

Methods to assess sexuality after stroke used in rehabilitation: a scoping review

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Acknowledgments

The authors gratefully acknowledge that the first author was supported by doctoral scholarships from the Canadian Institutes for Health Research, the Fonds de recherche du Québec en santé (FRQS), the School of Rehabilitation of the Université de Montréal (UdeM) and the Ordre des ergothérapeutes du Québec. The fourth and last author were supported by a career award from the FRQS. Our sincere thanks to the

bibliothèques/UdeM for enabling the participation of the third author in this research project. The authors would also like to thank Dr. Johanne Higgins, and Isabelle Quintal, MSc, for their insights on the manuscript.

Declaration of interest statement

The authors report no conflict of interest.

Abstract

Word count : 200

Purpose: The aim was to identify and describe the assessment methods used by rehabilitation professionals to evaluate sexuality for individuals post-stroke, as well as the domains of sexuality addressed.

Methods: Seven databases were selected for this scoping review. *Articles* needed to meet these inclusion criteria: published studies with a sample of $\geq 50\%$ stroke clients and describing a quantitative or qualitative assessment method that could be used by rehabilitation professionals. This study was conducted following the PRISMA guidelines and domains of sexuality were categorized using the ICF core set for stroke.

Results: Of the 2447 articles reviewed, the 96 that met the selection criteria identified a total of 116 assessment methods classified as standardized assessment tools ($n = 62$), original questionnaires ($n = 28$), semi-structured interviews ($n = 16$) or structured interviews ($n = 10$). Sexual functions were predominantly assessed using standardized tools, while intimate relationships and partner's perspective were generally addressed more by original questionnaires and qualitative methods. A stepwise approach combining relevant assessment methods is presented.

Conclusions: Individually, these diverse assessment methods addressed a limited scope of relevant domains. Future research should combine quantitative and qualitative methods to encompass most domains of sexuality of concern to post-stroke individuals.

Keywords: Stroke, Sexuality, Clinicians, Assessment, Evaluation, Rehabilitation

Main text

Word count: 4125

Introduction

Sexuality is among the domains that can be affected by a stroke [1] and is related to quality of life [2, 3] and depression [4, 5] in individuals post-stroke. Sexuality is part of the International Classification of Functioning, Disability and Health (ICF) core set for stroke as a relevant domain to be addressed [6]. However, stroke survivors rarely have the opportunity to address sexuality during rehabilitation [7, 8, 9] even though it is recommended that therapists address it with clients [10]. Among the factors explaining this situation are the taboo related to sexuality, the fear among both clinicians and clients of being inappropriate or causing offense, and the lack of concrete clinical guidelines for evaluation and treatment [11]. These factors can influence whether clinicians initiate a conversation on the subject with a client and follow up with an assessment of sexuality. In fact, in a cross-sectional study conducted among 813 healthcare professionals, including physicians (n = 110), nurses (n = 593), occupational therapists (n = 37) and physical therapists (n = 73), 94% were unlikely to address sexuality with their clients. Furthermore, therapists were even less likely to initiate a discussion on the subject than nurses or doctors [12]. Yet, rehabilitation professionals such as occupational and physical therapists are in a privileged position to address sexuality with their clients in stroke rehabilitation [13, 14] and could significantly increase the proportion of people who have the opportunity to address sexuality concerns in that context [15]. A recent qualitative study conducted with seven occupational therapists confirmed that they feel they lack knowledge and know-how regarding proper assessment of sexuality,

and mentioned that better access to assessment methods could positively influence their practice [16].

Even though sexuality after a stroke has been addressed in many studies over the last three decades, it remains unclear what assessment methods are available for this domain and which should be used in rehabilitation practice and research. To our knowledge, only two studies have addressed assessment of sexuality post-stroke: one systematic review for women with neurological conditions [17] and one narrative review focusing on men recovering from a stroke [18]. Courtois et al. [17] identified assessment methods according to three categories: 1) physiological assessments of reflexes and perineal sensitivity testing; 2) electrophysiological assessments; and 3) self-reported questionnaires on sexual function and sexual satisfaction (i.e. standardized assessment tools). Calabro et al. [18] recommended a multifactorial assessment conducted by a multidisciplinary team, including methods such as neurological and genital examinations, endocrine and metabolic testing and standardized assessment tools to measure sexual functioning. However, most of the methods identified by these two studies are mainly used by medical practitioners such as neurologists and urologists, rather than standardized assessment tools that can be used by most rehabilitation professionals in clinical practice. Although these reviews contribute to knowledge on the subject, they do not address the available standardized tools that can be used to assess sexuality with individuals post-stroke. Interestingly, past studies that showed that stroke can impact sexuality have used assessments to document the

effect. Consequently, reviewing those assessment methods may establish a knowledge base that could orient clinicians and investigators in the future.

The aim here was therefore to identify and describe the methods used in studies evaluating sexuality among individuals post-stroke that could be used by rehabilitation professionals, and to identify which domains of sexuality were assessed.

Materials and Methods

This scoping review was conducted using the Preferred Reporting Items for Systematic Review and meta-analysis extension for scoping reviews (PRISMA-ScR) guidelines [19].

