

NARRATIVE REVIEW



Toward a person-centered ethics framework for autonomy in spinal cord injury research and rehabilitation

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Abstract

In this paper, we explore how the concepts of autonomy and autonomous choice are understood in the context of spinal cord injury in the academic literature, both in reporting on research results and more broadly on outcomes and quality of life. We find inconsistent, framework-absent portrayals of autonomy as well as an absence of discourse that draws upon ethical constructs and theory. In response, we advance a person-centered framework for spinal cord injury research that combines both lived experience and a disability ethics approach to fill this gap.

INTRODUCTION

The purpose of this article is to explore how the concepts of autonomy and autonomous choice, which are central to ethical and legal analysis in the health care context, are portrayed and understood in the academic literature that specifically addresses spinal cord injury (SCI). We consider these concepts both in reporting on research results and more broadly on rehabilitation outcomes and quality of life. We address the problem of inconsistent portrayals of autonomy and related concepts and an absence of discourse and frameworks around ethical constructs and theory. In response, we offer a person-centered ethics framework to fill these gaps. The framework is designed to unify and reshape the understanding of autonomy for SCI by placing the

perspective of people with lived and living experience with SCI in central focus. It respects the diverse and intersectional identities and realities of people who live with SCI by placing experience of disability as a source of moral knowledge and ethical insight.

LITERATURE REVIEW

For this work, we reviewed 70 papers selected for their focus on qualitative aspects of life with SCI and identified the subset of papers in which discourse about autonomy was explicitly referenced. The project is part of a large, interdisciplinary program of work designed to develop and test a biomaterials-based platform for SCI repair. The authors who performed the analysis and

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TABLE 1 Discourse on autonomy in the peer-reviewed literature (2012–2021) on qualitative aspects of SCI.

Publication ^a	Location	Purpose	Major foci	Theoretical framework	Definition of autonomy	Discourse about autonomy	Excerpt
Kaiser et al. ¹	Canada	To understand the experiences of parents with SCI and their use of aids and adaptations in caring for children	Expectations, priorities, expressed needs	Disability culture perspective (social model of disability)	NA	Discussed in the context of control and functional independence	“Feelings of ‘frustration’ and ‘helplessness’ over their loss of control and autonomy stirred up underlying emotions regarding lack of disability acceptance.”
Van de Velde et al. ²	Belgium	To explore the experiences of individuals with SCI on their perceived autonomy in the transition period from hospital to home	Autonomy and decision-making	No explicit framework	“Applied to individuals, autonomy consist primarily in a person’s capacity to judge, decide, and act on the basis of her own attitudes and reasoning.”	Discussed in the context of decision-making. Referred to as a socially embedded and relational concept.	“The problem in our Western world could be that this myth teaches us to pretend that people who are disabled lose their independence, their autonomy and their dignity.”
Ide-Okochi et al. ³	Japan	To examine the impact of injury and the process of accommodation in people with cervical SCI	Sense of self and meaning making	No explicit framework	NA	Discussed in the context of independence and living according to ones’ values	“[W]e assume that Japanese women’s social status as a caregiver had in part influenced the participants’ autonomy because it is a mother’s obligation to protect their disabled children, although it often results in suppression of the disabled persons’ views.”
Nunnerley et al. ⁴	New Zealand	To investigate the experience of community reintegration from the perspective of people with SCI within 12 months of discharge from an SCI unit	Rehabilitation and community integration	No explicit framework	NA	Discussed in the context of control and decision-making	“The second theme of Power and Control encapsulated the imbalance in control which individuals experienced as a lack of control both physically in the functioning of their bodies, and feelings of reduced autonomy. This included decisions within the rehabilitation facility.”
Reinhardt et al. ⁵	Switzerland	To examine how integration and participation are understood by persons with SCI	Rehabilitation and community integration	No explicit framework	“Integration was defined in terms of autonomy – as freedom of choice and/or as autonomous functioning.”	Discussed in the context of decision-making and functional independence	“Two qualities of integration were clearly visible: social inclusion in the sense of granting full personhood and citizenship (see Parsons 1965) to the person with SCI and personal autonomy in making choices and conducting a life.”
Lennon et al. ⁶	Ireland	To investigate the ways in which people with SCI reconstruct their	Sense of self and meaning making	No explicit framework	NA	Discussed in the context of cognitive capacity	“Conversely individuals with SCI do not face cognitive impairments and, therefore, do not have increased difficulties with decision-making.

