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CASE REPORT

“My body was my temple”: a narrative revealing body image experiences following treatment of a spinal cord injury

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ABSTRACT

Purpose: This narrative explores the lived experience of a young woman, Rebecca, and her transitioned body image after sustaining and being treated for a spinal cord injury.

Method: Data were collected from a single semi-structured in-depth interview.

Results: Rebecca disclosed her transitioned body image experiences after sustaining a spinal cord injury and being treated by medical staff immediately following her injury. Before her injury, she described a holistic body experience and named this experience her “temple”. During intensive care in the hospital, she explained her body was treated as an object. The disconnected treatment of her body led to a loss of the private self, as she described her sacred body being stripped away – her “temple” lost and in ruins.

Conclusions: Body image may be an overlooked component of health following a spinal cord injury. This narrative emphasizes the importance of unveiling body image experiences after the treatment of a spinal cord injury to medical professionals. Lessons of the importance of considering the transitioned body experiences after a spinal cord injury may help prevent body-related depression and other subsequent health impacts. Recommendations for best practice are provided.

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► IMPLICATIONS FOR REHABILITATION

Spinal Cord Injury

- A spinal cord injury may drastically change a person’s body image, thereby significantly impacting psychological health
- More effective screening for body image within the medical/rehabilitation context is needed to help practitioners recognize distress
- Practitioners should be prepared to refer clients to distress hotlines they may need once released from treatment

Introduction

At present, ~86,000 Canadians [1] and 1,275,000 Americans [2] have a spinal cord injury. Spinal cord injuries can be categorized as traumatic (e.g., motor vehicle accident) or non-traumatic (e.g., virus) in cause. Individuals who have a spinal cord injury will experience impairment of the communication between their brain and the rest of their body. This impairment affects several body functions, including mobility, sensation, sexual function, and bladder and bowel function.[3] Paraplegia is the result of a lesion located at the level of the thoracic vertebra or lower and results in impairment of sensation and/or movement of the trunk, lower limbs, and pelvic region. Tetraplegia (otherwise known as quadriplegia) is the result of a lesion in the cervical vertebra. This results in impairment of motor and/or sensory function in the upper and lower extremities, trunk and pelvic region.[3]

Changes to the body that result from a spinal cord injury may include changes to appearance, such as loss of abdominal musculature,[4] functionality, such as incontinence,[5] and independence, such as depending on others or adaptive devices for transferring or bathing.[6] The severity of these changes can significantly affect one’s body image experiences.[7] Body image is defined as a

complex multidimensional concept reflecting perceptual, cognitive, affective and behavioral aspects of the physical self.[8] Perceptions, thoughts, feelings, and actions of the body can be experienced negatively and/or positively. A negative body image usually includes internalization of the Western cultural “ideal”, which for women is defined as being tall, thin, and large breasted and for men is tall with large muscle mass in the chest, shoulders, and back.[9] Internalization of the ideal often leads to high dissatisfaction of the body accompanied by high levels of guilt and shame, and may even include unhealthy eating and exercise behaviors.[10,11] On the contrary, a positive body image is distinct from negative body image. Rather than the mere absence of negative body image, positive body image is having overall acceptance and appreciation for the body despite not being completely satisfied with appearance.[12] Individuals who have a positive body image are aware of the fabricated nature of the media and do not give into cultural ideals of appearance, surround themselves with others who also have a positive body image, and are attuned with and take care of their body.[13]

Within a similar lens as the philosophy behind positive body image, activist Rosemarie Garland-Thomson discusses the

experience of the body from a feminist-disability perspective.[14] From this perspective, rather than conforming to society's demands and definition of beauty and disability, it is imperative to be critical of socially constructed ideologies. Liberation from society's demands on the body comes from not internalizing messages constructed to alter how we behave and feel about our bodies. This includes rejecting the notion that disability is pathology, that the body is easily changeable or "fixable", and that women's worth is solely their appearance.[15]

To better understand the experiences of having a disability, Taleporos and McCabe [16] conducted a qualitative study and found that body image experiences can vary greatly in those who have a disability. They found that bodily impairments had negative influences on their participants' feelings and attitudes towards their bodies, but that acceptance occurred over time. Overall, in individuals who acquire a spinal cord injury, some adjust well and have positive body image experiences,[17] whereas others may adjust more poorly.[18] A quantitative study on women with spinal cord injury revealed women were generally "a little dissatisfied" with their appearance and "a little satisfied" with their function.[19] A similar study [20] exploring body image in men with spinal cord injury revealed the participants' appearance and functional satisfaction scores were comparable to the general population. Furthermore, another study was conducted using interview-based research with men and women with spinal cord injury and found positive body image experiences were expressed by some of their participants.[21] These experiences included acceptance of their body and disability, as well as appreciation for their function, health, and independence.