Eligibility criteria

In order to be included in the present review, studies needed to report having used an assessment method to address sexuality post-stroke. Therefore, if a tool not specific to sexuality (e.g., an occupation-based assessment) was used to yield a better understanding of domains related to sexuality in a study involving stroke participants, it was included. All research designs were considered, and at least half of the total study sample needed to be individuals who had sustained a stroke. Studies that involved only specialized neurological assessments (i.e. physiological assessments of reflexes and perineal sensitivity testing, electrophysiological assessments) were excluded, as this review focused on assessment methods that could be used by rehabilitation professionals in a rehabilitation context. Methods used by physicians or other specialists that had the potential to be used by rehabilitation clinicians (e.g. self-reported questionnaires) were included. Only published papers written in English or French were considered.

Search strategy

The search strategy was developed collaboratively with the support of the librarian (MG) on the research team. A combination of keywords and descriptors were searched in MEDLINE, Embase, PsycINFO and CINAHL. Additional searches were conducted in Web of Science, PEDro and OTseeker. Relevant articles were also identified by examining reference lists of selected papers. The search strategy was customized for each database and included two key concepts: stroke and sexuality. A typical search strategy for one database (i.e. Medline) is shown in Appendix 1.

Data collection process

A literature search was conducted in each database from its inception up to May 29, 2020. For data extraction, all references from the initial search were first exported to EndNote X8 software and duplicates were removed. The first and third authors of the present study carried out data collection independently based on the inclusion and exclusion criteria. To standardize the process after the initial search, the two reviewers analysed the titles and abstracts from the database CINAHL and compared their results. Most differences between reviewers on whether or not to include the study were resolved by consensus-based discussion, in some cases followed by consultation with a third reviewer (last author). Once a common understanding of the inclusion and exclusion criteria was achieved, the two reviewers screened the remaining studies by title and abstract independently, and their results were pooled, again by consensus-based discussion and consultation with a third reviewer as needed. Subsequently, the full text content of the articles was screened by the first and last authors. Data from the selected articles was then extracted by the second author using templates that were designed by the research team. During data extraction, the first and last authors supervised the process and provided support as needed. More precisely, each assessment method

identified in the articles included in the review was categorized by type: 1) standardized assessment tool; 2) original questionnaire (i.e. specifically designed for the purpose of the study with no validation process); 3) semi-structured interview; or 4) structured interview. For standardized assessment tools, a description of each tool and, when applicable, items/questions specific to sexuality, were presented, along with scoring methods and interpretation of scores (e.g. interpretation of cut-off scores, if applicable). Additional non-exhaustive searches were conducted after consulting the reference lists of the eligible full texts in order to retrieve studies that examined the psychometric properties of standardized assessments tools for the stroke population or, if unavailable, the original study of the tool's development and psychometric properties. Raw data of psychometric properties with original authors' interpretations (e.g. fair, moderate, high) were extracted, when available. Standardized tools are described according to the "Consensus-based standards for the selection of health measurement instruments (COSMIN)" criteria [20]. For original questionnaires, semi-structured interviews and structured interviews, study objectives, questions participants were asked and response scale (if applicable), were extracted.

Synthesis of results

In order to identify the domains of sexuality considered by each approach, two independent reviewers (first and second authors) coded the methods. They used a data extraction grid based on the three categories (and their codes) relating to sexuality in the comprehensive ICF core set for stroke [6]: Sexual Functions (b640), Intimate Relationships (d770) and Environmental factors (i.e. Support and Relationships - e3). Sexual Functions (b640) included four ICF sub-categories: "Arousal" (b6400; i.e. desire, libido, sexual interest), "preparatory" (b6401; i.e. performance, penile erection, clitoral erection, vaginal lubrication), "orgasm" (b6402; including ejaculation) and

“satisfaction”, which is based on the ICF sub-category “resolution” (b6403; i.e. satisfaction and relaxation after orgasm) but also included notions of the individual’s satisfaction with their own sexual life. Intimate relationships (d770) included three sub-categories: “Romantic Relationships” (d7700; which included “Spousal Relationship” (d7701), as it was challenging to separate the two during the analysis), “Sexual Relationships” (d7702; e.g. frequency, duration, type of sexual activities) and “Individual sexual activities”, which was added by the research team to cover aspects such as masturbation and fantasies. Environmental factors were related to the inclusion of the partner in the assessment, and included one sub-category: “Immediate family” (e310). A final category, “Other”, was included in the data extraction grid for concepts covered in the assessments that could not be matched to the eight domains of sexuality drawn from the ICF.

Data Analysis

Both reviewers (first and second authors) analyzed each assessment method and completed the data extraction grid independently, then compared their results and reached consensus when differences were noted. Descriptive statistics (frequency and percentages) were computed for: 1) the sexual domains evaluated by each specific assessment method out of a maximum of eight); 2) the proportions (%) of domains evaluated by each type of assessment (standardized assessment tools, questionnaires and interviews); and 3) the proportion that each of the three categories (i.e. Sexual Functions (b640), Intimate Relationships (d770) and Environmental factors) represented of the total sexual domains evaluated among all assessment methods. The clinical utility, which refers to the ability to use the results of the standardized assessment tool in a useful or informative way within the clinical setting [21], was evaluated. Scoring and related interpretations, time of administration and sexual domains addressed for each

tool were analyzed. Tools were considered more clinically useful if they provided cut-off scores indicating the presence of sexual dysfunction, required less than 20 minutes to administer and addressed more than four sexual domains.

Results

Study selection

Data extracted

A total of 2447 articles remained after duplicates were removed from the initial database search and manual searches (see Figure 1). After irrelevant articles were excluded, 96 matched the inclusion criteria. Justifications for exclusion of full texts are presented in Figure 1.

