Exploring how People with Spinal Cord Injuries Seek Support on Social Media

Tamanna Motahar
University of Utah
Salt Lake City, USA
tamanna.motahar@utah.edu

Sara Nurollahian
University of Utah
Salt Lake City, USA
sara.nurollahian@utah.edu

YeonJae Kim
University of Utah
Salt Lake City, USA
yeonjae.kim@utah.edu

Marina Kogan
University of Utah
Salt Lake City, USA
kogan@cs.utah.edu

Jason Wiese
University of Utah
Salt Lake City, USA
jason.wiese@utah.edu

Abstract

Individuals who have sustained a Spinal Cord Injury (SCI) undergo abrupt changes in their functional abilities, impacting all aspects of their lives and imposing a life-long reliance on assistive tools and support from others. This paper aims to understand individuals' support-seeking behavior in social media as they adjust to their "new normal"—life with reduced mobility and sensation. To understand their online support-seeking behavior, we conducted content analysis on 960 post-threads from SCI-specific subreddit groups. We found that individuals seek informational and emotional support regardless of injury level and time elapsed since injury. Additionally, individuals seek and receive online informational support concerning assistive logistics, motor-functionality, newly acquired self-care, and daily living activities. Similarly, individuals seek emotional support for motivation, and creating new self-identity. Finally, we discuss how social media support dynamics might facilitate reconstructing self-identity, adopting assistive technology, and improving relationships to help adjust to the "new normal."

CCS Concepts

• **Human-centered computing**;

Keywords

Spinal Cord Injury, Online social space, Social support

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1 Introduction

Individuals who sustain a traumatic spinal cord injury (SCI) undergo an immediate and dramatic change that disrupts their lives. This sudden life-changing event mostly happens due to motor-vehicle accidents, catastrophic falls, or sports injuries [24] and typically results in losing a range of physical abilities and sensations. Additionally, individuals typically encounter medical consequences, including the development of respiratory failure or loss of bladder and bowel control, which make their lives more challenging. After an SCI, individuals undergo months of medical treatment and rehabilitation in the hospital. Although the primary goal of inpatient rehabilitation is to learn new ways to do activities of daily living independently, individuals struggle to adjust to the "new normal" following discharge [17, 54]. "New normal" refers to the need to make sense of the life-disrupting event or new reality after encountering an unexpected life event or health concern [5, 74, 91]. Any disruption may lead to a longing for their previous selves [96], or an exploration of what is normal for them now: defined as their "new normal" [74]. This phenomenon has been described in many other contexts, including cancer [47], chronic conditions [15], bereavement [74] and mental health conditions [38]. Prior HCI research showed that informational support seeking is crucial here, as Genuis and Bronstein [38] stated:

> "As participants interacted with information about the experiences of health challenged peers, socially constructed notions of normality emerged. This was internalized as a "new normal."

However, the adaptation to the post-injury life or the "new normal" for individuals with an SCI is not always mobility or health related, rather many life-facets get impacted by the injury. For instance, in their recent study, Motahar and Wiese [84] demonstrated that the transition from a "person" to a "person with a disability" is not a straight forward process. They identified several non-mobility related factors, such as acceptance to new-normal, prior experience, or motivation impacting the transition in the rehabilitation process (e.g., adoption of assistive technology)—soon after sustaining an SCI. Similarly, the critical lens [36] of disability theories that HCI and accessibility research embraced argues for a holistic perspective: disability cannot be abstracted to static and discrete categories of impairments, but instead understanding and elevating the holistic experiences of disabled people: "we need to know who they are, how they interact with their environments, what sort of complex

activity networks they are a part of, and what their specific task needs and interests are" [90]. Thus, to adjust to the "new normal," it is important to explore the holistic social support (e.g., information, emotional, or instrumental) dynamic individuals need.

Although research found that social support can significantly help people with an SCI to cope with their new life with a new set of abilities [10, 22], they often face challenges in obtaining in-person social support due to their restricted mobility[10, 22], difficulty in creating social connections with people without a disability [9] and concerns with their self-image [8]. Thus, seeking and receiving support online is invaluable for this population [89] and require more exploration. However, topics people with an SCI discuss, and types of support they seek and receive in the social media platforms are still unexplored.

To address this gap, we chose publicly available data from an online social space (Reddit) to explore the online social support dynamics of this target population to adapt to their "new normal." Generally, the experiences of the disabled population in accessibility research are drawn from standard HCI/user-centered methods, including observations, interviews, design activities, and user studies to investigate the challenges, frustrations, and opportunities for technological interventions. However, Kabir et al. [55] identified that using these methods for understanding the experiences of individuals with an SCI can be problematic as recruitment is often challenging for those methods [82] and may exclude people with more severe injuries because they often acquire multiple disabilities simultaneously (e.g., speech disabilities and motor disabilities together). In addition, people also behave differently when they know they are being observed, particularly by researchers [67, 75]. Thus, extracting publicly available social media data would avoid those observation biases.

This work is the first attempt to understand individuals' support seeking on the social media platform after sustaining an SCI. Our analysis provides **an in-depth understanding of people's social support dynamics (support seeking and receiving) in SCI-specific social media groups while adjusting to their post-SCI life**. This includes, the key topics people discuss and the types of support they seek and receive from their peers. Specifically, we 1. identified 39 topics under 13 broader categories from the online post threads that people with an SCI discuss online as crucial life factors and with which they seek support when adjusting to their "new normal," irrespective of level of injury and time since the injury. 2. foreground that online social support can facilitate reconstructing self-identity, adopting assistive technology, and improving close relationships in all the progressive stages of their post-SCI life. 3. exemplify using social media data to get more nuances about the challenges of people with an SCI, to overcome some typical methodical constraints of contemporary HCI research.

Our analysis elucidates a new understanding of people's social support need holistically on the social media platform after sustaining an SCI. The study emphasizes the necessity for future accessibility research domains to address the unique needs of this highly underrepresented population, ensuring seamless adjustment to their post-SCI life with limited physical abilities.

Content warning: People posting content in these subreddits shared their thoughts, frustrations and experiences of their post-SCI life in the reddit posts, which are sometimes highly emotional and which some people may find disturbing (e.g., contemplating self-harm). To articulate the emotions of the posters, we used some of these example posts, paraphrased, in different sections that have **highly intense emotional/ depressive content.**

2 Related Work

Having an SCI dramatically changes a person's life. Here we outline SCI and challenges in adapting to the "new normal" post-SCI, summarize prior research on the use of online social spaces for individuals with an SCI, and draw from accessibility research and disability studies to explore the potential of online social support to meet diverse needs.

2.1 Background on Spinal Cord Injury

An SCI is a traumatic event that can happen suddenly due to motor vehicle accidents, acts of violence, falls, and sports injuries and can cause different levels of disabilities. These typically result in loss of functional abilities [46]—mobility, motor function, and sensation—either through paralysis of only legs (paraplegia) or both legs and arms (tetraplegia). In the US, 17,730 people [87], and worldwide between 250,000 and 500,000 people acquire an SCI yearly [99]. In contrast to other progressive reasons for motor disabilities, an SCI causes an immediate loss of motor functions and causes motor disabilities that dramatically change an individual's life [68]. The resulting severity of motor disabilities varies by person, from imposing little or no limitation to causing minimal motor function. For instance, there can be four types of injury: injury impacts the head and neck region above the shoulders (cervical); and/or upper chest, mid-back, abdominal muscles, and arms (thoracic); and/or hips and legs resulting in difficulties to walk (lumber); and/or hips, back of the thighs, buttocks, and pelvic areas (sacral). More severe (e.g. upper body) injuries often require a powered wheelchair or other assistive technologies for mobility and the support of caregivers for activities of daily life [21]. Thus, sustaining an SCI brings drastic changes into a person's life.

2.2 Social Support Needs on Adapting "New Normal" After an SCI

Adapting to post-SCI life and accepting the "new normal" is complex due to the sudden changes in functional abilities [54]. In addition to changes in motor functions, people need to follow a new self-care activities, including management of bowel, bladder, respiratory, pain, and pressure relief to avoid pressure sores for the rest of their life [88]. These self-care activities are frequent, complex [82], individualized [18], and crucial for preventing secondary conditions (e.g., pressure sores, breathing problems) that people acquire after sustaining an SCI. Furthermore, irrespective of injury level, SCI is a unique scenario of people's lives that might need additional considerations with redeveloping a sense of self, re-establishing a place in the community, and regaining self-efficacy [101].

