

Guest Editorial

Neurosexuality: A transdisciplinary approach to sexuality in neurorehabilitation

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Research addressing the relationship between sexuality and the brain has a long history in neurological and behavioral sciences. For instance, studies about differences according to sex in brain structures (Ruigrok et al., 2014), the neurobiology of sexual behavior (Ågmo, 2007; Einstein, 2007; Normandin, Pfaff, & Murphy, 2013), the sexual differentiation of the brain (Matsuda, Mori, & Kawata, 2012), the neuroanatomy of sexual behavior (Georgiadis, 2015) and the determinants of sexual orientation and gender identity (Swaab & Bao, 2013) are topics that have intrigued numerous generations of scientists. Furthermore, there is an increasing interest in the role of sexuality in neurorehabilitation and mounting awareness of the fact that many individuals with neurodisabilities experience problems with their sexual lives. This increased awareness has led to a better understanding within the scientific community regarding the importance of sexuality as a health outcome to promote the quality of life of individuals with neurodisabilities.

Neurosexuality is a framework for the scientific study of the relationships between sexuality and the brain (Moreno, Gan, Zasler, & McKerral, 2014). As an emerging area of study and practice, neurosexuality focuses on the relationships between brain and sexual function in individuals with and without neurological disorders. As such, it encompasses

both human and animal research. Neurosexuality embraces different research approaches that account for the multifactorial nature of sexuality (both quantitative and qualitative). Neurosexuality is transdisciplinary (Choi & Pak, 2006, 2007, 2008) as it transcends traditional boundaries and integrates the perspectives of natural, social, and health sciences in a humanities context to build a comprehensive understanding of the neural correlates of sexual behavior. Consequently, natural, social, and health sciences intersect in the conception of basic aspects (e.g., human and animal research on neurochemical and neuroendocrinological foundations of sexuality), treatments (e.g., sexual rehabilitation of individuals with neurodisabilities from neuropharmacological to neurobehavioral approaches and family therapy), and the translation of this knowledge into clinical practice (e.g., equality of access to treatments, education, policies, and human rights concerns).

This thematic issue of NeuroRehabilitation emphasizes that neurosexuality care should be driven by a transdisciplinary approach to appraise the evidence base of the potential negative consequences of different neurodisabilities on sexuality and to build upon sound treatment strategies to address these complexities. When we conceptualize sexuality in a broader sense (WHO, 2017), we acknowledge the role of different disciplines in the research and rehabilitation of sexual problems in specific neurological disorders. As sexuality is multifactorial, different research methods and approaches are necessary to capture its complexities. In this thematic issue, we integrate different methods (e.g., interpretative

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phenomenological analysis, cluster analysis, scoping studies), include diverse groups across the life span (from children and adolescents to older adults), present a range of neurodisabilities (dementia, stroke, amyotrophic lateral sclerosis, multiple sclerosis, acquired/traumatic brain injuries and spinal cord injury) and address populations whose needs have often been overlooked in research and clinical practice (people with neurodisabilities who identify as lesbian, gay, bisexual, transgender, queer, intersex, asexual, and people with other sexual orientations and forms of gender expression – LGBTQIA+).

The opening paper of the special thematic issue by Simpson, Simons-Coghill, Bates and Gan presents the results of a scoping study of positive sexual health among children and adolescents with acquired brain injury (ABI). The authors reviewed 2021 studies and present their findings using a theoretical framework of pediatric sexual development that includes social competence, identity formation, physical development, sexual knowledge, sexual experience, and sexually appropriate behavior. The authors conclude that the literature about sexuality in children and adolescents with ABI has mainly addressed physical issues (e.g., precocious puberty), with positive sexual health needing further development in topics such as body image, sexual orientation, and social competence including flirting, dating and romance.

In the second paper, Moreno and McKerral present the first study that explores the sexuality of individuals with traumatic brain injury (TBI) using cluster analysis. They describe two groups of individuals with TBI presenting with and without sexual problems. Individuals with TBI presenting with sexual problems were older (mid-forty's on average), showed lower levels of sexual quality of life and sexual desire, and experienced significant symptoms of anxiety and depression. On the contrary, individuals with TBI without sexual problems were younger (thirty's on average), showed high levels of sexual quality of life and sexual desire, and reported low complaints of anxiety and depression. The results of the study point towards the refinement of a taxonomy of sexuality based on the sexual profiles and relevant clinical characteristics for sexual functioning in individuals with TBI.

