

Development of international standards to document sexual and reproductive functions after spinal cord injury: Preliminary report

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Abstract—Clinicians need standard terminology to communicate effectively about remaining autonomic function in persons after spinal cord injury. This article illustrates the development of standard nomenclature that describes the impact of injury on sexual functioning. A standard anatomic diagnosis and a secondary means of describing the presence of male and female sexual dysfunction, genital arousal, and orgasmic function are discussed.

Key words: arousal, assessment, female, fertility, male, menstruation, orgasm, sexuality, sexual response, spinal cord, standards.

INTRODUCTION

Communication about the effects of spinal cord injury (SCI) on motor and sensory functions is generally performed with the International Standards for Neurological Classification of Spinal Cord Injury of the American Spinal Injury Association (ASIA) [1]. In addition to clinicians using these standards to communicate the impact of SCI on neurological function, they have been using them as an outcome measure in a number of clinical trials to document the degree of remaining motor and sensory functions in persons with SCIs. However, these standards cannot be used to document the degree of preservation of autonomic function postinjury. In May 2004, ASIA appointed a working group to develop standards for professionals to communicate the characteristics of various aspects of

autonomic function remaining in persons with SCIs. This group included international participants involved in clinical trials in SCI and basic science researchers. (See the **Figure** for members.) With the group's agreement, the autonomic standards being developed quickly evolved into International Autonomic Standards, rather than those of just ASIA. The working group transitioned into a steering committee, and subgroups were appointed to discuss bladder, bowel, and sexual and general autonomic functions. Individual subgroups functioned via Internet communication, and from 2004 to early 2005, each subgroup drafted a set of standards for its section. This article describes aspects of the preliminary draft of standards for documenting remaining sexual function of persons after SCI. This draft was presented at the ASIA meeting in May 2005.

Abbreviations: ART = assisted reproductive technology, ASIA = American Spinal Injury Association, IVF = in vitro fertilization, L = lumbar, S = sacral, SCI = spinal cord injury, T = thoracic, TMS = total motile sperm.

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Figure.

Members of international working group appointed by American Spinal Injury Association to develop standards for professionals to communicate characteristics of autonomic function in persons after spinal cord injury.

INTERNATIONAL SEXUAL AND REPRODUCTIVE FUNCTION STANDARDS

While sex is a basic human need and leads to procreation and the maintenance of humanity, it is a unique system in that it is “optional.” As a basic human need, sex can be for pleasure or reproduction. Furthermore, some physiological and interpretive differences are apparent

between the sexual response in males and that in females. In light of these important issues, the group concurred that the International Standards to document sexual function after SCI should include four separate subsets to be used as appropriate for different categories of sexual function. These subsets include male sexual response, male reproductive function, female sexual response, and female reproductive function. Because each group member had expertise in a different area, various individuals or groups addressed the process by developing a set of recommended items to include in their particular areas of expertise, and then each group concurred on the entire product.

SEXUAL FUNCTION

Sexual function categories pertain to sexual response and sexual activity, not fertility. In this area, “sexual dysfunction” is unique from other physiological dysfunctions because alterations in response are not considered problematic unless they cause personal distress [2]. Thus, a separate category of sexual dysfunction and the ability to describe the presence of specific sexual dysfunctions is included under both male and female sexual and reproductive functions.

Male Sexual Function

See **Table 1** for the recommended standard format to describe male sexual response, along with accompanying definitions. Recently, the use of physiological studies to document the effects of SCI on male sexual response has increased. Based on this research, the potential for psychogenic erection is likely related to preservation of sympathetic function to the genitals [3–4]. Until this finding is further documented, psychogenic erection is recommended to be described as present, possible though partially impaired, or absent based on patient report or physiological data, whether available or not (**Table 1**). Similarly, the potential for reflex erection is apparently based on the presence of reflex function in the sacral level 2 (S2) to S5 spinal segments [3–4]; however, for purposes of the standards, reflex function is recommended to be described as present, possible though partially impaired, or absent. Because ejaculation is most intimately associated with reproductive functioning, it is documented under reproductive function rather than sexual function. Last, the potential to experience orgasmic sensation is described based on history and can be listed as present, unknown, or absent.