Prior research defined the adaptation to the "new normal" in post-SCI life as a "multi-factorial" process [37, 102] and emphasized on social support [12, 66, 85] for accepting the "new-self." Notably, social science researchers conceptualized social support (e.g., informational/ emotional support) as a form of assistance in coping with post-trauma [1, 41, 76, 100]. Additionally, individual's

perceptions of themselves and their close relationships contribute to their adaptation to the "new normal" in post-SCI life [13, 95].

Recently, HCI researchers started exploring ways to help people with an SCI to adjust to their new life. That includes supporting with health-related aspects, (e.g., improving adherence to the newly acquired self-care activities [17, 18, 82], and wheelchair-based physical exercises [39, 62]) and participation in adaptive sports [2, 3]. However, many other life factors get impacted by the transition. Particularly, acquiring a sudden disability comes with a different set of challenges than acquiring a disability from any chronic progressive disease (e.g., cerebral palsy, multiple sclerosis, etc.). Therefore, although HCI and accessibility research has explored challenges of individuals with wheelchair [21] or other assistive tools (e.g., cane, walker) as a monolithic group of disability, special attention is needed for the individuals who sustained an SCI. In addition, people with motor disabilities are studied in HCI in many other contexts, including physical activity and fitness tracking [19, 20, 39, 73]. However, people with severe motor disabilities (e.g., upper body impairments [69]), which are mostly resulting from an SCI, are often not well represented [83]. Thus, HCI researchers need to understand the challenges people with an SCI encounter holistically, beyond their health or functional limitations and explore the possibilities to enhance the social support.

2.3 Online Social Support After Traumatic Experiences

Online social spaces often facilitate people's engagement in expressions of distress and challenges associated with traumatic life incidents including sexual abuse [6], job loss [16], pregnancy loss [5], relationship breakups [42], mental illness [4], death of loved ones [48], postpartum depression [93], and foster social support [6, 43, 92]. Users benefit from these platforms because they are free of physical or social status cues [27], and allow users to connect with others easily and obtain necessary information [45]. Similarly, people use social media platforms to share chronic or progressive symptoms with people with similar conditions that others find hard to interpret, express the social consequences, and "seek a diagnosis" for their condition by sharing sensitive details [25, 97]. Notably, prior research on the disabled population found that the online environment is an essential platform for individuals with disabilities to communicate with others [58], fostering feelings of social connectedness and well-being. Indeed, having a disability is associated with having fewer friends, less social support, and more social isolation [79]; thus, internet usage can be a helpful tool to mitigate this phenomenon, enabling social integration, and social support [32].

Hogan et al. [51] reported that individuals with an SCI increase their internet use after sustaining an SCI, and most use it daily [40]. Likewise, people with an SCI watch internet-based educational videos to build their health-management knowledge (e.g., managing pressure ulcers and pain) and positively change their behavior [49, 70]. In addition, Munce et al. [86] identified that people with an SCI prefer internet-based health information delivery formats as they are more accessible. However, we do not yet know what topics this population discusses in the online social space to adjust to this changed life. That inspires us to ask our first and second research questions: **RQ1. What topics do people with an SCI discuss on the social media platform?**

2.4 Support Dynamics Through the Intersection of Disability Studies and Accessibility Research

Accessibility research has leveraged work from disability studies [78] to build a more inclusive society for people with disability. While disability is often described with a focus on medical concerns, such as lack of physical/sensory functions, limbs, health, or cognitive ability loss [103], and social concerns, including "removing social barriers and mitigating functional limitations"; disability studies emphasized on multifaceted life factors and related challenges [36]. Instead of the physical and functional limitations a person may demonstrate, disability is described as a holistic experience incorporating societal, medical, and intellectual policies and rhetoric related to disabilities. Mankoff et al. [72] conceptualized the significance of adopting this critical inquiry lens of disability studies in the accessibility research domain. Therefore, recent accessibility research often examines the experiences of disabled people, aiming to identify the challenges in their lives, frustrations, and opportunities to relieve access barriers [50] holistically. Thus, following the critical inquiry lens [36], it is imperative to explore existing sources of support (like online social media) for people with an SCI to design better support dynamics beyond illness, impairment, and functional limitations. This motivates us to explore the social support dynamics for individuals with an SCI in the online social space. In this work, we followed the framework of Kalichman et al. [56] for defining social support, which was used in earlier studies for online content analysis for different online communities (e.g., [23, 31, 34, 93, 94]). According to this framework, social support can be instrumental (e.g., tangible assistance), emotional (e.g., exchange with a close friend) or informational (e.g., advice from a peer). According to the previous works using similar categorization of social support [34, 93], tangible assistance or instrumental support is less evident in the online space. Thus, we excluded instrumental support from our exploration, and asked our second and third research questions: **RQ2. What types of informational support do individuals with an SCI seek and receive in an online social space**?, and **RQ3. What types of emotional support do individuals with an SCI seek and receive in an online social space**?

This study takes steps towards a deeper understanding of the support people seek and receive in social media platforms to adjust to their newly transitioned lives by analyzing the posts from SCI-specific online groups and discussing possible design directions to better support them.

3 Methods

Our primary goal in this study is to gain holistic insights into the social media support dynamics of individuals with an SCI. We chose to analyze data from *reddit.com* towards this goal because **Reddit facilitates small topic-specific subgroups (e.g., SCI) that are publicly accessible and are well-known to foster engaged communities**, including in the health and sensitive disclosure domain [6, 7, 25]. Additionally, Reddit—the seventh-most popularly

searched website in the United States and the seventeenth worldwide [59]—prioritizes pseudonymity that enables users to share and discuss topics without the concerns of stigma [25, 57]. Further, Reddit is an open data source, making it more accessible for research than other popular social media platforms (e.g., Meta, X–former Twitter).

3.1 Data Collection

The first author searched for Reddit communities where the members are mostly individuals with an SCI and discuss their lives, settling on *r/spinalcordinjuries* and *r/spinalcordinjury*. The first author read these two subreddits for several weeks—following daily updates on new posts and becoming familiar with the types of posts, medical jargon, and relevant acronyms. Next, with our IRB approval, we collected postings from the subreddit *r/spinalcordinjuries* as the primary source of data using Python-based Reddit API Wrapper PRAW (Python Reddit API Wrapper). This subreddit group is the largest SCI-related community on Reddit with over 7,000 members (as of September 2023) and was created on Dec 12, 2013, with the description as "community can discuss, share, and help each other." We used the PRAW model's subreddit.hot() function with a maximum limit of 1000 to get the posts for the subreddit that has been getting the most votes since the group creation, and the model returned 970 posts. To complement the data from *"r/spinalcordinjuries"*, we identified another subreddit group, *"r/spinalcordinjury"*, which has 579 members (as of September 2023) and was created on Oct 20, 2012. The description of this subreddit is "A place for those of us sustaining this unfortunate type of injury to talk to each other as it is hard for "normal" people to understand what we are going through." We used the same PRAW model with a maximum limit of 100 to get the posts from this subreddit, and the model returned 99 posts. Thus, As a result, 90% of our corpus originated from *"r/spinalcordinjuries"*, while 10% was from *"r/spinalcordinjury"*.

We prioritized the first subreddit heavily, because the initial observation showed that members are more active in this forum and post frequently. For the first subreddit group with over 7000 members, we targeted 1000 posts following previous works where Reddit data was similarly analyzed. For instance, Knittel et al. [59] scraped 1000 posts and Chopra et al. [25] scraped 996 posts from their targeted subreddit. The second subreddit had 579 members. Thus, the member number of the first subreddit group was more than ten times that of the second group. Thus, the study sample breakdown reflected the member number ratio. Notably, we examined two topic-wise similar online spaces to see if our findings were reflected across multiple contexts, which they were (similar to [59]).

3.2 Analysis

Our initial dataset contains 1069 posts together from *r/spinalcordinjuries* (970) and *r/spinalcordinjury* (99); we discarded 109 irrelevant posts (e.g., survey links and advertisements) resulting in 960 posts and 7635 comments for analysis. We chose content analysis [53] as our analysis method, which is appropriate when an existing theory or research literature on any phenomenon is limited.