In another qualitative study,[4] women with spinal cord injury described how they adjusted to their changed bodies. These women described a transition of changed body image experiences moving from discomfort with their body acutely after their injury to more comfort over time with an accepting social environment. The authors recommended that rehabilitation professionals may play a role in making women with spinal cord injury feel more comfortable through, for example, making sure their clients' individual needs are considered and not just classifying them by their injury. Overall, body image experiences in people with spinal cord injury can vary quite a bit, depending on factors such as time with injury, social support, and independence level.[4,19,21]

Body image is a subjective experience heavily affected by broader social determinants, such as interpersonal relationships, the media, and cultural socialization, and is therefore open to change from social interactions.[9] These social interactions may include those experienced during rehabilitation for an individual recently injured. Therapists' and physicians' perceptions, behaviors, and attitudes towards their clients' bodies may have an impact on clients' own opinions about their body.[4] Therefore, while the injury itself has a direct impact on body image experiences, the experience is further compounded by treatment and rehabilitation experiences and interactions. Moreover, as most of the research on people with spinal cord injury is focused on men, there is a "lack of knowledge about women with spinal cord injury" and their subjective experiences.[22] More in-depth qualitative research is needed to understand the role rehabilitation and medical/rehabilitation practitioners have on the development of body image in individuals recently injured with a spinal cord injury in order to develop best practices for health care professionals. Narratives can reveal recurring themes within rehabilitation, and therefore can inform best practice recommendations.[4] In fact, the field of medicine has always been a storied enterprise.[23] Patients' stories have an important epistemological function that builds up medical knowledge which can direct researchers, practitioners, and policy

makers to the areas of needed attention.[24] The purpose of this narrative was to unveil a rich in-depth story of a woman's experience of her changed body image after acquiring and being treated for a spinal cord injury.

Methods

Participant

Rebecca (pseudonym), the woman represented in this narrative, was recruited from the Neuromuscular Rehabilitation Lab associated with a university through purposeful sampling [25] of nine total participants recruited for a larger study exploring positive [21] and negative body image experiences in people with spinal cord injury.[18] Rebecca was 26 years old at the time of the interview. She was 21 years old when she sustained her spinal cord injury at the sixth thoracic segment, resulting in complete paraplegia.

Design

Narrative inquiry is a tradition of qualitative research, whereby meaning is created through story-telling.[26] Stories allow people to shape their identities through the act of story-telling. Research in the narrative domain invites individuals to share their stories and uses these stories as data itself. Narrative studies have moved with surprising speed from the once marginal status in human sciences to a more robust legitimacy.[27] Typically, stories are about past and present events which have a plot with a beginning, middle, and end.[28] Often individuals do not share their stories in chronological order, in which case the researcher must reorder the story in temporal order to make sense to the reader, which creates the narrative for further analysis.[29]

There is considerable variation in narrative approaches in research. For example, Polkinhorne [29] suggests there are two types of paradigmatic analyses of narratives. One approach derives concepts from previous theory that can be applied to the data deductively and in the other approach concepts are derived inductively from the data, which is similar to grounded theory analysis.[30] Mishler [31] introduced a more detailed and comprehensive model of narrative analysis, which he states demonstrates "the depth, strength, and diversity of the narrative turn in the many sciences". His typology attempts to cover the many ways researchers can story the world across different types of data, analytic methods and strategies, and genres. To provide a brief overview, in Mishler's first category, *Reference and Temporal Order: The "telling" and the "told"*, the methods focus on looking for temporal sequence of action events and their order of presentation in the data. In the second category, *Textual Sequence: Narrative Strategies*, the methods are grounded in a structuralist theory of language. These methods are more disposed towards spoken discourse than written text. Finally, the methods in the third category, *Narrative Functions: Contexts and Consequences*, are to illuminate the larger society through personal and group stories, using theoretical frameworks.

