospital, intent is that you will hear some of us. In my training centers, habilitation center, assistive PhD research project, I want to help caregivers voice improvements in follow-up care for device center, municipality, social insurance office, insurance company and school, to children and adolescents in Sweden. We will name a few. All these places and people rarely use participatory research methods to include caregivers and other people that are important communicate, coordinate, or plan activities together. Each clinic has its own communication for the children and their families, for example channel and schedule. It is our responsibility health professionals. The research will be a step

as parents to coordinate all the activities, book appointments and create a schedule that works for our child. I often fear that important information is getting lost in this complex system. I do not understand my role and I often feel like I am in a fight with the system instead of the system supporting us. We live in Sweden, but we have also been to the USA to access highly specialized SCI care for children, which is not available in our home country. I have met caregivers from all around the world when visiting the specialized hospital and I am part of several international communities of caregivers of children and adolescents with SCI. I hear similar experiences as mine, from caregivers in Sweden, other countries, and in research. We are part of a million voices describing a system that does not work and where our children are not getting the support they need.

Can you hear a million voices? In my first study as a PhD student, I have explored the voice of caregivers of children and adolescents with SCI in research. The results show that caregivers' voices are unheard. Most often their role is only to answer questionnaires to measure things or to develop a measure, and their answers are presented only as statistics. Representation of caregivers in research is additionally limited considering that more than 90% of the research is performed in the USA and to a large extent by the same specific hospital organization. When the research protocol is described in research articles, caregivers are often described in words that imply that they are just

towards hearing a million voices and improving the care and health for our children.

A complex system

Elin Salmiranta, B.eng, MSc, is a PhD student at the Research School of Health and Welfare, Jönköping University, Sweden. Her research focus is to explore and improve the health of children with SCI by focusing on the role of the caregivers. She is herself a caregiver and has a background as an IT engineer and business systems consultant. She chose to change her career because her son suffered from an acquired SCI in 2014 and she discovered many shortcomings within the healthcare system and other parts of society regarding care and support for children with SCI and their families.

Images provided by author

Accessible communication and research

Disability is an evolving condition with which the person with a spinal cord injury (SCI) lives. Disability concerns society and not the person with SCI.

Environmental factors can change, either suddenly or over the years, such as ageing, extreme weather events, pandemics, or leaving of the caregiver or the relative who may be caring for the person with SCI. All of these are reflected in the WHO Health Status Model, the ICF (International Classification of Functioning, Disability and Health). They interact and affect the individual's participation in family, professional and social life.

With a vision to 'facilitate healthy and inclusive long-life for people with spinal cord injury globally', the International Spinal Cord Society (ISCoS) has endeavoured to promote the highest standard of care, providing scientific exchange among our members and others.

Through this medical and multi-disciplinary team of professionals and giving the possibility of creating networks, collaborations, and participation in multicentre international studies, we foster education, research and clinical excellence.

Promoting international collaborations such as the one with the World Health Organisation (WHO) and International Society of Physical and Rehabilitation Medicine (ISPRM) and the creation of IPSCI (International Perspectives on SCI), ISCoS also aims to change health policies for individuals with SCI in different countries. The use of common terminology (ISNCSCI, ISAFSCI) and common Databases will give us the opportunity to have comparable results between different countries.

For over sixty years, we have shared evidence-based scientific information through our publications, correspondence, exhibits, regional and international seminars, symposia, conferences, e-learning, podcasts and webinars. Our podcast and webinar series SCI Care "What really matters," ensures information, education and communication are accessible to all. Healthcare professionals, persons with SCI, family members, and caregivers alike can learn and enjoy each episode.

With each initiative, we step further towards a unified standard of care within SCI worldwide. We cannot, however, do this alone, and working in collaboration with national and international bodies, encourages the most efficient use of available resources worldwide.

The contribution of the Spinal Research Institute towards research and communication in an accessible manner is of high importance, facilitating networking between health scientists in a modern way, effectively involving the people with SCI themselves and this is in agreement with the goals of ISCoS.