Male Reproductive Function

See **Table 2** for the recommended standard format to describe male reproductive function, along with accompanying definitions. The possibility for men to father children after SCI has changed tremendously in the past 20 years, largely because of clinicians' ability to stimulate ejaculation through assisted methods [5]. Thus, in men with SCI who are pursuing fertility, documenting the capacity for seminal emission or ejaculation through natural or medically assisted methods is important. The ability to produce antegrade ejaculation through sexual stimulation without vibratory stimulation is first recorded [6–7]. This ability, with normal forward projection as before injury, can be present, partially present, or absent (**Table 2**). The latter two categories may indicate partial or complete retrograde ejaculation, incomplete propulsatile ejaculation, or anejacu-

lation. The ability to undergo successful sperm retrieval is next documented, recorded as unknown, possible, or not possible. If possible, retrieval can be successful through assisted ejaculation (i.e., medication-enhanced, sexual aids other than vibrostimulation), penile vibratory stimulation, or electroejaculation [8–9]. Whether men experience autonomic dysreflexia with ejaculation in either private or sperm-retrieval clinic settings should be recorded and also the level of severity, because the occurrence of severe dysreflexia may alter recommended methods of sperm obtainment. If obtaining sperm is possible through surgical means, one should record how and where the sperm is able to be obtained. This could include testicular sperm aspiration, testicular sperm extraction, or other sites of sperm extraction including the epididymis or vas deferens.

Table 1.
Characteristics of sexual response in males after spinal cord injury (SCI).

Function	Primary Response Options	Subclassification
Erection		
Psychogenic	Present, possible though impaired, absent	—
Reflex	Present, possible though impaired, absent	—
Orgasm	Present, unknown, absent	—
Sexual Dysfunction	Present, absent	Desire, erectile, ejaculatory, or orgasmic dysfunction

Ejaculation = Forceful propulsion of semen externally from penis.
 Erection = Increase in penile tumescence with resulting size and firmness of penis. In usual circumstances should be adequate to allow vaginal penetration. In non-disabled men, erections are usually combination of psychogenic and reflex; however, in men with SCI, varying types of erectile function may occur.
 Orgasm = Perception of feeling peak physiological or mental excitement, sense of release of high arousal, or reaching climax, after which person with SCI feels satisfied and no longer desires further sexual stimulation. May be accompanied by overall increase and then decrease in muscle tone.
 Psychogenic erection = Erection that occurs solely based on arousal in brain, e.g., through hearing, seeing, feeling, or imagining erotic thoughts.
 Reflex erection = Erection that occurs solely based on genital or sacral stimulation.
 Sexual dysfunction = Complaint of specific sexual problem based on history and presence of personal distress. This may include desire, erectile dysfunction, ejaculatory, or orgasmic dysfunction.

Table 2.
Characteristics of reproductive function in males after spinal cord injury.

Function	Primary Response Options	Subclassification
Antegrade Ejaculation	Present, partial, absent	—
Sperm Retrieval	Unknown, possible, not possible	Assisted ejaculation, vibratory stimulation, electroejaculation, surgery. Also, indicate whether autonomic dysreflexia accompanies procedure of choice.
Count	Good, fair, poor	—
Assisted Reproductive Techniques	Unknown, possible, not possible	Indicate methods used: home intravaginal insemination, intrauterine insemination, in vitro fertilization (IVF), IVF/intracytoplasmic sperm injection.

Antegrade ejaculation = Ejaculation through penis through sexual stimulation without associated vibratory stimulation.

Sperm count (includes both antegrade and retrograde fractions):

 Good = 20 million total motile sperm (TMS) per ejaculate.