For the present study, we adopted a narrative approach from Mishler's [31] typologies to present one woman's changed bodily experiences within the medical system after sustaining and being treated for her spinal cord injury. Mishler believes narrative inquiry is a "problem-centered area of inquiry",[31] therefore the model of analysis we use is based on our research problem. Within Mishler's typologies, we selected category one – reference and temporal order: the telling and the told. Within category one, we used method two: restructuring the told from the telling. This analysis

entails reordering the story in a temporal order. We reassembled the data into a thematically coherent story. This strategy is similar to Polkinghorne's [29] narrative mode of analysis. We reordered (reconstructed) a storyline from the telling, then this reconstructed story becomes the "narrative for further analysis".[31]

Data collection

Narrative research takes the story itself as its object of study. The narrative data examined in this study originated in a project focused on positive and negative body image experiences in people with spinal cord injuries. The lead author contacted Rebecca as a participant in the larger study. When Rebecca expressed interest in participating, she was emailed a letter of invitation, all procedures and study materials. Then, the lead author arranged a telephone interview. The telephone interview was used as a way to build rapport and to book the one-on-one interview. A semi-structured interview guide was developed to ensure the interview focused on body image pre- and post-injury. See Table 1 for an outline of the questions asked during her interview. Rebecca's one-on-one interview was over two hours in length and produced data that was not fully included in the original study. The richness of her story and the detail she presented about her experience within the medical system is why her personal narrative was selected for further analysis here.

Data analysis

The analysis was guided by one of Mishler's [31] models of narrative analysis – reference and temporal order: the "telling" and the "told". Within this model of analysis, we reordered the storyline and then analyzed the new storyline to find a common pattern to the plot. From this approach, the story the researchers retell is a "series of temporally ordered events".[31] The interview was audio-taped and transcribed verbatim. Then, the transcript was repeatedly read in order to get an overall sense of the data. The first author used the NVivo 10 software package, a qualitative research analysis program,[32] as a way to organize the data and codes. Then, she actively searched for events in Rebecca's story and rearranged them in chronological order into a storyline. During this process, data that did not fit the storyline or purpose of the study were excluded. Revelatory information about her body image, treatment from her spinal cord injury, as well as biographical and contextual descriptions were included in the narrative to help build the plot. Then, the first and second authors met to discuss the final order and meaningfulness to the resulted story. Lastly, all

Table 1. Interview guide.

-
1. Can you tell me a bit about how you view your body?
 2. Tell me about how you first adjusted to your body after your injury?
 3. Describe your experience during rehabilitation immediately after your injury with regards to how you felt about your body?
 4. Will you talk about how you see and think about your body now?
 - a. How about before your injury?
 - b. How about acutely after your injury?
 5. Overall, how do you feel about your body now?
 - a. How about before injury?
 - b. How about acutely after your injury?
 6. In what ways do you act towards your body?
 - a. How about before injury?
 - b. How about acutely after your injury?
 7. What matters the most in regards to body image for someone who has a SCI?
 8. What do you consider to be the ideal body?
 9. Tell me about how people in your life (partners, family, friends) affect your body image.
-

researchers met and discussed the final themes of the storyline and applied their expertise and perspectives.

Results

From the analysis, the present story covers the time from about one year before Rebecca was injured to five years after her injury. First, we provide a description of Rebecca and her life before her accident as recounted by Rebecca to provide biographical context. Then, the story is organized by pivotal time-periods of her changed body image experiences. The main themes that frame the narrative are her body as her temple, her temple stripped, and her temple in ruins. Then, we finish by relating her story to relevant research, theory, and provide best practice recommendations.

Introducing Rebecca

Rebecca was a young university student living in Southern Ontario with her parents. She was very passionate about being physically active. Much of her motivation for being active was to maintain her very fit body – allowing her to receive a lot of attention from men. In many ways, she described fitting within the narrow definition of the North American ideal body – blonde, thin, fit, and large-breasted. Although she was always flattered by the attention she received from men, she was in a very committed relationship. Her boyfriend was an avid dirt biker and influenced Rebecca to start dirt biking. Dirt biking then became a large part of Rebecca's life and identity. Being a very attractive woman in a male-dominated sport was the source of a lot of pride in her life at the time. Then, during one of her dirt biking competitions, Rebecca violently tumbled off her bike in a life threatening accident that changed her life and body image completely.