(Insert Figure 1 approximately here)

How is sexuality after a stroke assessed in the literature?

Among the 96 studies included, a total of 116 methods of assessing sexuality were extracted (many studies used more than one assessment method), of which 90 were quantitative and 26 were qualitative. Among the 90 quantitative assessments, 27 standardized tools were used a total of 62 times and original questionnaires 28 times. The most frequently used standardized assessment tools were the International Index for Erectile Function - 5 (IIEF-5, n = 13), the Change in Sexual Function Questionnaire (CSFQ-14, n = 5), the Life Satisfaction Checklist with eleven (LiSat-11, n = 5) and nine items (LiSat-11, n = 4), the International Index for Erectile Function -15 (IIEF-15, n = 4) and the Female Sexual Function Index (FSFI, n = 3). Among standardized assessment tools, 20 out of 27 were used in only one study. Tools specific to men (i.e. IIEF-5, IIEF15, KEED) were used in 18 studies, whereas tools specific to women were used (i.e. FSFI) in three. Among the qualitative assessments, 16 were semi-structured interviews and 10 were structured interviews. Original questionnaires, structured interviews and semi-structured interviews are described in a table available as supplementary material. Among the 96 studies included, two used mixed methods [22, 23] to assess sexuality post-stroke.

The study by Thomas [22] combined the Canadian Occupational Performance Measure, the Quality of Sexual Function Scale and the Stroke Impact Scale with a semi-structured interview, and Millenbruch [23] combined a semi-structured interview with the use of the Sexual Self Schema Scale.

Description of standardized assessment tools

The 27 standardized assessment tools identified in this review are described in detail in Table 1. Reliability data were available for 25 tools, with internal consistency (n = 22) and test-retest reliability (n = 20) being the psychometric properties most frequently examined. Intra-rater reliability was reported for seven tools. Validity data were available for 23 tools, with construct validity being the most frequently reported (n = 21), followed by content validity (n = 11), criterion validity (n = 11) and responsiveness (n = 7). The Stroke Impact Scale (SIS) [24], the Quality of Life Index – Stroke version [25] and the Canadian Occupational Performance Measure (COPM) [26, 27] were the only three tools reporting psychometric properties specific to individuals post-stroke. It must be noted that the COPM was not initially developed for a stroke population.

“Insert Table 1 approximately here”

Domains of sexuality assessed

The complete list of sexual domains considered by the studies covered by this review is provided in Table 2. Assessment methods covered from zero to all eight of the sexual domains included in the data extraction grid. Assessments that did not specifically address any pre-defined sexual domain still addressed “other” dimensions that relate to sexuality (see below), which justified their inclusion. The assessment methods covering the most sexual domains were the Quality of Sexual Function Scale [28] (8/8) and

Mitchel-Pedersen et al.'s [29] semi-structured interview (7/8). The CSFQ-14 [30], the Eleven Questions about Sexual Functioning (ESF) [31], Giaquinto et al.'s questionnaire [32] and Lemieux et al.'s semi-structured interview [33] each covered six sexual domains. Specific proportions of measured categories are presented in Table 2. All assessment methods combined, domains of sexual body functions were the most frequently assessed (61.4%), followed by activity/participation in intimate relationships (34.1%) and environmental factors (4.5%). More specifically, the sexual domains assessed, in decreasing frequency, were sexual relationships (20.9%), arousal functions (17.3%), satisfaction (17.3%), preparatory functions (14.1%), orgasmic functions (12.7%), romantic relationships (10.5%), immediate relationships (4.5%) and individual sexual activities (2.7%).

“Insert Table 2 approximately here”

Other sexuality-related domains assessed post-stroke

Many assessment methods addressed “other” domains related to sexuality. Standardized assessment tools, original questionnaires and structured interviews mostly explored themes related to personal factors, such as beliefs and knowledge regarding sexuality, sexual inhibition, fears and appearance. Semi-structured interviews included broader questions related to sexuality, which could therefore not be associated to specific sexual domains. However, most semi-structured interviews addressed sexual changes related to the stroke, the person's perspective on various sexual issues, and the services sought or offered regarding sexual rehabilitation (type, frequency, appreciation).

Clinical utility of standardized assessment tools

Among the 27 standardized assessment tools included in this review, 13 focused specifically on sexuality [28, 30, 31, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43], two were non-specific to sexuality [24, 27] and 12 had some questions regarding sexuality, ranging from a single item (n=6) [44, 45, 46, 47, 48, 49] to multiple items (n=6) [25, 50, 51, 52, 53, 54]. Among the 13 tools that focused on sexuality, seven had cut-off scores indicating the presence of a sexual dysfunction [30, 34, 35, 36, 37, 38, 39]. The scores for the remaining five tools must be interpreted in proportion to the total score, as a higher score generally indicates a higher degree of sexual dysfunction. Although the Canadian Occupational Performance Measure (COPM) [26, 27] is not a standardized assessment tool specific to sexuality, but rather an occupation-based tool that addresses performance, satisfaction and importance, it was the only tool in which scores related to sensitivity to change were available, i.e. a change between 0.90/10 and 1.90/10 for evaluation improvement perceived by the client [55]. The COPM was used by Thomas [22] to assess sexual activities.