We primarily analyzed the posts by content analysis [53] to explore target populations' experiences. Conventional content analysis is generally used to describe a phenomenon, in our case, the transition of people's lives after sustaining an SCI. For coding, we opted for Interpretative Phenomenological Analysis (IPA) to conduct a more informed investigation of the posts from this homogeneous group who experienced a similar traumatic incident. The breadth of experience shared in the Reddit posts indicated that the data were suitable for such analysis, like in [98]. Thus, the combination of content analysis and IPA enabled us to capture a deep multidimensional understanding of the posts. IPA is designed to examine individuals' meaning making about their experiences [63]. Following the IPA process, we iteratively read the posts and made initial detailed notes. These notes were then developed into codes based on the topics and content, capturing key elements of the detailed notes.

The first author and an undergraduate student intern, performed coding individually on approximately 10% of the data (98 posts) randomly selected from the data corpus. We assigned two types of codes to each post: a topic code (39 codes) and a content code (54 codes). For topic coding, researchers first read each post and identified the high-level topic of the post, such as mobility, treatment, medicine or others to answer our **RQ1**. Simultaneously, researchers coded the content of each post to answer **RQ2** and **RQ3**. In each content code, we indicated the type of support (informational or emotional) the post was seeking, and added code according to the specific type of support poster was seeking. Examples of content codes are: informational support: finding an accessible Uber, informational support: finding a new job with new ability; emotional support: feeling helpless, emotional support: looking for hope for recovery.

We continued analyzing, tagging, and coding the rest of the data corpus using the identified topics and content codes. After analyzing and coding every 200 posts, the researchers met to discuss the precision and uniformity of the codes. Consequently, the topic and content codes underwent several iterative rounds of cross-checking and validation. The coders frequently met and discussed the coding (three to four times each week). Thus, no inter-coder reliability score or rate of agreement among the coders was calculated (following a method similar to that employed in [25]). After coding, we grouped the topic codes into 39 topic codegroups and the content codes into 54 codegroups (41 seeking informational support and 13 seeking emotional support) based on the types of support and their additional notes.

Finally, we clustered the 39 topic codegroups into 13 broad categories, such as health problem, or relationship (reported in section 4.1). Similarly, we formed six high-level clusters from the 54 content codegroups—according the types of support posters were seeking. Among them, we found four clusters (see section 4.2) where people were seeking informational support on **assistive logistics**, **changes in functional abilities**, **newly acquired self-care routines**, and **relearning activities of daily life**. In the remaining two clusters (see section 4.3) people were seeking emotional support for **motivation** and **re-creating self-identity**. Figure 1 describes our overall analysis flow.

The first author, and two other authors also qualitatively coded comments for each post for whether they provided informational or

emotional support. Comments not offering any support, primarily comprised general conversations, which were not included in our coding. This included commenters inquiring about the accident incidence, dates, and posing clarifying questions about the injury, and posters replying with clarification.

3.3 Ethical Considerations

While collecting data from Reddit, we did not directly interact with any of the users of this subreddit group. Our fundamental analysis was focused on the publicly shared text of the posts. We obtained a determination of a non-human subjects study from our Institutional Review Board (IRB) for this study. However, although the members of this subreddit group shared their personal experiences, feelings, frustration, and sensitive information publicly, there are particular members' expectations regarding the audience of their posts. Notably, while any internet user can access the contents without restriction, members of the online community (e.g., X, Reddit) expect that the audience is going through a similar experience or care about their experience. To account for the ethical and privacy concerns outlined by Fiesler and Proferes [35] regarding using the publicly shared posts of a specific online community, we did the following:

(1) did not collect any additional profile information, or information beyond the specific post including their comments in other posts or activities on other subreddits;
(2) anonymized user name and provided serial numbers (e.g., uXX) according to the order the data was scraped;
(3) reported completely curated and paraphrased posts and the relevant comments so that the post/comment cannot be traceable by a search [14, 80]
(4) reported the findings in a collective manner [77, 105].

Similarly, we omitted any potentially identifiable personal information such as location, age, or year of injury. We collected SCI type and time since the injury from the post (if available) and mentioned it in the findings section whenever applicable. We also found that other people—family members, friends, caregivers, and hospital staff—posted and asked questions on behalf of individuals who sustained an SCI. We also mentioned the poster's relation with the person with an SCI (for whom they made the post) in the findings section while mentioning the post.

3.4 Limitations

We analyzed the online discussions of people with an SCI from around 960 Reddit posts; however, by conducting similar research on other highly used social media spaces, other concerns might be identified that were not captured in this corpus. For instance, We did not capture the changes in support seekers'/givers' support seeking behaviors over time, or changes in roles in support dynamics on the social media platform. We also acknowledge that differences in people's technology literacy skills, access to online resources, negative experiences with social media platforms [64], and openness to sharing online might affect our results. However, we confirmed different levels of disability are represented in this corpus (see section 4.1.2). We did not look at the posters' other posts; instead, we considered each post as an individual data point. We avoided following individual posters' other activities (where they are commenting, what else they are posting) beyond the specific post so that we could adhere to the ethical and privacy guidelines recommended for social media research [35].

4 Findings

In this section, we report on the topics individuals discuss regarding their post-injury life (section 4.1), individuals' informational support seeking dynamics (section 4.2), and emotional support seeking dynamics (section 4.3) in the subreddit groups.

4.1 Posts Include a Wide-range of Discussion Topics Regardless of Injury Levels and Time since Injury

This section reports results for **RQ1**—topics people with an SCI discuss in the social media platform. We identified 13 broad topic categories being discussed in the subreddits, covering many topics beyond health or motor impairments. Additionally, one third of the posts contained the injury level of the poster, indicating that individuals with a wide range of injury levels, including cervical injuries (upper body impairment), participate in social media discussions. Further, individuals engage in discussions on various topics irrespective of the time elapsed since they sustained the injury. Notably, health problems related topics, new self-care activities, and motor functionality persist regardless of the time elapsed since the injury occurred. However, over time they tend to discuss other life factors more, e.g., mental health, relationships.

4.1.1 Discussion Topics Go far Beyond Physical Impairments. We found that discussion topics in subreddit groups were not limited to physical conditions. Instead, they discussed a wide range of factors related to adjusting to their "new normal." From the topic-wise analysis of the Reddit posts, we present a list of discussion topics (see Table 1) with 39 unique life factors in 13 broad categories. They include treatment, self-care activities, functional ability, mental health, sexual function, leisure activities, relationship, transportation, finance, activities of daily life (ADL), professional activities, assistance, and accommodation. In Table 1, we provide the details of 39 topics within 13 broad categories. Less frequent topics are still significant, despite the frequency of posts per topic.

4.1.2 Individuals Participate in Posting Irrespective of The Level of Injury or the Time Elapsed since Injury. Our analysis indicates that individuals with a wide range of injury levels and time elapsed since the injury participated on the Reddit platform. Additionally, we discovered 82 posts from members who have not sustained any SCI themselves; however, they are family members, partners, friends, or caregivers of someone who has sustained an SCI and are posting on their behalf. For the rest of the paper, we mention those individuals as "supporting-individuals".