Rebecca's accident resulted in complete paraplegia at the level of the sixth thoracic segment. This means she had full function of her arms, but no motor or sensory function at or below her trunk region. Furthermore, she described having impairment of her bladder, bowel, and sexual functioning. She used an intermittent catheter which means she had to insert and remove a catheter several times a day as a means to empty her bladder. She described having impaired sensation to feel when her bladder was full and needed to be emptied, so she used the bathroom on a scheduled routine in order to prevent incontinence. Despite having an organized bathroom routine, incontinence was something she inevitably dealt with sporadically. In order to empty her bowel, she relied on medication and depended on a scheduled routine during the day to attempt to empty her bowel. Although Rebecca did explain having reduced genital arousal, she also indicated being very capable of having an orgasm, something she was adamant about clarifying during the interview.

Her temple

Rebecca described being a very confident and conservative person before her injury. When she was asked to reflect on some of her thoughts about her body before her injury she said,

Before my injury, like I said, I am very athletic, very confident, I was a bartender, I was very much . . . [in] environments where I didn't mind showing off my body I didn't think twice going to the beach. I had a boyfriend but I, you know, got constantly hit on by other boys, so that just made my head a little bit bigger and I got compliments. So I was a very confident person with my body beforehand.

She also went on to say,

Definitely my temple, I'm a goddess, I can, you know, I can use my body to kind of get what I want kind of a thing, again, I was a bartender, I

was athletic, and plus I was a girl in a sport that was male-dominated and when I was out there, you know what I mean, guys were like 'WOW that's awesome!' ... So again it was another one of those things if you're hot you have more confidence so before my accident again being very confident knew what I had but also I had a boyfriend and I loved him very much and I was always in a relationship but I always flirted with the guys and I always hung out with the boys *but* they always knew I was off limits which almost made it more fun *right*, haha.

Although Rebecca was flattered by the attention she would receive from other men, she was very committed to her boyfriend. She described that he was the only one who ever saw her naked. This intimate and private connection she had was part of her temple experience. Her body was a sacred and holistic place. She could trust her body to get her what she wanted, she felt she was a goddess, and her temple was protected by the idea that she had complete control over who saw or interacted with her body.

Her temple stripped

The acute stage following her spinal cord injury, during hospitalization and rehabilitation, was a pivotal time point for her body image. It was during this time that she described her "temple" being slowly stripped away. After Rebecca's accident she was brought to the Intensive Care Unit (ICU). She was in ICU for several weeks coming in and out of a coma. After she finally came to consciousness, she described not being able to feel or see her body. Rebecca described her first interaction with a doctor as very defeating and disheartening. When divulging this moment, she said,

I didn't even know who this guy was at first, he didn't even act like a doctor, he just walked in and wasn't wearing the regular doctor clothes and he just sat at the end of my bed and I was like 'Who is this? Who are you?' kind of a thing and my parents were in the room and they were like 'Can we help you?' and he was like 'Oh! I'm a [Rebecca's] doctor' and we were like 'Great! We have questions for you!' and he's like 'Well, does [Rebecca] have any questions for me?' and I'm like 'Yeah! Am I ever going to walk again *ever*?' and he's just like 'Nope. Ok what's the next question?' and I was just like 'Oh my gosh couldn't you be the least bit sympathetic?!' and of course I just start balling and my parents are just like 'That's it!' they're like ... 'she's 21 years old and you know you just like crushed her *right*. She knew what the answer was but giving her a glimpse of hope is one thing but just putting out the flame is another' right so, he wasn't allowed again in my room after that and so, again, most doctors are like that unfortunately.

Rebecca tried to rationalize the doctor's behavior, she said,

...it's because they deal with it on a daily basis, but still you think people would have a heart. I was just trying to find people that were a lot more positive and sympathetic ... that was what helped me adjust as opposed to getting the hardcore truth.