Discussion

The aim of this study was to identify and describe the assessment methods used to evaluate sexuality among individuals post-stroke that could be used by rehabilitation professionals, and to identify which domains of sexuality were assessed. An inventory of the standardized assessment tools used to evaluate sexuality after a stroke, including psychometric and clinical utility data, was created alongside an analysis of the sexual domains targeted by each method.

This review shows that sexuality post-stroke is most often assessed through quantitative methods. In the majority of studies, these methods involved standardized assessment tools specific to sexuality (e.g. IIEF-5, CSFQ-14) or generic tools that

included items related to sexuality (e.g. LiSat-11). Gender-specific assessments were used six times more for men (i.e. IIEF-5, IIEF-15, KEED) than women (i.e. FSFI). This finding supports the issue raised previously by Lever and Pryor [56] that women are underrepresented in studies related to sexuality post-stroke. Even though standardized assessment tools were used predominantly, 31.1% of the quantitative assessments were based on original questionnaires that were not submitted to a validation process. This suggests that certain domains related to sexuality are not assessed by existing standardized assessment tools, or that the authors of these studies did not have access to tools covering both the construct and domains relevant to their research objectives [57]. For example, five studies included in our review based their questionnaires or structured interviews on Monga et al.'s [58] methods, which covered aspects such as attitudes related to sexuality, fear of impotence, fear of sexuality causing a stroke, ability to discuss sexuality and unwillingness to participate in sexuality. The important proportion of original questionnaires used may also be related to the fact that the only three standardized assessment tools in this review that had been previously validated with a post-stroke population were non-specific to sexuality, i.e. the Stroke Impact Scale [24], the Canadian Occupational Performance Measure (COPM) [26, 27] and the Quality of Life Index – Stroke Version [25]. Among these three tools, the COPM seems to be the most promising for addressing sexuality post-stroke, since it can be contextualized to a sexual activity (e.g. kissing, masturbation, intercourse) for the person and because it addresses his/her perception of the performance, satisfaction and importance of the activity. In our view, the COPM addresses sexuality issues more thoroughly than the Stroke Impact Scale or the Quality of Life Index – Stroke version, since these two only include one general question regarding sexuality or intimacy and relationships. However, specific studies should be conducted to confirm this hypothesis, since the validation study of the COPM

with a stroke population did not include sexual activities. Qualitative methods are by nature relevant for screening and gaining an in-depth understanding of a complex phenomenon, such as how a stroke impacts an individual's sexuality. The fact that 22.4% of the reviewed assessment methods were of a qualitative nature suggests that such methods can contribute to the assessment of sexuality after a stroke, in a way that complements quantitative methods [59]. For example, combining both methods could provide a clearer indication of the importance of specific sexual issues and their impact on sexual functioning. Such a combined approach would also better orient sexual rehabilitation interventions and foster understanding of the prescribed treatment and associated impacts. Moreover, considering that few clients have the opportunity to address sexuality with a professional, even fewer are likely to have the chance to be reassessed after receiving an intervention, which underlines the importance of a thorough assessment of sexuality when the subject is addressed. Mixed methods [60] are thus promising for assessing sexuality after a stroke, but few studies have used such approaches to date [22, 23].

Since few standardized assessment tools for evaluating sexuality have been validated with the stroke population despite the potential benefits, future research and clinical practice should seek to fill this gap. Moreover, considering that this review is dedicated to assessment methods that could be used by rehabilitation professionals, clinical utility was evaluated in order to identify the standardized assessment tools that provide a cut-off score, which is likely to facilitate decision-making for clinicians. In fact, by clearly indicating the presence or absence of a sexual dysfunction, the assessment tool may be more useful for a rehabilitation professional not specialized in sexuality in the process of assessment, intervention and/or referral to a specialist. Among the 27 standardized assessment tools reviewed, 12 had a single item addressing sexuality and

could therefore be considered generic screening tools for this domain. Although the answer to a single question provides too little information to draw conclusions about sexuality post-stroke, generic tools such as the LiSat-11 [45], whose main purpose is to assess life satisfaction, may represent a relevant approach to routinely screen for the need to address sexuality in rehabilitation in a stroke population. This approach could meet stroke rehabilitation guidelines [10] and promote appropriate use of resources, considering that around 50% of post-stroke individuals will not experience sexual issues [4], and therefore do not require a thorough assessment in this regard. Moreover, using generic tools for screening could facilitate the integration of sexuality in clinical practice, by addressing some of the barriers that rehabilitation professionals may experience [11].

Among the other 27 standardized assessment tools included in this review, 13 focused specifically on sexuality and would be more suitable for in-depth evaluation of sexuality with individuals post-stroke. Although investigators or clinicians should choose the appropriate method for the specific context of their client, the CSFQ-14 [30] appears promising for assessing sexuality since it includes different versions for use with men and women, reports psychometric properties and provides cut-off scores for the presence of dysfunction in the four categories of sexual body functions included in this review (i.e. arousal, preparatory, orgasmic functions and satisfaction). For rehabilitation professionals, cut-off scores are likely to better demonstrate the need to screen for a sexual dysfunction (e.g. to professionals not specialized in sexuality), and support referral to a specialized professional to guide diagnosis, when applicable. Therefore, considering that none of the sexuality-specific standardized tools reviewed has been validated for the stroke population, and that the other tools included in this review that presented cut-off scores focused on only one or two categories of sexual functioning, the CSFQ-14 meets most of our study's clinical utility criteria. Moreover, in a recent systematic review that

documented intervention studies in sexual rehabilitation after a stroke, the CSFQ-14 was used in four of the eight studies included [61]. Therefore, using this standardized assessment tool in future research could facilitate comparison of results between studies and benefit clinical practice.