Among the analyzed posts, one-third (325) contained injury level information (see Figure 2)—295 from individuals with an SCI, and 30 from supporting-individuals. Out of 150 posts mentioning sustaining single-level injuries, individuals with cervical (C5) injuries, which affect the head, neck, upper hand region, and above the shoulders, made the maximum posts (25) compared to others with single-level injuries. Similarly, out of the 126 posts created by individuals with multiple injuries, those with multiple cervical

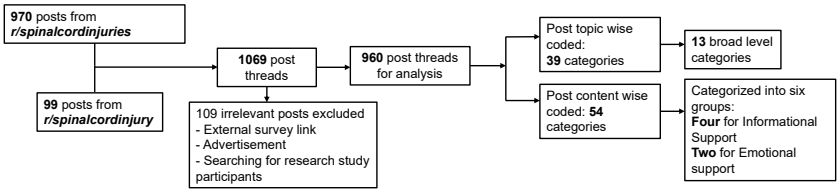

Figure 1: Flowchart of our data analysis process

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Table 1: We identified thirteen categories of topics discussed in the post threads: There are 39 unique topics grouped under the 13 categories

Life-factors	Description	Number of posts (Total=960)
Health Problem		***203***
1. Treatment	Diagnosis, symptoms, feedback of treatments, frustration with treatment research	150
2. Finding physicians	Finding SCI specialists, communication and visiting physicians	28
3. Medication	Side-effects, doses, and alternatives of medicines, availability of medicine	25
New Self-care Activities		***187***
4. Bladder management	Chronic UTI, catheterization, bladder control and managing spasms	64
5. Pain management	Managing chronic/ sudden and severe pain, spascity, muscle spasms	45
6. Exercise/ physical activity	Specific exercises for non/less functional body parts	31
7. Bowel management	Using ostomy bag, managing bowel movement	18
8. Pressure relief (PR)	Performing PR in every 20 minutes, examining skin	14
9. WC sitting behavior and transfer	Maintaining sitting posture, WC to bed	10
10. Diet (impacted by SCI)	Easy digestible diet, more water, concern about foods affecting bowel and bladder management	3
11. Respiratory management	Ventilation, managing breathing control	2
Functional Ability		***185***
12. Mobility	Depending on mobility assistive tools, challenges with tools in different context	99
13. Motor functions	Starting walking, standing, regaining muscle strength, movement of fingers	44
14. Sensation	Gaining back sensation, Newly developed sensation, sudden numbness	42
Mental Health		***130***
15. Positivity	Self-journaling, hope, gratitude	71
16. Frustration	Frustration, lack of motivation	54
17. Suicidal	No meaning of life, learning about voluntary assisted dying, suicidal thoughts	5
Sexual Function		***88***
18. Sexual function	Genital sensation, adaptive devices,	84
19. Women's reproductive health	Pregnancy, menopause, menstruation	4
Leisure activities		***35***
20. Sports	Learning adaptive sports, outdoor sports	24
21. Hobbies	Getting new hobbies, easy hobbies	11
Relationship		***30***
22. Social connection	Connection with people with similar injury, support group	13
23. Family members	Relationship with partner, parents, siblings	9
24. Dating	Finding new partner, communication	7
25. Parenting	Parenting while in a wheelchair	2
Transportation		***26***
26. Travelling	Rental cars, ride share, self-care during travelling	15
27. Driving	Hand control driving, driving with wheelchair	7
28. Flying	Boarding on airplane with mobility assistive tools, self-care during flight	4
Finance		***24***
29. Funding	Monetary assistance, crime fund, emergency fund	18
30. Insurance	Insurance for mobility assistive tools and treatment	6
Activities of Daily Life (ADL)		***15***
31. Dressing up	Easily wearable clothes, changing clothes, hair-do	9
32. Cooking	Cooking tools, accessible kitchen top	3
33. Other daily tasks	Daily life work	3
Professional activities		***15***
34. Work	Getting into work, preparing for work	11
35. School	Getting back to school, completing course	4
Assistance		***14***
36. Independence	Working without assistance, getting out alone	6
37. Pet	Getting service dog, permission for service dog	5
38. Caregiver	Getting Caregiver, constant caregiver, cost of caregiver	3
Accommodation		***8***
39. Accommodation	Rehab, finding accessible housing/hotel, buying new house with adequate features	7

(C5-C6) level injuries made the maximum posts (31) compared to those with other multiple-level injuries. Therefore, our analysis encompassed that individuals with a wide range of injury levels, even with severe cervical level injuries (which usually result in upper-body impairment) participate in online social media support seeking.

Similarly, in 219 posts, posters mentioned the time elapsed since the injury (see Table 2)—199 from individuals with an injury, and 20 posts from supporting individuals. Table 2 shows the time distribution since the injury occurred, as stated by the people with an SCI or supporting individuals. Among the 199 posts, 57 mention that it has been less than a year since the injury.

In addition, there were 89 posts indicating a period of one to five years since the injury; 12 mentioned a duration between five and ten years, and 41 stated a duration over ten years. In figure 3, We show the distribution of discussion topics (based on our topic categories) concerning the time since the injury mentioned in the posts. It shows that the discussion topics related to **health problem**, **newly acquired self-care activities**, and **motor functionality** persist regardless of the time that has passed since the poster sustained an injury.

4.2 Informational Support on Assistive Logistics, Health Concerns, Self-care and Activities of Daily Life

This section addresses **RQ2**—poster's informational support seeking and receiving in the subreddit groups to adjust to their new life. We found that individuals' information-seeking support mostly encompassed assistive logistics, health concerns, self-care, and activities of daily living to adjust to the different stages of their post-SCI life. Among the comments on these posts, 25-35% provided informational support (self-care posts got maximum informational support), 2-6% provided emotional support, and around 3-5% provided both informational and emotional support.

4.2.1 Assimilating New Assistive Tools, and Logistics. We found 159 posts—123 by people with SCI, and 36 by supporting-individuals—seeking informational support related to mobility assistance, accessible traveling and accommodation, and logistics necessary for adapting to a new life after sustaining an SCI. Posters sought information about wheelchairs and associated equipments, standing frames, and chest straps. Additionally, posters inquired about travel logistics, including hand controls for cars, rental vehicles, wheelchair-friendly Uber or Lyft services, boarding flights with wheelchairs, other mobility assistive tools, and rental wheelchairs. Posters also asked questions regarding rehabilitation housing with accessible features and accessible hotels. Posters also expressed context-specific challenges with assistive tools across several posts, such as malfunctioning powered wheelchairs during the holidays, experiencing discomfort due to the wrong alignment of wheelchair parts, and using a wheelchair within snow.

Notably, posters frequently seek informational support on technology-driven assistive tools (see Table 4): information on wearable health monitors for tracking exercise; adaptive software (e.g., voice-to-text), gadgets, and computer mice (for playing games); technologies integrated into the power wheelchairs [20], and smart home/voice control technologies. They also shared news about technological advancements in mobility and motor functions. Posters also sought suggestions on logistics, including health insurance, treatment cost, caregivers, service dogs, and hand-controlled vehicle driving. Similarly, supporting-individuals sought informational support on logistics to assist their loved ones:

> *One of my family members sustained a spinal cord injury from a severe accident. He now has constant pain. There isn't much I can do to help him. Is there anything a loved one did for you that you really appreciated?* (u932, Supporting-individual)

There were 1251 comments on these 159 information-seeking posts related to assistive tools and logistics; 33% provided informational support, while 2% offered emotional support.

4.2.2 Comprehending Frequent Changes in Health and Motor Functionalities . Recovery from an SCI is highly unpredictable. Posters often struggle to understand the progress or changes in their health or functional abilities, leading them to seek informational support in the subreddit group. Further, the lack of timely expert opinions or treatment made them dependent on online platforms for explanations and recommendations. We found 212 posts—203 by people with an SCI, and nine by supporting-individuals—to understand the ongoing changes in mobility, correlating them with hoped-for recovery processes and projecting how much recovery to expect. Additionally, posters are keen to track their functional abilities and sensations over time. However, being uncertain about the nature of progress or changes in mobility and sensation, they are not sure about *'what'* and *'how'* they should track, and asked questions on improvement progress: *"did not notice much new movement"*, or *"should I expect not to get much more back"*. The questions ranged from possible timelines for returning to walking, types of movements they can expect to make, and ways to speed up the process of regaining motor function (e.g., strengthening specific/less functioning body parts).

Mistrust and skepticism towards prescription medications also led posters to seek informational support about motor functions, sensations, and other health issues. Due to the lack of quick and convincing health outcomes, posters sought informational support about medication, doses, and side effects. Further, they expressed frustration over the lack of access to SCI specialists, difficulties communicating their level of discomfort, and misdiagnoses in the past. Thus, their frustrations with conventional treatment motivate them to research independently:

> *I am trying so many treatments but I can't find any specialist who believes in these treatments and interprets my MRIs regularly. Most of them think I don't need an MRI. I feel like I'm alone here and only can rely on Google as my best ally.* (u906)

For these 212 informational support seeking posts, there were 1870 comments—33% provided informational support, and 5% provided emotional support.

