Rehabilitation Science Research
Network for COVID

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A Qualitative Study to Explore Family Centered Care (FCC) Across the Spinal Cord Injury (SCI) Care Continuum in the Context of COVID-19

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Background & Objective(s)

- Within Canada, there are approximately 85,556 individuals living with a spinal cord injury (SCI), with an estimated 4,529 new cases of SCI occurring annually due to traumatic and non-traumatic injury (5).Common traumatic causes include vehicle accidents and sport injury, and common non-traumatic causes include disease (e.g., cancer), and amyotrophic lateral sclerosis (ALS) (5).
- Family caregivers play a critical role in the wellbeing of individuals with spinal cord injury and disease (SCI/D) (6). Due to limited preparation, caregivers can experience stress and anxiety, negatively impacting their experiences in caring for individuals with SCI/D (6). These challenges can be amplified with COVID-19, increasing caregiving stressors, and reducing Quality of Life (QOL) for both groups (4).
- Models of patient and family centered care are proposed to meet the needs of individuals with SCI and family caregivers (6).
  Primary Aim: Obtaining perspectives of family caregivers and people with SCI/D related to FCC within the context of COVID-19 on :

1. The development of patient care plans within the context of families
2. Collaboration between families and the care team
3. Policies and procedures to support families
4. Strategies to support family, patient and family health care education
5. Strategies to coordinate FCC across care environments

Methods

Design

- Qualitative descriptive methodology was utilized (1).

Participants

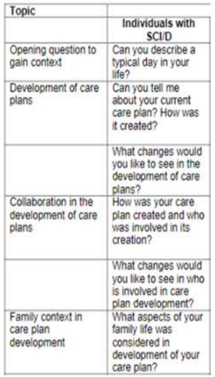
- Recruitment of family caregivers and individuals with SCI with and without COVID-19 were accomplished through purposive and snowball sampling.
- Inclusionary Criteria: Person with SCI/D to be at least 6 months post SCI injury; Family member assisting with at least 1 activity of daily living per week, participants must reside in Canada.

Data Collection

- Semi-structured interviews (40- 90 minutes) were conducted via Microsoft Teams.
- Interviews examined perceptions of FCC across the care continuum.
- Domains within the current Universal Model of FCC were used to guide interview questions (e.g., family context) (Figure 1).

Data Analysis

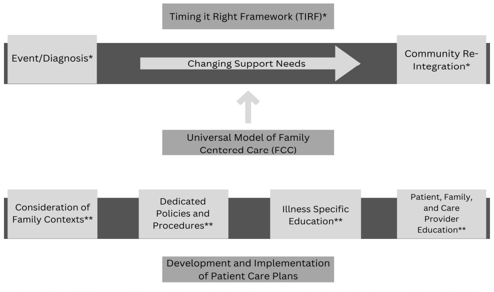
- Data were digitally recorded and transcribed verbatim.
- Data were analyzed using reflexive thematic analysis supported by NVivo Software (2).



Topic	
	Individuals with SCI/D
Opening question to gain context	Can you describe a typical day in your life?
Development of care plans	Can you tell me about your current care plan? How was it created?
	What changes would you like to see in the development of care plans?
Collaboration in the development of care plans	How was your care plan created and who was involved in its creation?
	What changes would you like to see in who is involved in care plan development?
Family context in care plan development	What aspects of your family life was considered in development of your care plan?

Figure 1.

Combined Model



Timing it Right Framework (TIRF)*

Event/Diagnosis*

Changing Support Needs

Community Re-Integration*

Universal Model of Family Centered Care (FCC)

Consideration of Family Contexts**

Dedicated Policies and Procedures**

Illness Specific Education**

Patient, Family, and Care Provider Education**

Development and Implementation of Patient Care Plans

*Cameron JI, Gignac MA. (2008). "Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. Patient Educ Couns.(3):305-14. doi: 10.1016/j.pec.2007.10.020. Epub 2007 Dec 21. PMID: 18155388
**Kokorelias KM, Gignac MAM, Naglie G, Cameron JI. (2019).Towards a universal model of family centered care: a scoping review. BMC Health Serv Res.19(1):564. doi: 10.1186/s12913-019-4394-5.

Figure 2.

Combined Model

- Combined model using the Universal Model of FCC and the Timing it Right Framework (TIRF) were created to guide interviews (3,6) (Figure 2.)

Results

- Participant characteristics are presented in Table 1.
- Interviews took an average of 70 (SD 16.9) minutes.
- Interviews with 18 participants (9 individuals with SCI ; 9 Family Caregivers) uncovers 4 themes.

Theme 1: Changes in Technology

"And what I am thankful for, 1 aspect is COVID came, and we've started this online face to face chats. Whether it's through teams or zoom. Whatever. Um, it really helps me because now I can stay home. So now I do a lot of my uh, medical appointments over a Zoom meeting. And it's- it's a huge help." – *Male, person with SCI/D, 48*

Theme 2: Changes in Access to Health Care

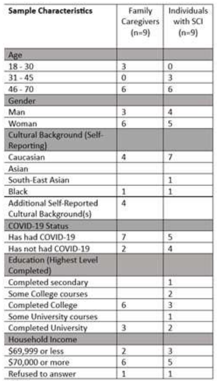
I didn't get any physiotherapy or OT time during the pandemic. Everything was shut down completely to all restrictions, so we were told not to leave our homes or do any of that stuff really." – *Male, person with SCI/D, 38*

Theme 3: Perception of COVID-19 Risk

"I feel like that was the worst time to have something health related happen to you because there is so *much fear and anxiety already tied to COVID 19." – Female, family caregiver, 26*

Theme 4: Impacts on Social Life in the Context of COVID-19

"I think that was the worst part is the family aspect, you know? We're so used to interacting with each other and then all of a sudden, it's like, cut off, right? That was tough. That was tough at times." – *Male, person with SCI/D, 59*



Sample Characteristics	Family Caregivers (n=9)	Individuals with SCI (n=9)
Age		
18 - 30	3	0
31 - 45	0	3
46 - 70	6	6
Gender		
Man	3	4
Woman	6	5
Cultural Background (Self-Reporting)		
Caucasian	4	7
Asian		
South-East Asian		1
Black	1	1
Additional Self-Reported Cultural Background(s)	4	
COVID-19 Status		
Has had COVID-19	7	5
Has not had COVID-19	2	4
Education (Highest Level Completed)		
Completed secondary		1
Some College courses		2
Completed College	6	3
Some University courses		1
Completed University	3	2
Household Income		
$69,999 or less	2	3
$70,000 or more	6	5
Refused to answer	1	1

Table 1.

Discussion

- Study will highlight key preferences of family caregivers related to FCC, supporting FCC during future pandemics.
- Findings may create a positive impact in rehabilitation and support family caregivers through their transitions by developing patient care plans in family context, promoting collaboration, creating policies, and developing strategies to support education, thus promoting FCC across care environments (3,6).
- Gaining a critical understanding of FCC within the COVID-19 pandemic can support the creation of adequate resources, policies, and procedure, ensuring their unique and changing caregiving needs are met during future pandemics (4,6).

Conclusions

- Assuming the role of a family caregiver within the context of COVID-19 can have detrimental effects on one's mental, physical, and psychosocial wellbeing, thus impacting one's ability to deliver quality family and person-centered care (4). Through understanding the experiences of FCC and changing needs of family caregivers, researchers can enhance models of care to influence health care systems in adequately addressing the needs of individuals with disability/disease and their family caregivers (1,3,6).

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