 Fair = 4–20 million TMS per ejaculate.

 Poor = 4 million TMS per ejaculate.

Sperm retrieval = Ability to retrieve sperm through assisted techniques based on number of TMS per ejaculate, including antegrade and/or retrograde fractions.

The presence of sperm is also documented as present or absent, and the count is graded if present [10–11] as good, fair, or poor based on total motile sperm (TMS) per ejaculate, including antegrade and/or retrograde fractions. A good sample has 20 million TMS per ejaculate, a fair sample has 4 to 20 million TMS per ejaculate, and a poor sample has 4 million TMS per ejaculate.

The use of and success with assisted reproductive technologies (ARTs) are also listed as possible or not possible if the person has no testicular function. If possible, the type of ART used is documented, including home intravaginal insemination, intrauterine insemination, in vitro fertilization (IVF), and IVF/intracytoplasmic sperm injection [11].

Female Sexual Function

See **Table 3** for the recommended standard format to describe female sexual response, along with accompanying definitions. Over the past 10 years, substantial research has been conducted to study whether remaining sensory function could be used to predict psychogenic genital arousal [12–13]. A number of studies have supported the hypothesis that the maintenance of psychogenic genital arousal could be predicted on the basis of the ability to perceive combined pinprick and sensory function in the thoracic level 11 (T11) to lumbar level 2 (L2) dermatomes [5,14–15]. In this area of the spinal cord, the cell bodies produce the sympathetic innervation of the genitals. Thus, when clinicians are performing physical examinations, they should give special attention to the T11 to L2 dermatomes when performing a neurological examination after SCI to document remaining female sexual potential.

Based on this examination and historical report, psychogenic arousal is documented as present, possible though partially impaired, or absent (**Table 3**).

Reflex genital arousal has also been studied, and research has supported the hypothesis that the potential for this function is based on presence of intact reflex function in S2 to S5 spinal cord segments [5–6,16]. On the basis of a physical examination and historical report, reflex arousal is described as present, possible though partially impaired, or absent (**Table 3**). The potential to experience the sensation of orgasm has been documented extensively in women with SCIs [5,17–20]. Furthermore, the ability to achieve orgasm has been found significantly diminished in women with complete lower motor neuron injuries affecting their S2 to S5 spinal segments as compared with all other levels and degrees of injuries [5]. Therefore, clinicians are advised to document the potential for orgasmic response and to give special attention to the physical examination of this area of the spinal cord. Those persons with intact bulbocavernosus and or anal wink reflexes should have the potential to experience the sensation of orgasm, whereas women without S2 to S5 sensation and absent bulbocavernosus and anal wink reflexes should not.

Female Reproductive Function

Table 4 details the recommended standard format with accompanying definitions for describing female reproductive function [21–23]. The status of reproductive functioning of women after SCI is affected by many non-SCI as well as SCI factors. A woman's ability to conceive may be affected immediately after injury if she experiences reproductive endocrine changes [12,24]. However, despite that

Table 3.

Characteristics of sexual response in females after spinal cord injury (SCI).

Function	Primary Response Options	Subclassification
Genital Arousal		
Psychogenic	Present, possible though impaired, absent	—
Reflex	Present, possible though impaired, absent	—
Orgasm	Present, possible though impaired, absent	—
Sexual Dysfunction	Present, absent	Desire, arousal, orgasmic, or pain dysfunction

Genital arousal = Increased genital vasocongestion that usually manifests itself with presence of clitoral engorgement and vaginal lubrication, amongst other signs.
 Orgasm = Perception of sensation of feeling good from sexual stimulation, reaching climax, after which person with SCI feels satisfied and no longer desires further sexual stimulation. May be accompanied by an overall increase and then decrease in muscle tone.
 Psychogenic genital arousal = Increased genital vasocongestion that occurs solely based on arousal in brain, e.g., through hearing, seeing, feeling, or imagining erotic thoughts.
 Reflex genital arousal = Increased genital vasocongestion that occurs solely based on genital or sacral stimulation.
 Sexual dysfunction = Alteration in aspect of sexual functioning that results in personal distress. If present, one should also indicate type of disorder: desire, arousal, orgasmic, or pain.