Rebecca's accident was very severe and she sustained many injuries to her face in addition to her spinal cord injury. In fact, she broke every single bone in her face and lost most of her teeth. Rebecca had gone through full facial and dental reconstruction as a result of her extensive injuries. When describing this painful memory, she said,

It took me a long time to learn how to smile in a way that I liked because I broke every single bone and because I had so many operations, certain muscles move different ways and I have certain scars and it took a long time for my face to go back the way it was, which there was no guarantees in general, but they, when it came to smiling I smiled differently and then I also knocked out a whole bunch of teeth and had a full, not just braces, but jaw reconstruction, so I for one, I absolutely hate my teeth now ... They are not *MY* teeth ...

I asked Rebecca to describe how she felt or saw her body acutely after her injury and she said,

The most awkward thing was not being able to feel or move those parts ... when lying still it was almost a feeling that you know your body is still there but when you go to use it, it doesn't react.

It was difficult for Rebecca to describe how she saw her body after her injury because she explained having the ability to see was taken away from her. Since she had full facial reconstruction and her body was paralyzed she was not able to move and see her body. Her eye sockets were shattered from the accident resulting in her eyes being extremely swollen. In addition, her parents did not allow her to use a mirror for several weeks because they were afraid of how she might react to the changes of her face. She could see some parts of her body but not her face. She describes this moment,

I was not allowed a mirror for four months after my accident because my family, and of course health personnel, were afraid of how I would *react* because I didn't know, I was not given the details or the extent of the injuries, just because losing mobility throughout my body was *more* than enough to overwhelm me that they did not want to sting me again with how I looked.

She continued to say, "So when I saw myself again it was like I saw myself but I couldn't see myself, so I wasn't allowed to see my face and I wasn't allowed to see."

During the acute stage after Rebecca's injury, she described her body being exposed to medical scrutiny. The experience of her naked body being completely exposed to doctors and nurses during treatment was degrading to her dignity. Slowly, her sacred body experience was taken away, she said,

...to have other people see me naked even though I couldn't feel it was like ... it was barrier crossing and eventually so much care that had to be done with my body that, that barrier got broken down so much that it was like 'who is it?' 'it's a male nurse' where at the beginning if it was a male nurse I was like 'turn around!' or like the male nurses hated [it] because they were like 'we don't look at your body like that!' and I'm like 'turn around! I don't care!' I'm like 'nope! Bring someone else!' and they would always have to go find some lady and after a while I was like 'yeah, just come in, I don't care'.

She continued to describe this undignified experience, "...it definitely felt degrading, the whole time felt degrading that I couldn't do anything for myself but also having doctors having to see me and often it was doctors I didn't know ... nurses are bathing me."

Her temple in ruins

After extensive treatment of her body Rebecca was left with a disconnected sense of embodiment. Since being released from the hospital and finishing rehabilitation, Rebecca's body experiences were much different than before her injury. What was once a sacred temple was stripped away to a point that impacted various aspects of her life. For example, something as simple as using the washroom was a completely different experience. Not only did she have to rely on a catheter and medication to empty her bladder and bowel, but her sense of private self was deteriorated. She explained this experience,

I don't think of it as going to the washroom because it's kinda weird because ... when I think of it I think 'ok I have to go cath [use a catheter]' and I don't think of it as 'oh I have to go to the washroom' so it's almost like it's just a procedure or something. I don't think of it like going to the washroom. I've gone on vacations with my girlfriends and stuff and I won't even shut the door and I'll be on the toilet cathing and my girlfriend will be like 'DUDE!' Shut the door!

Another aspect of her life that was impacted was sexual intimacy. Before her injury she described sex as a precious moment because only her boyfriend saw her naked and that was something unique each of them shared. After treatment of her body which included, but was not limited to, constant body

examinations, bed baths, and catheter insertions, sex was no longer a private intimate moment. For example, she said,

So when I am with someone now say intimately or when someone sees me naked it's like, if it's a doctor it's like 'oh whatever' and people are like 'oh! You can cover' you know what I mean 'you can cover up' and I'm like 'whatever'.

She also described the act of being naked with someone as not special or unique anymore. She said, "when I [think] of my body I don't think of it as something precious and my own anymore, unfortunately."