TABLE 1 (Continued)

Publication ^a	Location	Purpose	Major foci	Theoretical framework	Definition of autonomy	Discourse about autonomy	Excerpt
Giffre et al. ⁷	Spain	sense of self following injury in comparison to individuals with acquired brain injury To explore if and how people affected by SCI reconstruct their identity after injury	Sense of self and meaning making	Symbolic interactionism framework	NA	for decision-making Discussed in the context of decision-making and living according to one's values	Hence, the theme of lost autonomy did not appear in the narratives of individuals with SCI." "Being able to make their own decisions and to carry out their activities using the available resources increases SCI patients' perception of being in control and their sense of autonomy."
Engkasan et al. ⁸	Malaysia	To explore the decisional roles of patients, their caregivers, and doctors when choosing a method of bladder drainage	Autonomy and decision-making	No explicit framework	NA	Discussed in the context of the freedom to make choices	"[R]ehabilitation professionals in this study perceived the caregiver's decisions superior to that of the patients, particularly in cases where the patients became physically dependent on their caregivers ... This gives the impression that doctors in this study associated loss of executive autonomy with loss of decisional autonomy."
Locatelli et al. ⁹	United States	To examine perceptions about and characteristics that impact shared decision-making among individuals with SCI	Autonomy and decision-making	No explicit framework	NA (Defines shared decision-making but not autonomy)	Discussed in the context of decision-making, functional capacity for self-care, and access to resources	"[Individuals with tetraplegia] may require greater autonomy, due to the amount of self-care in which they engage." "Individuals with SCI/D may encounter barriers to health care ... resulting in a greater need for autonomy."
Piatt et al. ¹⁰	United States	To investigate how the perception of health can affect participation and autonomy among adults with SCI	Rehabilitation and community integration	International Classification of Functioning, Disability and Health framework	"Autonomy indoors includes 7 items that examine chances of looking after yourself ... Autonomy outdoors includes social contacts within outdoor activities, spending leisure time within	Discussed in the context of functional independence, capacity for self-care, and participation	"Individuals with an SCI want to be as autonomous as possible while managing their health, including within the context of participation and social roles."

(Continues)

TABLE 1 (Continued)

Publication ^a	Location	Purpose	Major foci	Theoretical framework	Definition of autonomy	Discourse about autonomy	Excerpt
Braaf et al. ¹¹	Australia	To explore the needs of people living with SCI receiving formal carer and hospital services	Expectations, priorities, expressed needs	No explicit framework	outdoor settings, and leading the life you choose.” NA	Discussed in the context of functional independence and ability to carry out activities of daily living	“For some participants, hospitalization resulted in reduced independence, privacy and dignity, as well as diminished autonomy. Many people with SCI had ordered routines for daily activities such as bowel actions, meals, pressure care, and exercises, which involved carers delivering personalized care at set times.”
Rohatinsky et al. ¹²	Canada	To explore how the empowerment process is expressed by persons with SCI	Empowerment	Lord's Process of Empowerment framework (1991)	NA	Discussed in the context of individual responsibility and empowerment.	“But, more broadly, [empowerment] seems to fit with the general expectations of persons in modern western culture: taking responsibility for that which one can and being autonomous.”
Scheel-Sailer et al. ¹³	Switzerland	To explore SCI patients' views on their participation in decision-making during their first inpatient rehabilitation after SCI	Autonomy and decision-making	No explicit framework	“As a normative concept, autonomy is a person's right to be respected as a subject and entails the ability to judge, decide and act upon one's personal attitude, values and reasoning.” NA	Discussed in the context of decision-making	“Looking back several years post-injury, participants reported that their initial dependency even led to the unconscious surrender of any wish to decide autonomously and the assumption that the therapists and nurses were in charge of everything.”
Mahooti et al. ¹⁴	Iran	To identify the psychosocial challenges of social reintegration for people with SCI	Rehabilitation and community integration	No explicit framework	NA	Discussed in the context of community integration as a socially embedded concept	“Autonomy is a key ethical principle in the health care profession. The most important factors affecting the autonomy are: self-development skills, self-evaluations and scope for action within a social context.”
McRae et al. ¹⁵	United Kingdom	To explore the experiences of postinjury care for individuals with cervical SCI and	Rehabilitation and community integration	No explicit framework	NA	Discussed in the context of decision-making	“Participants described how the decisions to remain nil by mouth were made by staff without full explanation or consultation, reflecting a paternalistic attitude