4.2.3 Getting Accustomed to New Self-care Routines. In post-injury life, individuals need to adapt a new set of self-care activities (e.g., bladder, bowel, pain, pressure sores and respiratory management) depending on the level of injury. In 197 posts—178 by individuals with SCI, and 19 by supporting-individuals—posters sought informational support regarding those self-care activities. Procedures

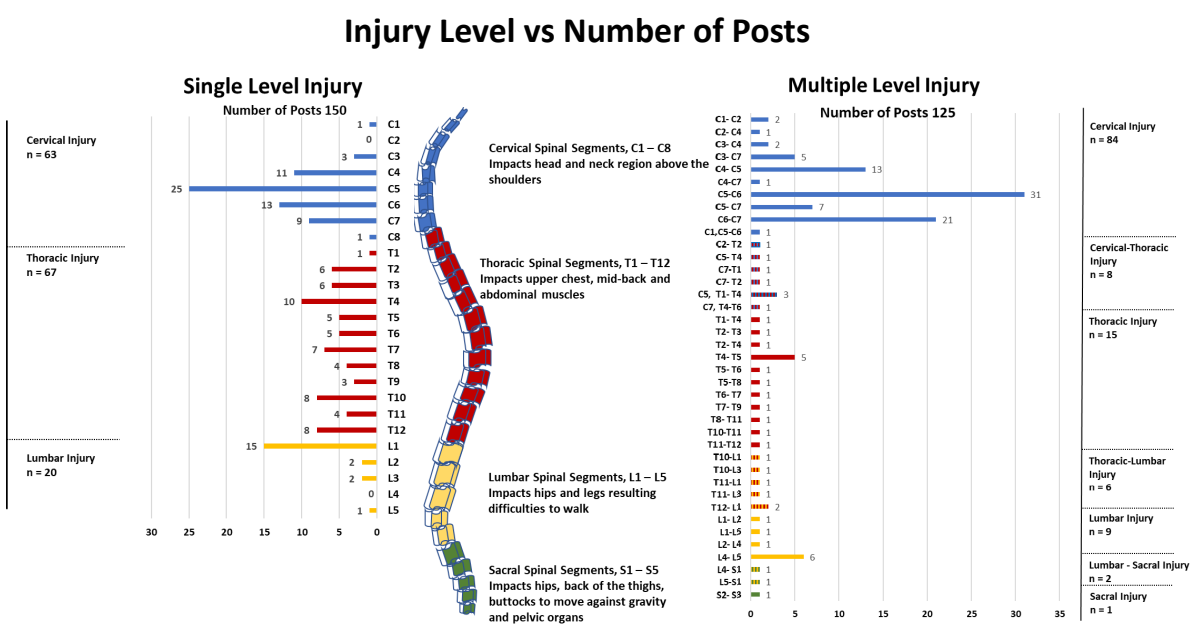

Figure 2: The Reddit posts we analyzed represented individuals with a wide range of injuries (single and multiple level). This figure provides posters' injury details and corresponding post numbers. Notably, the maximum number of posts (84) were from posters who had sustained multiple level cervical injuries. These injuries tend to be more severe because they are higher up on the spinal cord, often leading to paralysis in the head and neck region above the shoulders

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Table 2: Posts mentioned a wide range of elapsed time since individuals sustained spinal cord injuries

Duration since the injury happened	Number of Posts by individuals with SCI (Total= 199)	Number of Posts by supporting-individuals (Total= 20)
Less than one month	3	3
Within one - two months	11	0
Within three - five months	16	1
Within six - twelve months	27	0
Less than a year (Total)	*57*	*4*
Between one to two years	32	8
Between two to three years	31	3
Between three to five years	26	0
Between one to five years (Total)	*89*	*11*
Between five to ten years (Total)	*12*	*2*
Injury happened 10+ years ago (Total)	*41*	*3*

Table 3: An example (completely rephrased) of an individual seeking and receiving informational support on assistive tools and logistics through a post and a corresponding comment.

Post	*How's the manual chair for people with higher injury levels? I've lost strength in my arms from using an electric chair.* (u948)
Comment	*Due to a C7 injury, I use a Tilite AeroZ [type of manual wheelchair]. But, it's too heavy. [So], I have removed things like anti-tippers, side guards and mounts, to make it lighter.*

and frequencies of these activities vary based on functional capabilities, secondary conditions, and treatment recommendations, among others. Thus, posters seek informational support to get habituated with these activities, irrespective of the time since the injury (see Table 6).

Additionally, posters sought suggestions regarding contexts or special situations where following self-care guidelines is difficult. We found posts on bladder or bowel management while flying, exercising/therapy sessions, and performing pressure relief within vehicles. Likewise, posters were also concerned about the consequences of not following the self-care routine (e.g.,at work or school).

For these 197 posts, we found 1985 comments—35% provided informational support, and 4% provided emotional support.

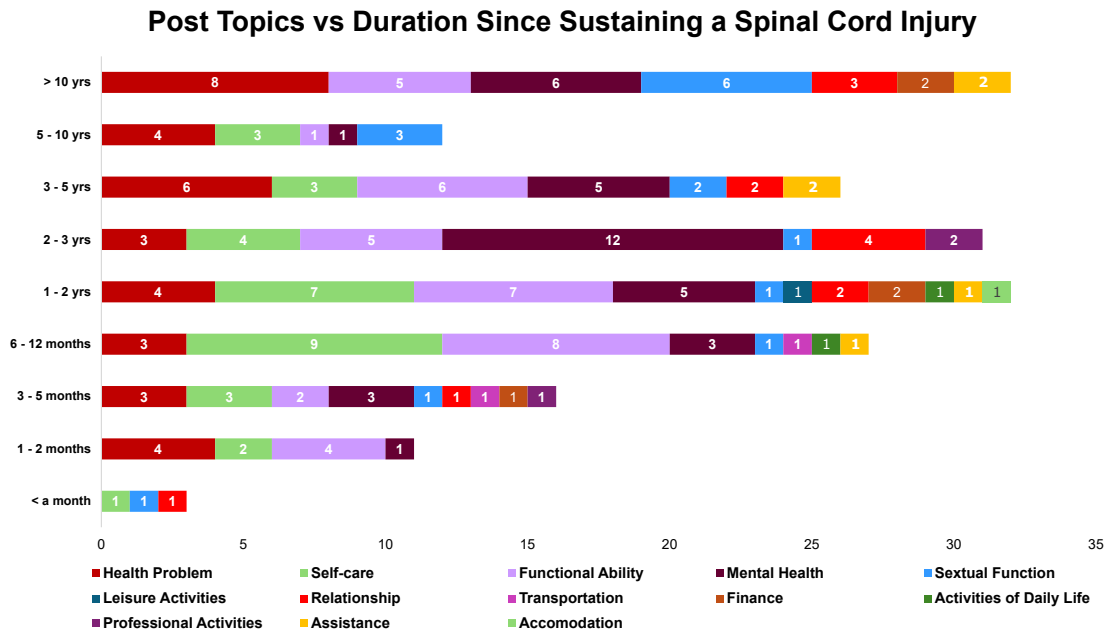

Figure 3: Topics discussed in the posts, with respect to the time since the posters sustained the injury. The discussion topics related to health problem, newly acquired self-care activities, and motor functionality are persistent irrespective of how much time has passed. Later, individuals discuss other life factors more, such as mental health, sexual functions, and relationships.

Table 4: Individuals with an SCI and supporting-individuals sought information on technology-driven assistive tools for different levels of injuries to assist with disability: tracking technologies, adaptive software, task automation, communication devices, chairable technology, hand control assistance, and adaptive mobile interaction.