One of the most devastating results of her spinal cord injury was the immense psychological suffering she described experiencing when she was alone. Although she described being very good at putting up a front that she is confident and happy, she described that when she is alone her true emotions are revealed. Since her injury, she depends even more on men for reassurance that she is attractive. Much of her self-worth is caught up in her negative thoughts and beliefs about her appearance. When describing some of these struggles, she said,

After my accident I cried maybe every night for like a year and then even so it would be, you know, every couple days and then every six months. I would go through a depression period and there's definitely times when I don't feel beautiful, I wish I were standing, I wish I were this, I wish I would look like I did, and so I did go through a period when I used to cut myself, I used to use, or abuse drugs, I guess you could say, there has been two times where I tried to commit suicide.

Rebecca's body experience is concluded with living in the ruins which consists of a persistent lack of comfort with her body. Rebecca is left yearning for the body she once had. Her body is no longer a place of enjoyment, familiarity, comfort, or pride. Between the actual spinal cord injury itself and the medical treatment of her body, these two experiences have left Rebecca longing for the temple she once had.

Discussion

This study unveiled the rich in-depth experience of acquiring a spinal cord injury and then being medically treated for an injury in relation to one woman's body image. The striking contrast of Rebecca's body image before and after her injury is compelling. It is important to note that Rebecca's conception of her body before her injury conformed to the normalized and unrealistic notions of Western beauty. She defined her attractiveness, hyper-femininity in a male-dominated sport, and the attention received from men as her self-worth. According to critics of westernized ideologies of beauty, gender roles, and heterosexuality, society's constructed standards of beauty act as a method of social control to maintain oppression of women and people with disability.[9,14,33,34] Women are socialized to compulsively monitor and treat their bodies as a sexual object to be evaluated by others.[35]

Powerfully intertwined in Rebecca's sense of beauty, objectification, and self-worth is her able-bodiedness, which is then vastly interrupted after her traumatic spinal cord injury. Disability studies and more recent territory chartered by Crip theorists have criticized what is understood as a "normal body" and challenges the construction of able-bodiedness and heteronormativity.[36–39] Activist Garland-Thomson [14] scrutinizes the politics of appearance, the medicalization of the body, the privilege of normalcy, sexuality, and the social construction of identity. Rather than conforming to society's demands and definition of beauty, it is imperative to be critical of socially constructed norms. From this perspective, liberation from society's demands on the body and disability comes from not internalizing messages constructed to alter how we

behave and feel about our bodies. This includes rejecting the notion that disability is pathology, that the body is easily changeable or "fixable", and that women's worth is their appearance. Critical and radical scholars such as Crip theorists can help inform medical practice and illuminate gaps in rehabilitative literature. Therefore, Rebecca's experience of her body as in ruins is a combination of a disruption to her constructed sense of self as well as the medicalization she experienced for her injury – both of which objectified her body.

The distress evoked in this narrative uncovers the complex psychological changes that occur after acquiring and being treated for a spinal cord injury. Although this story is unique to Rebecca's experiences, there are other people with spinal cord injury who may be able to relate to many aspects of this narrative. It is fair to say that Rebecca's medical experiences had an adverse impact on her psychological well-being. Very similar stories have been disclosed in previous research. For example, in their qualitative study about self-concept in women with spinal cord injury, some of Chau and colleagues' [4] participants voiced how their privacy needs in the hospital were not met. Furthermore, they too expressed dehumanized feelings associated with the care of their bodily functions. One participant described feeling as though she was not looked at as if she were human. Instead, she even described being treated as though she was part of a production line and emphasized the importance of patients' individual needs being treated instead. Their participants felt characterized by their injury and not treated as individuals. These authors described how this experience seemingly perpetuated participants' negative attitudes towards their bodies.

There has been a recent growth in interest of patients' stories in the health care field; however, the value of listening to patients' experiences is far from being the "gold standard".[27] A significant factor in the initial shift of attention towards patients' stories was the widespread dissatisfaction with the care patients received from their health care providers. This dehumanized practice severely compromised the doctor–patient relationship. In Cassell's [40] influential volumes, *Talking with Patients*, he states, "Doctors are very powerful people. Properly used, their powers can lift the burden of sickness, relieve suffering, and do enormous good. Used wrongly, their power can do great harm". In Rebecca's case, it is clear that the first doctor who treated her left a lasting negative impression. Perhaps, if that interaction had been more positive, her body image experiences would have been shaped much differently.