Grenier-Genest, Gérard and Courtois present the results of a literature review about post-stroke sexual functioning, including programs targeting individuals with post-stroke sexuality challenges. The authors describe different aspects of sexual dysfunction in individuals with stroke (e.g., erectile dysfunction,

ejaculatory problems, vaginal lubrication, orgasm, desire, sexual frequency, and sexual satisfaction) as a function of stroke location and laterality, physical sequelae, and mood changes. They also subsequently present three programs to address post-stroke sexual rehabilitation.

Delaney and Donovan present a narrative review of sexual dysfunction in the context of multiple sclerosis (MS). The authors describe the prevalence, pathophysiology, and impact of sexual dysfunction in individuals with multiple sclerosis, as a result of primary, secondary, and tertiary mechanisms. The authors describe information regarding assessment and treatment, including sexual assessment tools for MS. In addition, they explore related topics including relationships, fertility, pregnancy, and parenting issues. Like other neurological disorders, there is a need for more collaboration among providers in addressing sexual concerns in MS.

Shabazi, Holzberg, Thirunavukkarasu and Ciani introduce us to the perceptions of sexuality in individuals with amyotrophic lateral sclerosis (ALS) and their treating clinicians who were recruited online in ALS clinics across Canada and the United States. The results revealed that almost half of ALS clinic specialists reported feeling uncomfortable discussing sexuality-related topics with their clients, while individuals with ALS express readiness to address the topic and recognize the negative effect of the disease in their sexual lives. In fact, individuals with ALS have a preference to speak about their sexual concerns with any qualified health professional or to speak to the health professional with which they personally have the best rapport. The authors call for more education among ALS specialists in sexuality and a policy change that guarantees the inclusion of sexuality in their guidelines.

Sipski, Aisen, Alexander and Aisen provide an overview of the sexuality of individuals with spinal cord injuries (SCI), including the impact of SCI on sexual response, male infertility and its treatments, as well as pregnancy issues after SCI. The authors underscore the importance of providing education and specific sexual recommendations based on the individual's remaining sexual potential, and to include their partners, when available. They also present basic and advanced treatments for sexual dysfunctions and discuss the role of medical comorbidities that can represent an additional challenge in the management of sexual dysfunction of individuals with SCI. Their proposed treatment approach advocates for a progressive protocol of treatment

that starts with education and moves to the use of first line therapies when conservative management is not successful. They recommend the use of common research protocols (e.g., international data sets) to increase collaboration in multi-center clinical trials.

There is still a fair amount of controversy regarding research consent by individuals with cognitive impairment. Roelofs, Luijkx and Embregts discuss the methodological challenges to studying sexuality and intimacy in individuals with dementia living in a residential care facility, using interpretive phenomenological analysis. The authors propose a multi-step approach to recruit individuals with dementia involving authorized representatives (e.g., family caregivers), professional caregivers working in the residential care facility, a pre-consent phase, a consent presentation phase, and a final consent right before data collection. Also, they advocate for a person-centered approach that includes the perspectives of individuals with dementia in different phases of the research process. The authors' reflections and suggestions provide a contribution to the research around the ethical challenges involved in the study of sexuality and intimacy in individuals with severe cognitive impairment.

In the closing paper of the current thematic issue, Moreno, Laoch and Zasler provide a critical review of the literature about neurological disorders in people who identify as lesbian, gay, bisexual, transgender, queer, intersex, asexual, and people with other sexual orientations and forms of gender expression (LGBTQIA+). The review includes different neurodisabilities, such as epilepsy, intellectual disability, autism spectrum disorder, dementia, spinal cord injury, traumatic brain injury and stroke. The results show that dementia is the most common neurodisability studied in LGBTQIA+ people. The authors provide useful and actionable clinical recommendations to create a safe space and to promote a change in the culture of neurodisability aiming to reduce health disparities and barriers of access to healthcare. They also present a list of resources for LGBTQIA+ individuals with neurodisabilities and healthcare professionals who wish to increase their cultural competency to enhance equity, diversity, and inclusion in their clinical practice. This paper is a call for a reflective and inclusive ethical practice that involves sexual diversity and gender expression in the research and clinical protocols.