Regarding the sexual domains assessed in studies on sexuality after a stroke, this review shows that sexual body functions are emphasized more than activity/participation in sexual relationships and the environmental factors (i.e. partners). This suggests that sexuality has been mostly assessed in a restrictive way in the literature, focusing on its physiological aspects over activity/participation, and even less on environmental factors that may also affect participation [53, 62]. It may also be that the search terms did not enable identification of assessments focusing on relationships or their environment. However, this is unlikely since the search strategy was designed to be broad and included every study pertaining to sexuality and stroke. Sexual relationships were evaluated, especially in regard to the frequency of intercourse, along with aspects of the relationship from the post-stroke individuals' point of view, although individual sexual activities were addressed in only 3% of the methods. This suggests an omission of this subject and a focus on partnered sexual activities. The environment of the post-stroke individual was the least addressed in the review, since only the social aspects (i.e. partner) were covered. In fact, semi-structured interviews addressed the most aspects related to partners, and the Quality of Sexual Function Scale [28] was the only standardized assessment tool specific to sexuality that addressed the partner's perspective. Interestingly, no method addressed the physical environment, such as the accessibility of the home (e.g. bedroom). The standardized assessment tools that addressed the greatest variety of sexual domains were the Quality of Sexual Function Scale [28], followed by the CSFQ-14 [30] and the "11 questions on sexual function" tool [31]. Considering that they cover a wider range of

relevant domains related to sexuality, these tools should be prioritized in future studies with the stroke population.

Strengths and Limitations

One of the strengths of this scoping review is the fact that it was conducted according to the PRISMA guidelines for such reviews [19]. Moreover, the research team included an American Library Association accredited librarian who was involved in the whole process and ensured that a comprehensive search strategy was developed. Finally, blinded data collection, as well as data extraction according to the COSMIN criteria [20] and the ICF core set for stroke [6], attest to the quality and transferability of the data reported, and its usefulness for clinical and research purposes.

This review also has limitations. First, the process of extracting standardized tools' psychometric data did not include an assessment of the risk of bias of the original studies, since it was not the focus of this study. This limits the inventory of the standardized assessment tools to a presentation of the data that requires further analysis by the reader. Moreover, the analysis of sexual domains focused on aspects directly related to sexuality (e.g. sexual functions, intimate relationships), which may have led the reviewers to omit other relevant elements relating to a stroke that could affect sexuality. However, the category "other" was created to include aspects not directly related to sexual function, and reviewers were invited to modify the analysis scheme based upon the ICF core set for stroke if needed. Finally, clinical utility was evaluated based on the theoretical and tacit knowledge of the first author, with criteria contextualized for the present review. Results should therefore be interpreted with caution. However, our results concur with those of other studies that used the same assessment tools, and the specific criteria that were used to determine clinical utility were detailed, which facilitates their replication.

In conclusion, this scoping review showed that sexuality after a stroke is assessed with a wide variety of methods described in the literature, including standardized assessment tools, original questionnaires, semi-structured interviews and structured interviews. A majority of the studies reviewed here used standardized assessment tools that were not previously validated among a stroke population, not specific to sexuality or that included only a few items about sexuality. Moreover, this review showed that sexuality is assessed in disparate ways, which is suboptimal and highlights the need to orient future clinical practice and research towards adopting a stepwise approach that would include a screening process followed by an in-depth assessment of specific domains pertaining to sexuality. As such, some assessment methods could act as screening tools for sexual difficulties or dysfunctions, while others could be used to improve the assessment of specific domains of sexuality post-stroke. Future studies should explore the validity and reliability of using sexuality-specific standardized tools with a stroke population, and the CSFQ-14 should be prioritized since it was the most promising tool identified according to the criteria in our review. Finally, assessments need to include all factors that may have an impact on sexuality after stroke, namely personal and environmental factors, body structure, body functions and activity/participation, rather than focusing solely on sexual body functions. The combination of standardized tools and semi-structured interviews is likely to be the most promising approach to address all potentially relevant domains during assessment of sexuality post-stroke.

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Appendix 1 – Search strategy in Medline

1. exp Stroke/ or exp Stroke Rehabilitation/
2. (stroke* or cerebrovascular accident* or cerebr* vascular accident* or poststroke).ab,kf,kw,ti.
3. 1 or 2
4. exp Sexual Behavior/
5. exp Sexual Dysfunctions, Psychological/ or exp Sexual Dysfunction, Physiological/
6. exp Sexuality/
7. exp Orgasm/
8. exp Sex Counseling/
9. (sexual* or sexolog* or psychosex* or intimac* or intimate*).ab,kf,kw,ti.
10. (sex adj1 (satisfaction or therap* or dysfunction* or counsel* or activit* or behavior* or rehabilitation or life or health)).ab,kf,kw,ti.
11. 4 or 5 or 6 or 7 or 8 or 9 or 10
12. 3 and 11

Table 1: Description of standardised tools used to assess sexuality in stroke literature (n=27) according to their psychometric properties and clinical characteristics