Do you have research to share? We invite you to submit an abstract for the 62nd ISCoS Annual Scientific Meeting taking place in Edinburgh, UK 8 – 11 October 2023.

Dr Christina-Anastasia Rapidi

Hon. Secretary of ISCoS & Head of PRM Department, Rehabilitation physician, MD, PhD, LFEBPRM at General Hospital of Athens "G.Gennimatas"

Why Research Matters - Previous Editions

The 2021 edition of Why Research Matters contained 8 written pieces.

Contributing researchers were from 5 countries.

View Edition 2, 2021

The 2020 edition of Why Research Matters contained 12 written pieces.

Contributing researchers were from 8 countries.

View Edition 1, 2020

The Spinal Research Institute's Programs

Spinal Cord Research Hub (SCoRH)

The Spinal Cord Research Hub (SCoRH) is the world's first online platform for spinal cord injury research collaboration. This Australian innovation was developed by the Spinal Research Institute, with support from leading local and international experts in spinal cord injury research, and launched in 2018. SCoRH enables researchers and clinicians to connect, share and collaborate in one easy-to-use online space, and to work across health disciplines and geographic boundaries to impact greater numbers of health outcomes for spinal cord injury.

Mentor Program

The Spinal Research Institute's Mentor Program was established in 2021 after being successfully piloted in 2019. The program has four aims:

- Progress the research careers of talented emerging researchers.
- Provide guidance and support to strengthen their specific research projects.
- Produce the next generation of leaders to advance spinal cord injury research more broadly.
- Enhance international collaborations in spinal cord injury research.

Mentoring in research equips individuals with skills that might not be available within their own organisation or institution. The mentor/mentee relationship is not bound by geographical limits, and supports growth beyond the mentee's physical location to help develop their networks for collaboration.

SCI Research Collaboration Grants

In 2017, the SRI commenced offering SCI Research Collaboration Grants to facilitate early to midcareer researcher attendance at the ISCoS Annual Scientific Meeting, with a particular focus on researchers from middle and low income countries. The objective of this grant is to support researchers to build their collaboration networks and develop future leaders for the next generation of researchers. Over the past five years, the Spinal Research Institute has offered 91 Research Collaboration Grants to researchers from 24 countries including 13 low and middle income countries. Five grantees had lived experience of SCI, and nearly 50% have been given to female researchers.

The grant enables recipients to exchange knowledge, and to build relationships with other researchers, institutions and countries involved in spinal cord research. Recipients of the grants represent diverse areas of research such as Psychology, Physiotherapy, Occupational Therapy, Nursing, Medical and Science backgrounds. Research focus areas include health integration, electrical stimulation, trunk control, food nutrition and epidemiology.

Collaboration Workshops

Collaboration workshops are all about connecting people, sharing practices, and disseminating information. These workshops provide the Spinal Research Institute with an opportunity to co-host with leading institutions in spinal cord injury research as well as connect with the international research community in an open discussion-style setting.

Outcomes from these workshops further our goal of building international research collaboration in a meaningful way for researchers, clinicians and consumers.

Consumer Engagement Program

In Australia, 20,800 people live with a spinal cord injury. They are key stakeholders in the research process and it is vital that their voice is heard to ensure that research meets their needs and priorities.

For the past two years the Spinal Research Institute has been actively progressing our innovative Consumer Engagement Program. This flagship program is working to transform the spinal cord injury research field by, for the first time in Australia, supporting people with lived experience of spinal cord injury ('consumers') to become involved in co-design and co-delivery of research projects. It does this by improving knowledge and understanding of the research process and upskilling members of the spinal cord injury community so that they can participate as partners in research.

The program also engages researchers, championing the inclusion of lived experience in research, and we aim to create a set of world first protocols to formalise and guide the consumer engagement process.

Increased collaboration between researchers and consumers will result in more relevant research, to improve outcomes for people with spinal cord injury in areas such as: respiratory and cardiovascular health, bladder and bowel function, sexual function, pain manegement, upper limb function (for people with quadriplegia), treatment of pressure sores, and management of sleep apnea - all secondary health complications of spinal cord injury that can impact on quality of life.

Discover more in our Impact Report 2022

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