TABLE 1 (Continued)

Publication ^a	Location	Purpose	Major foci	Theoretical framework	Definition of autonomy	Discourse about autonomy	Excerpt
Zuchetto et al. ¹⁶	Brazil	their family members The meaning of hope for individuals with SCI in Brazil	Coping and adjustment	Bloch's Principle of Hope framework (1954)	NA	Discussed in the context of functional independence	towards SCI care that has been reported in other clinical scenarios." "Getting out of a wheelchair is a hard thing to learn; there is a lot of falling and frustration. But I searched for autonomy; I didn't want to sit, waiting for someone, forever."
Farahani et al. ¹⁷	Iran	To understand the experiences of individuals with SCI in terms of regaining autonomy during transition from hospital to community	Rehabilitation and community integration	No explicit framework	"Personal autonomy is the functional capacity for self-management and engagement and participation in activities of choice within one's community."	Discussed in the context of functional independence and ability to carry out activities of daily living	"This category reflects the impact of self-management behaviors on the daily activities of individuals with SCI. These behaviors helped them maintain their physical and mental health and played an important role in regaining their autonomy."
Tchajkova et al. ¹⁸	Canada	To examine whether individuals with SCI would have considered and had the capacity to make an informed decision about medically assisted dying early in their experience	Autonomy and decision-making	No explicit framework	NA	Discussed in the context of cognitive and emotional capacity for decision-making	"Participants described the importance of being provided with the option to make their own informed decisions regarding their health and treatment. This desire for autonomy extended to the decision of whether to end his or her own life."

Abbreviations: NA, not applicable; SCI, spinal cord injury.
^aFull references listed in supplemental file in order of appearance in Table 1.

contributed to the paper have expertise in ethics, rehabilitation science, the life sciences, and lived and living experience with SCI. Members of a larger ethics and knowledge translation advisory group comprising people with diverse expertise and abilities provided valuable feedback during early phases of the work. The authors acknowledge both the strengths and limitations of the intersectionality of these identities.

Sixty-eight publications were coded into five major emergent topic areas: (1) coping, adjustment, acceptance; (2) rehabilitation and community integration; (3) expectations, priorities, expressed needs; (4) sense of self and meaning-making; and (5) autonomy and decision-making. Two publications were not categorized due to their unique foci on empowerment and injustice, respectively. Autonomy was a focus of or discussed in a subset of papers spanning all themes.

Co-lead authors (A.N. and A.O.P.) read each paper in full text and extracted themes pertaining to study purpose, theoretical research framework, definition of the term autonomy, discourse pertaining to autonomy, and illustrative excerpts. Data were organized into a table by major foci and year. All authors collaboratively reviewed the data and interpreted them to describe trends and patterns.