Technology Domain	Example	Example of Post	Intended Person's Injury Level
Tracking Technology	Wearable health monitor	*After my injury, I have difficulty feeling when my muscles or body are tired or sore I am looking for a wearable health monitor that can help me track my exercise and tell me when to rest.* **(u177)**	L1 incomplete
Adaptive Software	Typing with Less Hand Function	*It would be very helpful if I could use a keyboard of any sort for my creative writing course. The left hand is my weakest hand, so applying pressure is difficult for me since I sustained a cervical injury. Voice to text doesn't appeal to me, because I just feel like it'd be a hassle to constantly correct my mistakes.* **(u238)**	C7 incomplete
Task Automation	Smart house, Voice control	*I am planning to set up home automation and would appreciate any suggestions or experience you might have or perhaps other products I don't know about.* **(u747)**	Unknown
Communication	Communication Device	*My aunt is a quadriplegic and She cannot speak after her injury. I am seeking a consultant to help us set up assistive technology so she can communicate effectively as I know there are technologies that can help my aunt but my family cannot use them.* (**u1888**, Family member)	Quadriplegic
Assistive Technology	Technology for Transfer	*My friend has always done chair to bed transfer by himself for 40 years after the injury. But, a recent shoulder injury is making him unable to transfer by himself. Can anyone recommend any techniques or aids to make this process more efficient?* (**u142**, Friend)	C6-C7
Hand Control Assistance	Assistive Grabber	*My husband has very reduced grip strength since he was injured, so he always drops things. It's very difficult or sometimes impossible for him to retrieve these items. We've tried several reacher/grabbers, but most of them he can't squeeze or snap shut smoothly, so they're useless for picking up things. Is there any grabbing tool that's easy to squeeze?* (**u483**, Spouse)	C5-C6 Quad
Interaction with Mobile	Adaptive Application	*There is a patient in the hospital who is recently injured. We're looking for apps so he can play music on his phone. Are there any apps or other tools to help him use his phone independently?* (**u426**, Hospital staff)	Quadriplegic

4.2.4 Readjusting with Activities of Daily Life (ADL). After an SCI, relearning how to perform daily life activities, including professional and leisure activities, is a significant challenge. In 144 posts—141 by people with SCI, and 3 by supporting-individuals—posters sought information regarding ADLs, such as how to relearn driving with hand-controlled features, how to use cooking tools, or suggestions on appropriate clothing. Posters also asked about professional activities, including returning to work or school, looking for jobs, starting new careers, and attending classes.

Further, some posters asked for suggestions on hobbies or leisure activities: ideas on adaptive outdoor sports, and indoor hobbies. For instance, u360, who sustained an SCI two years ago, is seeking suitable recreational activities since outdoor activities are now difficult:

Table 5: An example (completely rephrased) of an individual seeking and receiving informational support on motor functions through a post and a corresponding comment

Post	*My neck feels burning, and the temperature is higher than the rest of my body. I had a cervical level surgery recently, but I have never had such a feeling before. Have you ever encountered this type of problem?* (u237)
Comment	*I guess this doesn't have anything to do with your injury. I had the same surgery but never felt like that. Any quick medicine like an anti-inflammatory might help, but you need to consult with the doctor.*

Table 6: Posters sought informational support on newly developed self-care activities irrespective of time elapsed since injury. To maintain the anonymity of posters, all examples provided here have been completely rephrased.

Self-Care Type	Examples of post	Time elapsed since injury
Pain Management	*I have been experiencing very severe neck pain and it spreads to my head and gives me pretty serious headaches. Does anyone else experience this? Am I healing?* ***(u941)***	One and half months
Bladder Management	*Sometimes, I get UTIs that result in bladder spasms. In general, I can last four hours without cathing, but during UTIs, I can last only two hours. I also get bad spasms during the UTIs. What should I do to prevent those?* **(u067)**	Two years
Bowel Management	*I am now in a rehab but I will get discharged soon. I am scared regarding my bowel cares after returning home. My father and brother will live with me. However, I don't want to ask for their help. How will I take care of my bowels without their help?* **(u321)**	Recently Injured
Respiratory Management	*There are some mornings, like today, when I wake up feeling like I can't breathe It helps a little to use an inhaler. Can anyone else relate to random breathing difficulties?* **(u013)**	Unknown
Exercise and Weight Management	*I was very active and participated in many sports prior to my injury. Currently, I have gained some extra weight. Is there any advice on weight loss?* **(u356)**	One year
WC Sitting Behavior and PR	*I sustained the injury long ago. I'm worried about getting a pressure sore because I don't change positions as often as I should. How should I deal it?* **(u355)**	16 years

Table 7: An example (completely paraphrased) of an individual seeking and receiving informational support on evolving self-care routines through a post and a corresponding comment.

Post	*Over the past few months, I've had a pressure sore on my left ischium, and it is blanching. I am worried that it is getting worse and it makes me stay in bed a lot. I want to return to work for a full day, but I'm not sure when or if I can. Do you have any advice for me on when I'll be able to work full time again?* (u430)
Comment	*When you blanch, you're recovering. To get back to my normal schedule, it took a while. Whenever I got uncomfortable with the sore, I'd go to my wound clinic and have them check it out.*

> *I regained some of the functionality to walk slowly. Prior to my injury, my favorite sports were mosh pits, backpacking, roller coasters, and motorcycle riding, but I can't do those anymore. Have you found any new fun things to do?* (u360, two years post injury)

Additionally, several posters sought informational support on a variety of sensitive and personal matters, such as dating, sexual activity, and intimate partner interactions.

For these 144 information-seeking posts, we found 1272 comments where 25% provided informational support, and 6% offered emotional support (see Table 8).

Overall, figure 4 shows the informational support dynamics in the subreddit groups. It shows that for all types of informational support seeking posts, commenters provided a wide range of informational support, and some emotional support. For instance, in response to the 144 posts seeking informational support on readjusting with activities of daily life, 25% comments provided informational support, 6% provided emotional support, and 3.5% provided both informational and emotional support. Furthermore, commenters provided the most informational support for newly acquired self-care activities (35%) compared to other informational support categories.

4.3 Emotional Support Dynamics for Gaining Motivation, and Recreating Self-identity

Here we address **RQ3**—posters' emotional support-seeking and receiving in the subreddit groups to adjust to their new life. We found that individuals' sought motivation and support for recreating self-identity through the emotional support seeking posts. Among the comments on these posts, 21% provided support for motivation, and only 9% provided support for recreating self-identity. Additionally, 12 - 14% of the comments provided informational support, and 4 - 7% provided both informational and emotional support.

4.3.1 Gaining Motivation with Hope and Positivity. We found 220 posts—206 by individuals with an SCI, and 14 by supporting-individuals—seeking motivation for adjusting to their newly changed lives after an SCI. Posters frequently expressed feelings of helplessness, guilt, and depression following the dramatic change in their motor functions, and requested positive suggestions. For instance, u002 shared their frustration as their life completely changed post-injury:

> *My life drastically changed after that accident. My partner left me, and I lost my job. There's no way I can take care of myself anymore. Do you have any tips on how to start over?* (u002, two years post-injury)

Table 8: An example (completely paraphrased) of an individual seeking and receiving informational support on activities of daily living through a post and a corresponding comment.

Post	*As I have limited hand functions, I am looking for other's experience of cooking pasta. The most difficult part is how to drain the water and get the pasta out of that pot after boiling? Any ideas on that ?* (u349)
Comment	*It is unthinkable to move a pot of boiling water while using a wheelchair. I have full hand function and I use a hand-held spider strainer which might work for you as well. It takes just a few minutes for pasta to go from pot to pan or plate.*

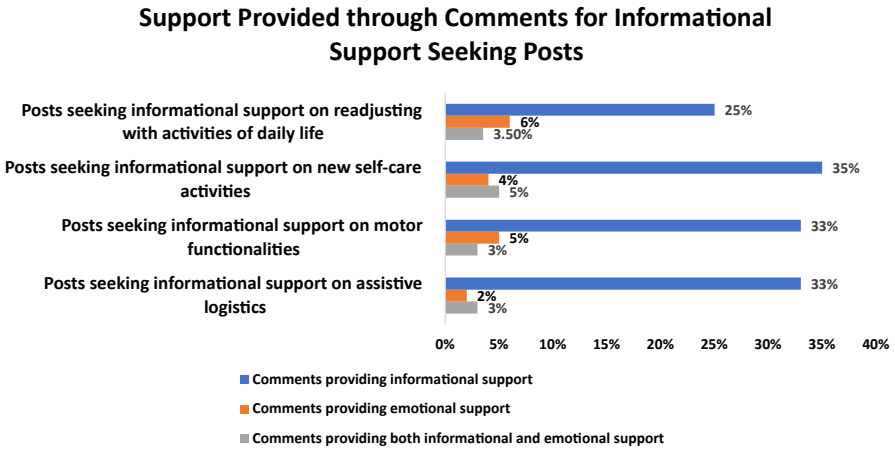

Figure 4: The figure shows the "Informational Support Dynamics" on the Reddit platform. Posters seeking informational support in the subreddit groups received comments with several informational support and a small amount of emotional support for each category of posts. Other comments in each support-seeking post category mainly consisted of general conversations.

