NASCIC – SCI Moving Forwards Webinar Summary

Episode 1 – Virtual Care and Assistance

* Ask you provider what their current telehealth option is
* United spinal implementing tele-peer support options & peer support train-the-mentor is now online
* Medicare has lifted many prior restrictions on telehealth nationwide
* Pre-pandemic: very little access to virtual care. Ontario had something called Ontario Telehealth Network, which was a video link for remote, often specialist, consultations, where it required the healthcare provider to be present with a patient in a designated location. So, it wasn't particularly user-friendly, but it was far better than not having any remote support
* Post-pandemic: surge in use of virtual platforms; video approach to meet health provider needs. Increase use of public video conferencing platforms for 1:1 and group sessions
* VIP4SCI 🡪 Launched on April 2020. Readily available for computer, tablet, and phone.
* Client perspective:
* Improve access to primary care and community support closer to or at home
* Reduce travel and need for accessible transportation
* Improve information sharing and coordination between their service providers
* Single platform with which to manage their various supports
* Control – ability to decide who to invite in, when to invite them and what to share
* SCIO Perspective
* Increase frequency and ease of contact with clients in remote communities
* Reduce travel time and costs
* Increase capacity to support more clients
* Improve information sharing and coordination between the client’s service providers
* Challenges:
* Access to technology and reliable internet, especially remote communities
* Physicians could not originally bill for virtual visits – changing now

Episode 2 – Attendant Care in the time of COVID-19

* Hired care providers:
* Fearful of contracting COVID19
* Asymptomatic carriers
* Suddenly require self-isolation = not show up
* Not use newest PPE effectively/ shortfall of equipment
* Create a list of your network of supports: family, friends, students, unemployed friends 🡪 identify 2-3 individuals who agree to provide back-up care if required
* Familiarize yourself with training resources (ex; YouTube) to help your back up care providers deliver safe services to you
* Document your personal care plan/ directives in case of difficulty communicating
* Spinal Cord Injury Alberta developed online care provider training recourse
* Skin care and pressure ulcer prevention
* Feeding eating and swallowing
* General safety
* Mental health
* Personal care
* Respiratory care
* Basic anatomy
* Medication assistance
* Multiple resources for those needing care during this crisis:
* National disability COVID-19 healthcare advocacy and rapid response support hotline
* TAP partner – Facebook group for members needing a care attendant and share resources

Episode 3 – COVID-19 and the Latinx Community

* Latin community in San Francisco Bay area, they represent the highest percentage of COVID-19 cases and highest percent of hospital cases
* The reason Latinx communities are at risk of COVID-19 is because they have a higher prevalence of having diabetes and high blood pressure and in the Bay area they are of lower socioeconomic status 🡪 multiple generational households with small living space therefore difficult of social distancing
* Immigrants have fear of testing due to fear of tracing (undocumented)
* Immigrants are scared of going to hospitals for possible contamination
* Current solution: reach out to the Latinx community and emphasize they can reach their doctor through phone call or video call (TELEHEALTH). Additionally, can ask for a video interpreter.
* Due to COVID-19 many are fearful of health care services and care givers
* COVID-19 has impacted ability to hire, screen, and welcome them into someone’s home
* Pandemic also effected basic needs – difficulty getting groceries, transportation making it hard to access COVID tests, etc.
* Social isolation has increased
* Patients weren’t allowed to have family members during rehab process. Also, makes it challenging if the patient is monolingual in Spanish. The family support serves a critical component. Right now, they provide translators.
* Undocumented resources:
* Lots of organization that provide assistance regardless of immigration status
* Churches
* Get education and training services that can help yourself or a closer family member
* Independent living centers
* Important to have an advocate
* Culturally, Latinx individuals do not ask questions to authoritative figures due to not wanting to be perceived as less-understanding. Make it a point to get all the information and insist on asking questions.
* Important to determine if patient can get a professional translator – important for medical terms