Table 4.
Characteristics of reproductive function in females after spinal cord injury (SCI).

Function	Primary Response Options	Subclassification
Menstruation*	Normal, amenorrhea, dysfunctional uterine bleeding	Indicate type of abnormal menstruation and timing in relation to injury.
Fertility	Pregnancy, no pregnancy	Indicate before or after SCI in addition to other information as appropriate.
Labor Complications	Normal, complications	Indicate specific associated problems if complications exist.
Pregnancy Outcomes†	Normal, complications, significant maternal problems during pregnancy, significant fetal problems	Indicate gravida, para, abortion status. Also indicate any specific maternal problems.
Menopause	No, perimenopausal, yes	If yes, indicate date and whether natural or surgical.

*Possible types of menstrual abnormalities:

Dysfunctional uterine bleeding = Excessive uterine bleeding without organic cause. Cycle length may be regular or irregular.

Intermenstrual bleeding = Bleeding of variable amounts occurring between regular menstrual periods.

Menometrorrhagia = Prolonged uterine bleeding occurring regularly.

Menorrhagia = Prolonged (>7 days) or excessive (>80 cc) uterine bleeding with regular menstrual cycle length.

Metrorrhagia = Irregular and frequent (occurring at least twice within 28–32-day cycle) uterine bleeding.

Mittelschmerz = Midcycle pelvic pain usually related to ovulation.

Polymenorrhea = Uterine bleeding occurring regularly of <21-day intervals.

Primary dysmenorrhea = Painful cramping just before or during menses that begins at or shortly after menarche and is usually not accompanied by pelvic pathologic conditions.

Secondary dysmenorrhea = Painful cramping just before or during menses that develops several years after menarche and is associated with other pelvic conditions.

Premenstrual syndrome = Constellation of emotional, behavioral, and physical symptoms that occur in premenstrual phase of menstrual cycle and subside with onset of menstruation; characterized by swelling and weight gain due to fluid retention, breast tenderness, irritability, mood swings, anxiety, depression, drowsiness, fatigue, difficulty concentrating, and changes in appetite and libido.

†Possible subclassifications for pregnancy outcomes:

Abortion = Number of spontaneous miscarriages and abortions.

Full-term but infant stillborn = Infant who has achieved 20 wk of gestation and shows no evidence of life after birth.

Gravida = Number of pregnancies.

Para = Number of live births.

Spontaneous abortion or miscarriage = Spontaneous expulsion of products of pregnancy before middle of second trimester.

women with SCI are generally older when they have children (which may affect fertility) compared with their fertile nondisabled counterparts, apparently the ability to conceive is not under the autonomic control that is important in sexual function. Autonomic dysfunction, however, may affect labor and delivery. Since reproductive capacity depends on these issues, as well as the stage in life that the woman is experiencing, an expanded data set is recommended for individualized classification.

Menstruation has been studied in detail postinjury [25–27] and is often disrupted. Thus, documenting the effects of SCI on menstruation is important. Also important to identify is whether the condition was present or absent before and after injury and whether the condition was present within or after 12 months postinjury. Menstruation can be classified as normal, amenorrhea, or dysfunctional uterine bleeding (Table 4). Menstruation can be further stratified into a normal hypothalamic-pituitary-ovarian axis that directs a regular cycle of average length or a normal cycle from the use of oral contraceptive hormones. A

woman with amenorrhea may be further classified as premenarche, primary amenorrhea, nontraumatic secondary amenorrhea (which includes any type of secondary amenorrhea not related to spinal cord trauma), or traumatic secondary amenorrhea. Posttraumatic secondary amenorrhea is further classified on the basis of whether the return of menses is delayed <3 months post-SCI, ≥3 months and ≤12 months post-SCI, or >12 months post-SCI. Other causes for absence of menstruation should also be documented and include the date of hysterectomy without or with removal of ovaries, the date of menopause, and whether the woman is amenorrheic because of pregnancy.