Additionally, posters sought peers' success stories to find motivation for regaining mobility, or improving their functional abilities. Similarly, several posters sought motivation and feedback by sharing their own experiences, videos, blogs, or photos regarding regaining mobility or sensation. That includes first-time walking/running, walking without assistance, successful self-transfer from the wheelchair, regaining sensation and strength in the limbs, first bike riding, standing up unaided, and accomplishing target footstep counts. As u379 shared:

> *For the first time today after my injury, I used my wheelchair to go to the elevator today, at my apartment complex. It made me feel like I had progressed. After losing so much in the accident, I finally felt good.* (u379, seven months post-injury)

For these 220 emotional support-seeking posts, we found 3014 comments, where 12% provided informational support, and 21% provided emotional support.

4.3.2 Redefining Self-identity. We found that posters often struggle with their new identity. Fifty-four posts—53 by people with SCI, one by supporting-individual—sought emotional support to recreate their self-identity through redefining their self-image, gaining independence, and improving personal relationships, and social connectedness. For instance, posters shared the frustration that they do not feel like themselves anymore, and suffer from self-guilt; thus they seek emotional support to recreate the self-image:

> *I am not the person I used to be; now I feel like useless. Even though my disability has taken away my physical ability, appearance, and ability to be a person worth loving, I desperately seek to be loved.* (u454, 2.5 years post-injury)

Further, their independence was interfered due to lack of public access, occupied parking spaces, infantilization, or assumptions about their need for help. Posters sought emotional support to manage their self-image by building people's respect and maintaining self-dignity.

> *People often assume I need their help, which frustrates me. It's just like they grab my chair and put it in the car for me. My chair is basically an extension of my body now, and it feels violated when people touch it without asking.* (u108)

Posters also sought inspiration to regain independence by getting out of the house alone, moving to another city for a job, and doing personal tasks without assistance (e.g., using smart devices). Furthermore, posters' functional abilities dramatically impacted their relationships with family, friends, and significant others. Those factors include losing partners/friends, the primary caregiver becoming frustrated, family members frequently expressing excessive expectations of recovery, and some people having to live with their parents. Further, posters sought empathy and guidance on how to create new intimate relationships (e.g., in dating platforms) or improve existing ones:

> *Although I would love to take my son on my own so my wife could have a break, I can't keep up with him. He won't even*

Table 9: An example post (completely paraphrased) of an individual seeking and receiving emotional support in gaining motivation through a post and a corresponding comment.

Post	*I don't think it's worth living now after the injury. Modeling and sports were my things, and whenever I could, I would travel. I can no longer do anything I enjoy. There is almost nothing I can do without assistance. Recently, my girlfriend also left me. I am living a miserable life. I'll need a wheelchair all the time. Is it worth living? I am so lost, so maybe you can share your own stories and give me some hope.* (u335)
Comment	*In the beginning, I was depressed and addicted to drugs. Even now, I'm not comfortable with myself. Your story can be a powerful positive story for yourself. I do that to myself all the time. And your life isn't over. There are still plenty of things to do and enjoy here, even if it might take a little longer.*

> *stay still so I can change his diaper, and I feel pretty useless as a dad in a wheelchair. In what ways do other dads in wheelchairs handle toddlers?* (u879, C6)

For these 54 posts, we found 744 comments, 14% provided informational support, and 9% offered emotional support—thus, commenters offered more informational support than emotional support.

Figure 5 shows the emotional support dynamics in the subreddit groups. It indicates that commenters offered higher emotional support (21% of all comments) for posts seeking motivational support compared to those seeking emotional support for identity reconstruction. Among the 220 posts seeking motivation, 106 posters replied to the commenters once or more than once—in 42 of those 106 posts, the original posters expressed their overall satisfaction with the comments mentioning:"*Thanks for the support*", "*Thank you for sharing*". In the remaining posts it was uncertain whether the posters were satisfied with the support they received through the comments. However, among the 54 posts where posters sought emotional support for recreating identity, 26 posters replied to the commenters once or more than once—only ten of those 26 posters seemed satisfied. In remaining 16 among those 26 posts, posters had to rephrase their questions to make them more understandable in response to the information that commenters provided:"*I'm not looking for anything right now*", "*I think you and the guy above are distracted from my primary question*", or they stopped replying making it uncertain if their need was satisfied or not. That depicts that, posters' emotional support need to recreate their self-identity in their post-SCI life are often not fulfilled on these platforms.

5 Discussion

In this work, we respond to a call to the HCI and accessibility research community to adopt the lens of critical reflection on disability theories [72] to investigate social support seeking and receiving of individuals with an SCI in social media platforms. We found that individuals discuss a wide-range of topics and seek informational and emotional support online related to adapting to the "new normal," which is far beyond only adapting to the physical impairment that contemporary assistive technology design focuses on. Based on our findings, we reflect on social media support dynamics for people with an SCI and recommend moving the support design towards contemplating a non-reductionist critical realism perspective [36]—considering complex layers that drastically change people's lives and identity [101]. We also highlight how our findings can help in designing more inclusive online support technology for this underrepresentative population.

5.1 Implication of Online Social Support in Adjusting to Different Stages of Life by Creating "Self-identity"

Adjusting to the "new normal" after sustaining an SCI involves substantial changes in personal identity [33, 44, 61]. Thus, individuals seek informational and emotional support for recreating their identity [107]. We found that individuals seek informational support on Reddit to re-adjust several life factors, including choosing assistive tools, career and education pathways, or finding a place to live. They also seek emotional support to define their identity (e.g., being a parent or a romantic partner as a wheelchair user). Furthermore, we found that social media support may facilitate acceptance of the new self-image through inspiration from peers: "there is still much to live to enjoy out here" or "you're still the same you" or "you are a person and your life has value" as a response to the emotional support seeking posts: "I used to be a person. Now I feel like a thing" or "I am a human being and my chair is basically part of my body." Thus, through emotional support and peers' experiences, social media platforms can be a powerful tool to help individuals to find their "self-worth" [81] or "self-efficacy" [60] and accept and adjust to their new identity [102], where only informational support is not enough.

Additionally, these changes are similar to other significant life transitions that prior HCI research has discussed, such as losing one's job [16], death of loved ones [48], gender transition [44], retirement, and marital separation [43]). However, individuals with an SCI need to adapt to these changes in addition to the factors that are more directly related to environmental factors; including environmental barriers [52], transportation issues [104], health problems, managing care providers, and dealing with evolving motor functionalities and sensation.

Although prior HCI research considered sustaining an SCI as a pivotal point in one's life [43], our findings demonstrate that the above-mentioned adjustment continues to impact successive life-stages regardless of the amount of time passed since the injury. In addition, We explored that SCI-specific social media platforms have tremendous potential to support individuals in adjusting to the various stages of post-SCI life. Pre-SCI life to post-SCI life is not a one-time transition, and there is no definitive recovery time or certainty of returning to pre-SCI status. Notably, **identity re-creation is significantly impacted by the periodic changes in people's motor functionality**, such as gaining more sensation in hands and arms, learning to walk again, or starting to use a walker from a wheelchair. Therefore, individuals need informational and emotional support online for validation and reassurance of the

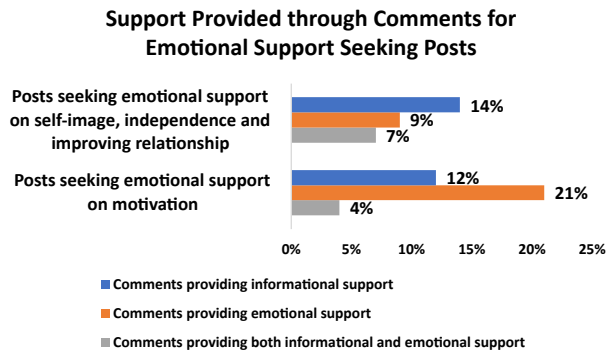

Figure 5: The figure shows the "Emotional Support Dynamics" on the Reddit platform. It shows that the emotional support seeking posts are also receiving informational support in addition to emotional support. Compared to posts seeking motivation, posters are receiving less emotional support for posts regarding self-image, independence and improving relationships. Other comments in each support-seeking post category mainly consisted of general conversations.

Table 10: An example (completely paraphrased) of an individual seeking and receiving emotional support on improving relationship as a part of recreating self-identity through a post and a corresponding comment.