Eighteen papers (18/70; 26%) referring to or exploring the concept of autonomy were included in the analysis (Table 1). The remainder were excluded. Of these, five explicitly defined the term.^{1–5} Discourse was most frequently defined and discussed in the context of decision-making and the freedom to make choices, but definitions varied, encapsulating participation,^{3,5} self-management,⁵ and autonomous functioning.² Autonomy was used interchangeably with related but distinctive terms: cognitive capacity^{2,6} and functional independence.⁷ Van de Velde et al.¹ advocated for a relational approach to autonomy over the Western, individualistic viewpoint that associates functional independence with autonomy and dignity. Five papers used theoretical frameworks to guide the research design,^{3,7–10} but only one referenced a specific framework – the International Classification of Functioning, Disability, and Health – for autonomy.³ In some cases, references to theoretical ethics frameworks, such as those exploring concepts of patient autonomy¹¹ and biomedical ethics,¹² were made, but these frameworks were not discussed in detail or used to explicitly frame understandings of autonomy.

DISCUSSION

Autonomy is one of the cornerstones of modern European philosophy,¹³ and a basic principle within Euro-colonial¹⁴ health-related ethics frameworks, such as the broadly known principles derived from the Report of the National Commission for the Protection of

Human Subjects of Biomedical and Behavioral Research.¹⁵ In this context, autonomy is generally portrayed as self-governance and is framed within objective rationality.

The individualistic and functional-based view of autonomy from a Euro-colonial perspective has spread beyond the context of the original concept, particularly in health care.¹² Although autonomy is a philosophical-legal concept that did not originate within the medico-philosophical tradition, it has become a basic tenet of biomedical ethics in the past century. Informed consent, an ethical and legal concept developed and crystallized through many landmark legal cases that followed the professionalization of medicine and subsequent regulation and standardization of medical practice,¹⁶ is the foundation of biomedical engagement in the current context. It is also consistently recognized throughout national and international legislation and documents that aim for the protection of human rights related to health and health care. Although autonomy and respect for autonomy are not guaranteed in the process of informed decision-making, they are central to realizing individual values through informed choices.

Autonomy is a complex concept, but it can be understood from a subjective perspective – *being* autonomous – and objective perspective – *acting* autonomously. This distinction highlights that every person should, from an ethical and philosophical standpoint, be considered an autonomous being (an end in themselves with intrinsic value), as opposed to an extension of others or as a means to achieve other ends, but that not everyone is able in all circumstances to act autonomously (to uphold their values). The latter can be achieved only if the conditions surrounding a choice are optimal, such as having enough information to make the choice at hand and being free from coercion or violence and other forms of undue influence at the time when the choice is to be made. This differs, for example, from having the cognitive skills to perform the task of decision-making, which is referred to as decision-making capacity. We note that capacity can be lost, temporarily -or permanently, restored, regained, and enhanced.

Regardless of whether a person has capacity or is making an autonomous choice, every person should be respected and treated as an autonomous being when choices are made that pertain to their interests, as subjective autonomy should always be respected. It also should be separated from executive autonomy, or being able to act upon a decision with minimal to no supports. An important issue to consider is how inherent systems of oppression at the foundation of colonial thinking, including ableism, shape the understanding or interpretation of autonomy and capacity. In this context, the social and environmental conditions that frame the experiences of people living with a disability such as

SCI must be integrated into conceptualizations of autonomy and decision-making.¹⁷

SCI is a heterogeneous condition associated with a range of functional impairments, including impaired bladder and sexual function and loss of hand, arm, and leg sensation or movement, which present challenges for aspects of daily living. The sudden, life-altering nature of traumatic SCI could affect a person's autonomy and decision-making, although not necessarily their capacity, including during the acute phase of injury.¹⁸ Any conceptualization of autonomy in the context of health care, specifically if it pertains to people with lived and living experience of disability such as SCI, should move past a generalized idea of autonomy that can result in marginalizing or excluding these experiences. A range of different approaches to understanding autonomy in SCI has also been proposed. For example, one study to identify strategies for autonomy among individuals with cervical SCI¹⁹ conceptualized autonomy according to four dimensions: independence in daily life (executorial autonomy), self-determination (decisional autonomy), participation, and identification.¹ A more recent study investigating facilitators of regaining autonomy in individuals with SCI defined personal autonomy as the “functional capacity for self-management and engagement and participation in activities of choice within one's community.”⁵