Following SCI, women may develop hyperprolactinemia. Studies have reported as many as 60 percent of women may experience elevated prolactin levels and almost half these women will progress to galactorrhea [28–30]. Several studies have described a neurogenic amenorrheic-prolactinemia-galactorrhea syndrome [31–32]. The autonomic repercussions of this syndrome have not been studied in women with SCI, but studies have

shown that many of the neurotransmitters important in the sympathetic and parasympathetic nervous systems are involved in the hypothalamic-pituitary axis responsible for this phenomena [33–35]. Since autonomic symptoms of SCI may be exacerbated by hormonal fluctuations, SCI-related symptoms should be documented and details provided, if available. Increased muscle spasticity, bladder spasms, bowel reflexes (with or without diarrhea), autonomic dysreflexia, or other autonomic symptoms can occur at specific times during the menstrual cycle. When researchers focus on the reproductive system for clinical trials, the elucidation of these patterns is important.

When an obstetric history is appropriate to include, fertility should be documented post-SCI. For women who have never been pregnant, reasons should be determined. Possibilities include never having had sex (i.e., virgin); never attempting pregnancy (by any means); attempted pregnancy (for at least 12 months), yet unable to conceive (for any reason of the woman); and finally, unable to conceive due to hysterectomy, sterilization, or infertility of male partner. For those women who have had pregnancies, the date of birth of each offspring should be documented. Furthermore, whether pregnancy was attained before or after 12 months postinjury and whether infertility medications were needed should be determined.

Pregnancy outcomes should be documented with details provided as appropriate. Outcomes can be normal, i.e., full-term pregnancy with live birth, or with complications such as spontaneous abortion or miscarriage, voluntary abortion, preterm birth, or full-term birth but infant stillborn [36]. Significant maternal problems during pregnancy can include preeclampsia, eclampsia, prolonged labor and delivery, gestational diabetes, frequent urinary tract infections, autonomic dysreflexia, severe spasticity, and a change in bladder function.

Labor symptoms for women with SCI should be documented as appropriate. Possible responses include none, normal uterine-contraction pain, ruptured membranes, abnormal pain not associated with uterine contraction, vaginal hemorrhaging, pain above the injury level, autonomic dysreflexia, and significantly increased spasticity.

The nerves important for lactation correspond to dermatome levels of T2 to T4. Thus, as appropriate, document whether lactation was attempted and was normal, not attempted, or attempted but insufficient breast milk was produced.

Menopause in nondisabled women is associated with autonomic instability [37] but may also be affected by SCI. At a minimum, including the date of menopause is

appropriate. Further details may include documentation of normal menopause greater than 6 months before SCI, hysterectomy (with or without oophorectomy) before or after SCI, perimenopausal within 6 months before SCI but no periods after SCI, or regular menstruation within 6 months before SCI but no periods after SCI. Following an SCI, women may also experience menopause with or without postmenopausal dysautonomic symptoms.

CONCLUSIONS

We have presented a preliminary draft of a potential means to document the effects of SCI on sexual function as of 2005. Further work continued on these standards with the bladder, bowel, and general autonomic standards in June 2006 at the combined ASIA and International Spinal Cord Society meeting, and they are now available on the ASIA (<http://www.asia-spinalinjury.org/>) and International Spinal Cord Society Web sites (<http://www.iscos.org.uk/>). Because the standards are currently being developed, any comments or suggestions are appreciated and can be forwarded to the primary author of this article. Once developed, the standards will be validated and a training program developed to ensure their proper use.

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