Episode 4 – SCI Specific Health Concerns & Risks amid COVID-19 Crisis

* Not enough data to prove 🡪 Though SCI can affect the immune system, we do not know that it increases the risk of contracting COVID-19
* Anyone who has a significant health issue, such as respiratory compromise, is at a higher risk for complications if COVID-19 is contracted
* Test vital capacity (if vc remains the same as baseline, lung function is stable)
* Additional precautions for people with SCI:
* Ask your caregiver about travel history and exposure to people with symptoms
* Caregivers should be washing their hands before and after coming in contact with you
* Careful cleaning of common surfaces and equipment i.e. wheelchair, BiPAP
* Keeping in contact with your healthcare team (family doctor, respiratory doctor, pharmacist, case manager, caregiver, etc.)
* Proper use and dispose of PPE
* Reasons to seek medical attention
* Very short of breath
* Very high fever
* Low oxygen level, if measured
* Are unable to receive home care
* Self-advocacy 🡪 utilize resources such as My Health Passport to document all your care and medical needs

Episode 5 – Isolation & Mental Wellness During COVID-19

* Cognitive behavioural therapy (CBT) 🡪 understand and relate one’s thoughts, behaviours and emotions
* Cognitive distortions 🡪 tendencies or patterns of think or believing; that are false or inaccurate; and can cause psychological damage
* All-or-nothing thinking
* Overgeneralization
* Negative filter – focusing only on the negatives
* Jumping to conclusions
* Emotional reasoning – “I feel like a bad friend, therefore I must be a bad friend”
* Should statements
* Labelling and mislabeling – assign judgement of value to ourselves or to others based on one instance or experience
* Personalization – taking everything personally and assigning blame to yourself
* What is another way to think about the situation (without distortions) – important to modify thought
* We spend 40-80% of our day in automatic brain setting; we should learn to use prefrontal cortex more
* Practice wellness of curiosity and mindfulness
* 5 suggestions to help fend stressors off; bubble wrap:
* Morning gratitude 🡪 5 people in your life that mean a lot to you and send them silent gratitude
* Gratitude Jar 🡪 Before going to bed or during day, write something you are grateful for
* 2-minute rule 🡪 2 min of undivided attention to a person who might not be getting it (families)
* Increasing curiosity 🡪 find one new detail (FOND)
* Kin attention practice 🡪 send a silent good wish out to the people you see during the day

Episode 6 – SCI Nutrition 101: Health and Wellness during COVID-19

* COVID-19 Facts
* Best way to kill virus is to use soap to kill it
* Virus causes cytokine storm – over reaction of immune system. Causes tissue inflammation and damage
* SCI can have a negative impact on the immune system – therefore higher risk. Body’s do not initiate or respond to bacteria and viruses as strongly as they did pre-injury.
* Lymphatic system – dispose of toxins, waste and unwanted material in body – requires body movement to move fluid
* Poor diets/ nutrient deficiencies could be caused by economic costs, inability to make, etc.
* SCI are higher risk as they are higher risk of developing secondary health complications
* Average 7 secondary complications
* Body needs extra calories and nutrients to deal with all stress
* Stress can also lead to poor dietary choice and over-eating/ weight gain, both of which in turn decrease immune function
* Nutrients to support immune function:
* Vitamin C
* Vitamin A
* Vitamin D
* Selenium
* Zinc
* Omega 3
* Probiotics
* Herbs & spices (ex: garlic, turmeric, ginger, basil, cinnamon, etc.)
* Mushrooms
* Green Tea
* Eliminate to decrease inflammation:
* Refined sugar
* Refined grains
* Cow’s milk
* Salt
* Health tips:
* Sunshine
* Movement & Exercise
* Sleep