As transversal findings across the papers presented in this thematic issue, between 19 to 75% of individuals experience sexual problems at different points of

the rehabilitation continuum following a diagnosis of a neurodisability. In different neurological disorders, a biopsychosocial approach (Moreno, Gan, Zasler, & McKerral, 2015) seems to be a suitable theoretical framework to address the sexual problems encountered in the primary (i.e., sexual dysfunction resulting from a physiologic cause), secondary (i.e., sexual dysfunction as a result of iatrogenesis), or tertiary levels (i.e., sexual dysfunction explained by psychosocial or contextual factors). Sexual problems include a reduction in the expression of affection and intimacy (e.g., hand holding, sensual touch, kissing), diminished frequency of sexual activities (e.g., intercourse and masturbation), sexual dysfunction (e.g., loss of sexual desire, erectile dysfunction, vaginismus, anorgasmia, and pain), and contextual barriers preventing the free expression of their sexual orientations or gender identities. In the worse case scenario, the sexual rights of individuals with neurodisabilities are not acknowledged at all. When considered asexual, individuals with neurodisabilities experience limited opportunities for sexual education, dating, and romance that are important to live a fulfilling life.

We can summarize some trends for future directions in neurosexuality research. Compared to the sexuality of women with neurodisabilities, male sexual problems and treatments are better documented. This is alarming considering the higher prevalence of females in some neurological disorders (e.g., dementia, multiple sclerosis, amyotrophic lateral sclerosis). In addition, the sexuality of older adults, as well as children and adolescents with neurodisabilities needs further exploration to help parents, partners, and family caregivers to address this important area of function. The person-centered approach in sexuality research is being recognized as a way to understand the priorities and needs of individuals with neurodisabilities. Including individuals with neurodisabilities in different phases of the research design and implementation can facilitate knowledge translation, and generate meaningful and actionable knowledge that is relevant to their realities.

The person-centered approach is also necessary in service delivery, as treatment must be tailor-made and planned with the client. In terms of rehabilitation, there is a pressing need to target healthcare professionals' knowledge, attitudes, and practice. Methods to improve comfort levels of healthcare professionals addressing sexual concerns are still needed. Future research in neurosexuality should address the use of communication and information technologies (ICT)

to deliver sexual education content, and the use of assistive technologies for pleasure. This is an opportunity supported by transdisciplinarity because interventions in neurosexuality require the amalgamation of collective expertise and the use of novel approaches to solve “wicked problems” (Boger et al., 2016). ICTs can support sexual education and be a solution for the time constraints that many rehabilitation professionals experience in different healthcare settings. Websites with high-quality sexuality information (Moreno & das Nair, 2015), online support groups, discussion boards, video, chat rooms and other forms of computer or mobile-mediated communication can be an avenue to provide virtual safe spaces to educate and deliver support (Buhi, Blunt, Wheldon, & Bull, 2014). However, online information provision and interactions need to be adapted and/or monitored for individuals with neurodisabilities to avoid misunderstandings and undesirable outcomes, especially with children and adolescents (e.g., sexual solicitation, cyberstalking, cyberbullying, and undesired exposure to sexually explicit materials). Information provision does not replace sexual therapy but it is an essential part of the first steps of sexual rehabilitation, as described in different models including the PLISSIT model (Khakbazan et al., 2016), the Ex-PLISSIT model (Taylor & Davis, 2007), and the BETTER model (Steinke et al., 2013). Rehabilitation efforts should also include spouses, parents, or significant family caregivers given the central role they play in the ongoing support of their loved ones. The potential benefits of sexual assistance with surrogate partner therapy (Rosenbaum, Aloni, & Heruti, 2014) need further exploration in individuals with neurodisabilities. LGBTQIA+ issues in individuals with neurodisabilities need to be further addressed to reduce disparities in healthcare. Additionally, future research on the sexual consequences of concurrent neurodisabilities (e.g., SCI+TBI) can lead to a better understanding of the effects of coexisting neurological conditions on sexuality. Finally, the spiritual and religious dimensions of sexuality and neurodisability have received little attention. Belief systems can influence the approach to care decisions in individuals with neurodisabilities and practitioners, as the topic of sexuality can be taboo in some cultures and religious groups. Recognizing the influence of belief systems can help to understand the obstacles to equality in healthcare delivery and advance sexual and reproductive health. For instance, research in biology, psychology, and sexuality has challenged and changed assumptions

and teachings of religious traditions (Green, 2013). Interestingly, some traditions have adapted to the possibilities that science has offered regarding sexual and reproductive health (e.g., contraception and *in vitro* fertilization).

This thematic issue of *NeuroRehabilitation* on neurosexuality does not include other important neurological disorders (e.g., Huntington’s disease). The specific recommendations of assessment and more specific treatment approaches are beyond the scope of this special thematic number. For those interested in greater detail on this topic, we refer the reader to a collection of writings on the neurology of sexual disorders (Vodusek & Boller, 2015). We hope that this thematic issue provides an impetus for rehabilitation and other health professionals, students in the health sciences, and researchers to develop their competence and awareness of the importance of sexual neurorehabilitation in persons with neurodisabilities.

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