Assesment tool	Description	Reliability	Validity	Clinical utility
VALIDATED FOR THE STROKE POPULATION				
Canadian Occupational Performance Measure (Law et al. [27]) Used in [22]	Standardized semi-structured interview where the client identifies the five most important activities for him/her, and then rate the performance and satisfaction for each of them. He then rates his satisfaction and his performance in those activities. The client can choose to abord sexuality. Scoring: The importance is rated in a 10 points scale from 1 (“Not important at all”) to 10 (“Extremely important”). The satisfaction is rated in a 10 points scale from 1 (“Not satisfied at all”) to 10 (“Extremely satisfied”). The performance is rated in a 10 points scale from 1 (“Not able to do it at all”) to 10 (“Able to do it extremely well”). A Cutoff between 0.90 and 1.90 as perceived by the client suggests significant improvement ([55])	Test-retest: r= 0.89 for performance and 0.88 for satisfaction (p<0.001) for the stroke population [63]; r = 0.88-0.89 for the stroke population [64]; Intra/inter-rater: Not found Internal consistency: Not found	Construct validity: Good construct responsiveness [55]; <i>Convergent and discriminant validity</i> significantly different from the KB-ADL scale and not strongly correlated with the SPSQ or the FIM [64] Criterion validity: Not found Content validity: Not found Responsiveness: AUC (area under the curve) = 0.79-0.85 for the criterion responsiveness. Good discriminatory power to detect improvement. [55]	Time: 20-40 min Therapist training: Not mandatory, reading of the manual and consultation of caot.ca and thecopm.ca for more information Cost and ordering information: About 50\$ http://www.thecopm.ca/buy/
Stroke Impact Scale (Duncan et al. [65])	Self-reported questionnaire of 64 items to determine the impact of the stroke on the health and life of the person. Strength, hand function, activities of daily	Test-retest:	Construct validity:	Time: 15-20 min

Used in [66]	<p>living (ADL), mobility, communication, emotion, memory and social participation are the eight domains assessed. No direct question about sexuality but 4 indirect questions about sexuality: 3 questions on control of the bladder and bowels and 1 question about the ability to feel emotionally connected to another person.</p>	<p>ICCs: 0.7 – 0.92 for the 8 domains except for emotion (0.57) [65]</p>	<p>Reasonable: item-domain correlations ≥ 0.4 (except 1 in the emotion domain) [65]</p>	<p>Therapist training: None</p>
	<p>Scoring: Scale from 1 to 5 for each item, with a higher score indicating a higher functioning and less limitations from stroke. A change of 10 to 15 points represents a clinically meaningful change. Adding each item's score on a scale of 1 to 100 at the end to indicate the level of recovery since the stroke.</p>	<p>Intra/inter-rater: Not found</p>	<p><i>Discriminant validity:</i> Excellent [65]</p>	<p>Cost and ordering information: Free, available online: https://www.stroking.ca/pdf/sis.pdf</p>
		<p>Internal consistency: Cronbach's alpha: 0.83-0.90 [65]</p>	<p>Criterion validity: Good [65]</p>	<p>or in the Appendix of Duncan et al. [65], cost according to the value of the article.</p>
			<p>Content validity: “Potential for floor effect in hand in hand function domain and possibility for a ceiling effect in communication domain.” (Duncan et al. [65])</p>	
			<p>Responsiveness: Sensitivity to change regarding the severity and time since stroke [65]</p>	
Quality of Life Index - Stroke version (Ferrans and Powers [25])	<p>Questionnaire of 76 items assessing Quality of life (QOL) after stroke. 4 domains are assessed: health and functioning, socioeconomic, psychological-spiritual and family; 4 questions are about the degree of satisfaction and importance of the sex life and the partner.</p>	<p>Test-retest: 0.87 for two weeks and 0.81 for one month [25]</p>	<p>Construct validity: Good: $r > 0.3$ between factors [67]</p>	<p>Time: 5-10 min</p>
Used in [23]	<p>Scoring: 6-points Likert-type scale for each item from 1 ("very unsatisfied" or "very unimportant") to 6 ("very</p>	<p>Intra/inter-rater: Not found</p>	<p><i>Convergent validity:</i> Good: $r = 0.77$ with the single-item life satisfaction assessment [67]</p>	<p>Therapist training: None</p>
		<p>Internal consistency: Cronbach's alpha = 0.93 for the entire instrument,</p>	<p>Criterion validity: Not found</p>	<p>Cost and ordering information: Free, available online https://qli.org.uic.edu/questionnaires/pdf/strokeversionIII/stroke.PDF</p>

satisfied" or "very important"). A higher score indicates a higher QOL.

0.87 for the health and functioning subscale, 0.82 for the socioeconomic subscale, 0.90 for the psychological/spiritual subscale and 0.77 for the family subscale [67]; Cronbach's alpha = 0.90-0.93 [25]

Content validity:
The content was based on a literature review of issues related to QOL and on the reports of patients [25]