Body image is often an unspoken and neglected aspect of health within the medical system. Pain, loss of motor and/or sensory functioning, and changes to appearance may dramatically impact the psychological experience of the body. Adjustment to these changes may be crucial for well-being and quality of life for individuals who have gone through changes to their body. However, within spinal cord injury rehabilitation, physical therapy focuses primarily on physical issues related to recovery, thereby ignoring the social-psychological concerns associated with a changed body.[41] This could be due to reduced hospital and rehabilitation stay periods. For example, hospital stay was reported to have reduced from 24 days to 11 days and rehabilitation stay from 98 days to 36 days since the 1970s.[42] Therefore, practitioners may feel as though there is simply not enough time to address the social-psychological concerns of their clients in addition to the physical issues.

Regardless of reduced stay periods during which patients are treated for their spinal cord injury, medical personnel may feel it is hard to recognize social-psychological concerns of their patients. Pruzinsky [43] suggested there should be more effective screening for body image within the medical context to help practitioners

recognize when there may be distress. In most medical treatment contexts, patients' body image concerns are not explicitly addressed by any member of the treatment team, even in instances whereby body image distress may be very likely (e.g., severe changes to appearance or function). Since physicians or other medical professionals may feel unskilled to identify body image distress, standardized screening protocols are necessary. Giving a body image measure, such as the Body Image Quality of Life Inventory,[44] as part of routine pre-consultation paperwork normalizes body image assessment and provides a platform for medical staff to initiate discussion on body image.[43] In the present example of Rebecca, if it could have been recognized early on that she was experiencing severe body image distress, then maybe intervention during the acute stages could have prevented some of her subsequent psychological anguish.

One area of medicine that body image assessment needs have been emphasized is in breast cancer treatment.[45] In fact, body image scales specific to breast cancer have been developed and validated to be used in practice to recognize distress with body image fluctuations.[46] Furthermore, body image assessment has been included in the official best clinical practice guidelines issued by Alberta Health Services in Canada.[47] Body image assessment should be mandated within best practices guidelines for other conditions whereby body image may be a pressing issue, such as after a spinal cord injury.

This study demonstrates the importance of narrative research within medical and rehabilitative sciences. Narrative research is important for illuminating the individual and collective meanings which may allude to larger social processes where change may be needed, particularly in the medical context.[27] For example, Rebecca's personal narrative reveals deep experiences that were altered by her spinal cord injury. Part of this experience was her interactions with doctors, nurses, and rehabilitation personnel. These deep experiences cannot be documented objectively, but rather these subjective transactions can be explored through narrative approaches where rich nuances are not missed. For example, as suggested by Greenhalgh and Hurwitz,[48] narratives offer a method for addressing inner hurt, despair, hope, grief, and moral pain which frequently accompany, and may even constitute, people's illnesses. Narratives offer the opportunity to explore the meaning, context, and perspective for the patient's predicament. This allows questions such as, how, why, and in what way he or she is feeling, to be answered. This narrative-based study, along with others,[22,49,50] further expands the understanding of living with a spinal cord injury. It is through the collection of multiple narratives from diverse perspectives that best practice can be informed. Based on the present narrative and past literature, the following recommendations are offered:

1. Seminar series should be led to teach practitioners what body image is, the importance it may have on their clients, and how to recognize body image distress.
2. Body image screening should be implemented as routine practice during pre-consultation to recognize early on when clients are experiencing grief.
3. Practitioners should be equipped with referrals of body image programs in the area or at least refer clients to distress hotlines they may need once released from treatment.

Conclusions

All members of the medical treatment team can have a profound impact on clients' social-psychological experiences and health. To ensure optimal recovery of any condition, all aspects of health need to be considered, including body image. Simple changes

such as the inclusion of a body image measure during treatment may have positive impacts on long-term health, particularly for individuals whereby body image may be a particular concern.

Future directions

Literature on the lived experience of clients is growing; however, other areas of research are also needed. For example, a major gap in the literature is narratives of practitioners' experiences with their clients. To have a more complete representation of the practitioner–client relationship, it is important to collect narratives of both experiences. Practitioners' experiences are important because they may also shed insight on recommendations for best practice. The use of narratives within medicine should be expanded to encourage ways to improve quality of care within all domains of the medical context.

Disclosure statement

The authors report no conflicts of interest.

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