In the present analysis, we find inconsistent portrayals of autonomy and minimal references to specific ethics frameworks grounding them. The majority of papers discussed autonomy in the context of an individual's capacity for, control of, and freedom to make decisions, but the term was defined as and used interchangeably with related but distinct references to cognitive capacity and functional independence. Despite significant discourse about the influential role of relationships and social support identified in the primary analysis,²⁰ autonomy as a socially embedded and relational construct was discussed at length in only one paper. Further, although a few papers used theoretical frameworks to guide their studies, we note an absence of explicit frameworks for conceptualizing autonomy. This may contribute to the varied definitions and uses of the term. The finding of mixed uses of autonomy is congruent with a study that also revealed interchanging references in the literature between 2006 and 2016.²¹ This similarity in results may be a function of the dynamic nature of autonomy that varies across contexts. It may also indicate a broader lack of agreement and understanding of the term in research relevant to SCI.

The emphasis on capacity for decision-making – a transient construct that can be gained or lost – may give the impression that capacity is a prerequisite for autonomy. If autonomy is to be understood as the ability to uphold and live according to personal values, it can be supported and upheld even in the context of

diminished or absent capacity or executive autonomy. Moreover, neither the capacity to make decisions nor decision-making overall occurs in isolation. Even when autonomy is not the focus of the research, discourse pertaining to autonomy should be contextualized in a relevant theoretical framework that accounts for the social and relational environment in which choices are made, and beneficially guide the design and framing of empirical research and the clinical elements of postrehabilitation quality of life.

Any framework underlying research that aims to benefit people with lived and living experience, specifically with disability, should be informed by the perspectives and experiences of the population that the research intends to benefit. Given the heterogeneity of both the clinical features and sociocultural factors that affect the experience of SCI, such a framework for autonomy should be flexible, culturally competent, and focus on the realities of living with a disability. In this regard, the framework we propose has four critical features:

1. **Centering lived experience.** As Stramondo²² has stated, intentionally incorporating, “nuanced, politically aware narratives of life with disability” will result in a “richer understanding of disability from which to deliberate.” As such, disability becomes a source of moral knowledge and ethical insight.
2. **Respecting the heterogeneity of SCI.** This vital attribute of the framework foregrounds the heterogeneity of SCI and the diversity of affected people, including identity factors such as age, gender, race, and culture.
3. **Recognizing intersectionality.** By incorporating intersectionality into the framework, different way of knowing, theories, epistemologies, and antioppression ethical approaches can be explicitly addressed.
4. **Grounding the concept of autonomy.** The conceptualization and interpretation of autonomy in the context of decision-making must be informed by disability ethics. Conflating capacity and autonomy with executive autonomy, function, or independence is dismissive of fundamental human rights considerations and inconsistent with relevant health ethics frameworks, including disability ethics. It perpetuates ableism and other systems of oppression and ignores the diversity of human experience.

CONCLUSION

Autonomy is central to the experience of human dignity. The adoption of an explicit framework for contextualizing autonomy in SCI research will limit bias in research design, mitigate risks associated with the misinterpretation of results, and maximize translational benefit. A

person-centered framework can be an empowering force for all people living with SCI and those people engaged in working with SCI in research and clinical care settings.

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DISCLOSURES

None to declare.

DATA AVAILABILITY STATEMENT

The data supporting the findings of this study, including all relevant raw data, will be made freely available by the corresponding author upon request.

ETHICS STATEMENT

Ethics approval was not required as this study is based exclusively on published literature.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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