Responsiveness:
Not found

SEXUALITY-SPECIFIC TOOLS

International Index for Erectile Function – 5 (IIEF-5) (Rosen et al. [34])	Self-reported questionnaire of 5 items assessing erectile dysfunction (ED). The five items are: patient's confidence to maintain an erection, level of penile tumescence, ability to maintain an erection at the beginning of sexual intercourse, ability to maintain the erection until completion of sexual intercourse and overall sexual satisfaction.	Test-retest: Sufficient*** [80]	Construct validity: Sufficient [80]	Time: < 5 min
Used in [18, 68, 69, 70, 71, 72, 73, 74, 75, 76, 77, 78, 79]	<p style="text-align: center;">Scoring:</p> Maximum score of 5 for each item and 25 for the total score. Score of 21 or below suggests ED; 22-25 points: no ED, 17-21 points: mild ED, 12-16 points: mild to moderate ED, 8-11 points: moderate ED, 1-7 points: severe ED.	Inter/intra-rater: Not found	Criterion validity: Sufficient [80] <i>Sensitivity:</i> 0.98 [34] <i>Specificity:</i> 0.88 [34]	Therapist training: None Cost and ordering information: Free, available online https://www.urofrance.org/fileadmin/medias/scores/score-IIEF5.pdf
International Index for Erectile Function (IIEF-15) (Rosen et al. [35])	Self-reported questionnaire of 15 items assessing erectile dysfunction (ED). The 5 themes addressed are: erectile function, orgasmic function, sexual desire, intercourse satisfaction and overall satisfaction.	Test-retest: Relatively high ($r = 0.82$ for the total scale) [35]; Inconsistent [80]	Construct validity: Adequate (Rosen et al.,[35]) <i>Discriminant validity:</i>	Time: 5-10 min Therapist training: None

Used in [81, 82, 83, 84]

Scoring:
5 points scale for each item, the total score is the sum of the score of each item. Degree of ED: severe (score 6-10), moderate (score 11-16), mild to moderate (score 17-21), mild (score 22-25) no dysfunction (26-30).

Intra/inter-rater:
Not found

Internal consistency:
Highly consistent (alpha values greater than 0.90 for the total scale) [35];
Inconsistent[80]

Highly significant differences between patients with ED and control group [35]

Convergent and divergent validity:
No statistical significance with the Marital adjustment test [85] and the Marlowe–Crowne Social Desirability Scale [86] [35]

Cost and ordering information:
Free, available online:
<https://www.baus.org.uk/userfiles/pages/files/Patients/Leaflets/iief.pdf>

Criterion validity:
Sufficient[80]
Sensitivity:
High [35]
Specificity:
High [35])

Content validity:
Not found

Responsivness:
Sufficient [80]

Female Sexual Function Index (FSFI)
(Rosen et al. [36])

Used in [81, 87, 88]

Self-reported questionnaire of 19 items about sexual function for women. Desire, arousal, lubrication, orgasm, satisfaction and pain are assessed.
Scoring:
6 grade scale for each item, from 0 to 5. A higher score shows a better sexual function. A 0 score implies no sexual intercourse within the last month. A

Test-retest:
r = 0.88 for the total scale [36]

Intra/inter-rater:
Not found

Construct validity:
Inconsistent [89]
Discriminant validity:
Good [36]
Divergent validity:

Time:
5-10 min

Therapist training:
None

Cost and ordering information:

	cut off score of 26 or less indicates female sexual dysfunction.	Internal consistency: Cronbach's alpha \geq 0.82 and higher [36]; Sufficient [89]	“Low” to “Very low” correlations with the Marital Adjustment Test [85] [36]	Free, available online : https://eprovide.mapi-trust.org/instruments/female-sexual-function-index
			Criterion validity: Sufficient [89]	
			Content validity: Not found	
			Responsiveness: Indeterminate [89]	
Change in Sexual Functioning Questionnaire Short Form (CSFQ-14Q) (Keller, McGarvey and Clayton [30])	Self-reported questionnaire of 14 question about currents sexual behaviors and problems. Male and female version. Desire/frequency, arousal/excitement, orgasm/completion and pleasure are assessed.	Test-retest: Not found	Construct validity: Good, >0.4 for each item (except 14) [30]	Time: Average time = 15-19min
Used in [14, 90, 91, 92, 93]	Scoring: 5-point scale frequency, from 1 (“Never”) to 5 (“Every day/Always”) (items 10 and 14 are reversed). The total score is the sum of the score of each item. Total score ranges from 14 and 70. Cut off scores indicating sexual dysfunction: total score \leq 41; desire phase \leq 15; arousal phase \leq 12; orgasm phase \leq 11; desire/frequency phase \leq 6; desire/interest phase \leq 9; pleasure phase \leq 4.	Intra/inter-rater: Not found	Criterion validity: <i>Sensitivity:</i> 92.9% for male and 91.9% for female version [94] <i>Specificity:</i> 59.5% for male and 62.5% for female version [94]	Therapist training: None
		Internal consistency: Cronbach's alpha for the total score = 0.90 for female and 0.89 for male version [30]	Content validity: Not found	Cost and ordering information: Free, available online: https://www.dbsalliance.org/wp-content/uploads/2019/02/Restoring_Intimacy_CSFQ_Handout.pdf
			Responsiveness: Not found	