Post	*My motorcycle accident happened 20 months ago. Due to my new lifestyle, my husband had a small breakdown this morning. He is still upset with me for riding a motorcycle. What are your spouses'/partners' reactions to your changes?(u20)*
Comment	*Many people around us are impacted indirectly by this injury and dealing with the changes are difficult for some of them. They compare you to your former self. He will eventually overcome those challenges once he realizes you are still the same person. You won't see change overnight, but acknowledging their concerns and talking about their guilt, anger, etc will help.*

physical changes [25, 93] that impact their identity creation. Future accessibility research can draw a useful research direction into how to help individuals with an SCI reconstruct a valued sense of self-identity while adjusting to their evolving transitions [61] of post-SCI life. For instance, SCI-specific social media groups can categorize posts based on "topic" to help facilitate providing better informational and emotional support by helping people to make explicit what they are seeking. In addition, to help reconstruct "self-identity" social media platforms can facilitate creating social circles with similar "values" and "interests" (e.g., recreational or leisure activities, travel groups) for individuals with similar level of disabilities. Our findings also suggest that the multidimensional nature of support-seeking impedes users from interacting with others who have similar challenges, interests, and have comparable level of injuries. Therefore, these social media groups could be better designed to facilitate more effective interactions between posters and commenters. For instance, help-seeking posts could be more explicitly categorized (e.g., type of injury, duration since injury), and commenters could be automatically prompted with insights on how to make their responses more helpful.

5.2 Implications on Supporting Technology Adoption

Our study revealed that individuals deliberately seek informational support regarding assistive tools and technology. Adopting assistive technology, particularly technology specific to their functional needs, is crucial to adjust to the "new normal" after sustaining an SCI [84]. People receive initial training and information on assistive technology from a rehabilitation hospital immediately after sustaining their injury [29, 30]. However, there is often not easy access to professional support for assistive technology after the rehabilitation period [18]. We found that with the changes in their functional abilities (e.g., transferring from a power wheelchair to a manual wheelchair) and needs of different life stages (e.g., starting a new career, self-tracking exercise routines), individuals often seek informational support from others who have also had an SCI and use assistive technology. Notably, people also need to re-learn some technologies after the injury, such as using mobile phones with voice control, driving a car with assistive tools, or typing with smart keyboards with less hand function, which they used differently before the injury. Prior research found that self-efficacy is essential in adopting and learning new technologies [28], where any negative experience can result in self-doubt and reduced self-efficacy. Thus, **social media can play an important role in supporting assistive technology adoption in part by reinforcing self-efficacy**, in addition to providing informational support about assistive technologies. Thus, accessibility researchers should explore social media platforms as a critical venue for facilitating assistive technology adoption for people with an SCI, or perhaps any context where technology adoption is difficult.

5.3 Implications on Emotional Support around Post-SCI Trauma and Uncertainty

Our study found that one challenge of providing support on social media for the people who sustained an SCI is fostering emotional assistance for post-SCI trauma and uncertainty. Social support theory proposes that sharing experiences and expressing feelings among people facing similar stressors reduces deviance, validates emotions, and promotes mutual aid [26]. It is also evident that sharing of negative feelings with the peers in a social media platform can also be therapeutic [106]. However, our findings show that posters are often not satisfied with the responses they receive when they ask for such emotional support. While Andalibi et al. [6] demonstrated that sharing traumatic experiences on Reddit leads to personalized emotional support—indicating a sense of community—our study revealed that posters with an SCI dealing with the evolving health and motor functionalities—irrespective of the duration since the traumatic injury (see Fig 3)— face uncertainty. The uncertainty leaves posters skeptical about the progress of their recovery process and whether their peers are undergoing similar situations. Thus, fostering personalized emotional support for individuals with an SCI is challenging due to the diverse recovery journeys experienced by each person. Additionally, individuals may not be ready to offer emotional support in sensitive contexts, such as posts discussing self-harm contemplation. The text-based nature of communication on platforms like Reddit may also hinder emotional support, as indicated by previous research [6, 27].

As our analysis only scratches the surface of emotional support seeking and receiving mismatches, future accessibility researchers should explore the reasons behind these disparities. They could also implement of various technology-based solutions, such as AI-supported comment prompts that could help commenters to offer more meaningful emotional support to individuals seeking to adjust to their post-SCI life. Additionally, social media could be designed to facilitate access to resources such as trained peer mentors, counselors, or therapists just-in-time, to help posters work through destructive thoughts, emotional struggles, or thoughts of self-harm. The system could detect such posts and connect users to immediate support. Additionally, posts containing relevant success stories could be utilized as inspirational tools for users seeking emotional support.

5.4 Implications for Improving Relationships with "Supporting Individuals"

We found that the transition after SCI and adjusting to the "new normal" also impacts the lives of people around individuals with an SCI (e.g., partners, family members, and friends) who often have little understanding of the life of SCI survivors and how to help their loved ones. Thus, friends and family also use social media platforms to search for information, including seeking answers to SCI-related questions, and asking for other peoples' experiences. However, similar to prior research, our study also shows that the relationship between individuals with an SCI and their caregivers may eventually deteriorate [54], which is a critical challenge for them to adjust to their "new normal." We suggest that social media designers might look for ways to bring supporting-individuals closer to the community of people with an SCI through a "being-with" approach [11], where supporting individuals would learn the holistic "lived-experience" from other individuals with an SCI or other supporting-individuals as a companion, and create more empathetic companionship through cross-community support, similar to the peer-to-peer support discussed by O'Riley et al. [89]). We also observed differences in the information-seeking behavior of supporting individuals related to assistive technology. Specifically, we noted that supporting individuals mostly sought information regarding assistive technologies that will enhance the independence of persons with an SCI. Thus, social media platform can facilitate the education of supporting individuals about various available technologies through short demonstration videos or by connecting them with other supporting individuals for discussion and collaborative learning.

5.5 HCI Research Methods for Availing More User Data from Broader Population with Disabilities

There are ongoing opportunities to enhance HCI research methods for improved accessibility and participation among people with disabilities, capturing a broader range of diverse lived experiences. For instance, to adopt the Critical Realism [36] lens of the multi-faceted disabled experience, researchers need to recognize people's multi-dimensional lives, including physical, biological, psychological, psycho-social, cultural, and emotional states. Although HCI literature has started to explore the nuances of people's lives with SCI, it has yet to provide efficient guidelines for working with people with SCI to elicit this rich multi-faceted data. Prior research [55, 65, 71] also identified that because of the multiple levels of injury and co-morbidities, it can be difficult to recruit people with SCI for conventional HCI research methods (e.g., interviews). Researchers have also explored design methodologies such as Speed Dating [82]; however, recruitment and accessibility of the methods remained challenges that limited the number of participants.

In this paper, we leveraged publicly-available data from an online social space, which enabled us to learn about people's challenges living with an SCI. This approach may help researchers overcome some of these typical methodological challenges encountered when working with this population. In addition, it can help include people from geographically distributed places and ethnicities, which can inform important factors in people's lives. Until now, HCI research with people with an SCI has focused on western societies, which might lead to a lack of understanding of people from other places. Of course, this is balanced with the ethics of doing this type of data collection, including protecting posters' identities by anonymizing the poster, paraphrasing/summarizing posts [14, 77]) and not following the poster's other activities over the online social spaces [80]. Overall, the benefits of social media data while considering ethics make it a valuable addition to the HCI accessibility researcher's toolbox.

6 Conclusion

This work develops an understanding of the support needs of people with an SCI through social media platforms by exploring *what* topics people with an SCI discuss and *what types* of support they

seek. We identified 39 life factors under 13 broad categories that people discuss online; these can help future CSCW and accessibility researchers to explore opportunities to design features that are more inclusive and facilitate a better match between the kind of support desired and the kind of support provided. We also uncovered the types of informational and emotional support these posters seek and receive while adjusting to their "new normal." Reflecting on our findings, we discussed the potential for social media support in creating a new self-identity, adopting new assistive tools, and fostering emotional support. Thus, our findings depict the potential of social media platforms to support adjustment to peoples' post-SCI life with their new physical abilities, which needs more attention in future HCI research in-terms of fostering inclusion and diversity on social media platforms. Finally, we discussed collecting data from the broader disabled community through social media platforms and making HCI research methods more inclusive of the disabled community.

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