Episode 7 – SCI Adapted Exercise Resources

* Lack of assistance, lack of access, and pain are most common barriers
* Exercise guidelines for the SCI population
* Barriers to exercise
* Biological 🡪 body system
* Environmental 🡪 access to facility or equipment
* Psychological 🡪 motivation
* Sociological 🡪 don’t have assistance
* Inactivity or change in schedule can cause decrease in bone density, decrease in muscle strength, decrease lung capacity (diaphragm) and tissue necrosis
* Isolation can cause depression and stress (fight or flight)
* Studies found relationships between psychological anxiety, stress, depression and immune system suppression/ decrease in function 🡪 increase inflammatory responses 🡪 secondary conditions
* Exercise can be used as a healthy coping mechanism for depression
* SCI can improve respiratory function with exercise
* Active individuals can improve resilient to stressors and therefore reduced disease vulnerability
* Implementing treatment plans for SCI individuals:
* Patterned neural activity
* High intensity
* Load bearing
* Cardiovascular/muscular strengthening and endurance
* Locomotor training
* Meditation excellent for mental health and energy

Episode 8 – SCI Advocacy During COVID-19 and Beyond

* Advocacy vs activism
* Peer support, system navigation and advocacy addressing and resolving systemic barriers that impact quality of life for SCI individuals
* Important to have all; people living with SCI, policy makers/providers, researchers to give the best viewpoint for the community
* What best practices and process have been used?
* Pivoted activities toward social distancing and do more virtual assistance
* Funding research – reduce risk of COVID-19 in population
* Connected with corporate donors to ensure community stays safe (donate funds for equipment and medical supplies needed for independence)
* How had the COVID-19 crisis and the SCI community’s response awoken us?
* Research community – many labs were shut down. Frustration; fear
* Frustration and time at home caused community to voice that they are a priority since COVID-19 thought of disabled people as an afterthought 🡪inequality
* How does the economics of the pandemic impact funding with our respective prioritizes – care, policy, and research?
* Success in research when SCI patient, policy makers, physicians, and researchers all come together to navigate the SCI world – funding might decrease
* Cancel a lot of in person events
* Leaning on volunteers
* Corporate support
* Make telemedicine permanent – send message to policy makers from SCI community

Episode 9 – SCI Latinx Community and COVID-19: Continued Conversation

* Parents are fearful in taking their kids to go get immunized
* Health care providers are pivoting towards telemedicine – many Latinx families do not have necessary technology and some are worried of getting taped on video
* Emphasize that care can be delivered via phone call
* Social outreach calls – members can call each other to mitigate social isolation occurring from COVID-19
* Trying to figure out ways to get undocumented individuals tested and food (food dispensaries ask for ID)
* Private funders giving resources for those in need
* Individuals fear that their undocumented status will get them publicly charged at hospital or as they get food
* Many hospitals/rehab centers have increased bilingual translators to provide more insight and information
* Important to build trust and make connection with Latinx families
* Lack on insurance, status, etc. may limit equipment an individual can get; therefore, many funds have been put in place to provide individuals with what they need (catheters, PPE, etc.)
* The Latinx communities requires lots more effort to get them to trust (more time on phone, more time making outreach call) so it is important to emphasize their safety and options many times

Episode 10 – Positive Learnings from COVID-19

* Canada made tele-medicine billable, with the hope that it will remain in place after COVID-19
* SCI community has had the opportunity to talk with friend, family and caregivers about difficult topics, i.e. end of life plans
* More resources available to help assist SCI population 🡪 handwashing guide, wheelchair and assistive technology users: precautions for COVID-19, etc.
* COVID-19 has given us the opportunity to stop and take some much-needed time for ourselves
* Important for SCI population to continue implementing a balanced diet and exercise in their everyday life to maintain a healthy immune system 🡪 best defense against COVID-19
* SCI organizations across North America are joining together to make the voice of the SCI community louder
* Cultural diversity is relevant when handling medical issues, treatments, and advocacy initiatives
* Work of the local and frontline organizations that is so important to the Latinx community