<p>Hudson's Index of Sexual Satisfaction (ISS) (Hudson, Harrison and Crosscup [95])</p>	<p>25-item questionnaire measuring sexual discord or dissatisfaction with a partner as seen by the respondent. It was designed for therapist to use in repeated administration.</p>	<p>Test-retest: 0.93 [95]</p>	<p>Construct validity: Good; Excellent measurement error characteristics [95]</p>	<p>Time: 5-10min</p>
<p>Used in [96]</p>	<p>Scoring : 5-point scale for each item. 1 = "Rarely or none of the time", 2 = "A little of the time", 3 = "Some of the time", 4 = "Good part of the time", 5 = "Most or all of the time". The score is calculated by reverse-scoring the 12 positive items and then by adding each item's score. A higher score indicated greater sexual problems. Cut off score = 28 [95]</p>	<p>Intra/inter-rater: Not found</p>	<p><i>Discriminant validity</i> Good [95]</p>	<p>Therapist training: None</p>
<p>Arizona Sexual Experience Scale (ASEX) (McGahuey et al. [38])</p>	<p>5-item Self-reported questionnaire assessing sexual functioning, including drive, arousal, penile erection/vaginal lubrication, ability to reach orgasm and satisfaction with orgasm.</p>	<p>Test-retest: Strong ($r = 0.801$ for patients and $r = 0.892$ for controls, $p < 0.01$) [38]</p>	<p>Construct validity: Positive predictive value (PPV) = 88% and negative predictive value (NPV) = 85%; items correlated with the Brief Index of Sexual Functioning for Women [97] factors [38]</p>	<p>Time: Less than 5min</p>
<p>Used in [18]</p>	<p>Scoring: 6-point scale from 1 ("Extremely") to 6 ("Never"). The total score is the sum of individual scores and ranges from 5 to 30. A higher score indicates higher sexual dysfunction. Arbitrary cut off from the author: total score > 19, any one item with an individual score > 5, or any three items with individual scores > 4.</p>	<p>Intra/inter-rater: Not found</p>	<p>Criterion validity: <i>Sensitivity:</i> 82% [38] <i>Specificity:</i> 90% [38]</p>	<p>Therapist training: None</p>
		<p>Internal consistency: Excellent: Cronbach's alpha = 0.901 [38]</p>	<p>Content validity: Not found</p>	<p>Cost and ordering information: Free, available online :</p>
			<p>Responsiveness: Area under the curve = 0.929 [38]</p>	<p>https://www.mirecc.va.gov/vision22/Arizona_Sexual_Experiences_Scale.pdf or http://depts.washington.edu/psychres/wordpress/wp-content/uploads/2017/09/asex_scale.pdf</p>

<p>Kflner [Cologne] Evaluation of Erectile Dysfunction (KEED) (Braun et al. [39])</p>	<p>18-item Self-reported questionnaire to identify symptoms of erectile dysfunction (ED) and its effects on quality of life. The tool evaluates sociodemographic characteristics, medical history, medication, smoking and alcohol consumption habits, sexual desire and frequency of sexual activities, erectile and orgasmic function, satisfaction with sex life and general well-being.</p>	<p>Test-retest: Not found</p> <p>Intra/inter-rater: Not found</p> <p>Internal consistency: Not found</p>	<p>Construct validity: Not found</p> <p>Criterion validity: Predictive value = 0.98 [39] <i>Sensitivity:</i> 0.97 [39] <i>Specificity:</i> 0.93 [39]</p> <p>Content validity: Not found</p> <p>Responsiveness: Not found</p>	<p>Time: 5-10min</p> <p>Therapist training: None</p> <p>Cost and ordering information: Appendix 1 of Braun et al. [39], cost according to the value of the article.</p>
<p>Used in [98]</p>	<p>Scoring: 5-point Likert scale for questions 11-16. A higher score indicates higher ED symptoms. Cut off score of >17 points indicate presence of ED.</p>			
<p>Quality of Sexual Function Scale (Heinemann et al. [99])</p>	<p>Self-reported questionnaire of 40 items. 4 domains are assessed: quality of life, sexual activity level, sexual dysfunction and satisfaction from the patient perspective and sexual dysfunction and satisfaction from the partner's perspective.</p>	<p>Test-retest: Not found</p> <p>Intra/inter-rater: Not found</p> <p>Internal consistency: Cronbach's alpha = 0.8 for the total scale, 0.90 for the subscale "psycho-somatic quality of life", 0.82 for "sexual activity", 0.75 for "sexual (dys)function-self-reflection" and 0.57 for "sexual (dys)function-partner's view" [99]</p>	<p>Construct validity: Correlations of the subscales with the total scale range from 0.30 to 0.77. Correlations among the subscales are in majority well under 0.20 with many not significant [99].</p> <p>Criterion validity: Not found</p> <p>Content validity: Promising [99]</p> <p>Responsiveness: Not found</p>	<p>Time: Less than 10 min</p> <p>Therapist training: None,</p> <p>Cost and ordering information: Appendix of Heinemann et al. [99], cost according to the value of the article.</p>
<p>Used in [22, 66]</p>	<p>Scoring: Scales from 1 (no/little problems or complains) to 5 (most problematic) for each question, 0 indicates "no partner". The total score is obtained with the sum of each item's score. A higher score indicates greater impairments in sexual function.</p>			

<p>Sexual Beliefs and Information Questionnaire (SBIQ) (Adams et al. [40])</p>	<p>25 items Self-reported questionnaire to evaluate sexual knowledge and belief.</p> <p>Scoring: Respondents select "True", "False" or "don't know (?)" for each item. Correct answers are scored 1, incorrect were scored 0 and "?" are scored 9. The total score is calculated by summing the number of correct responses, ranging from 0 to 24. A higher score indicates higher sexual knowledge.</p>	<p>Test-retest: 0.82, $p < 0.001$ [40]</p> <p>Intra/inter-rater: Not found</p> <p>Internal consistency: $r = 0.82$ ($p < 0.001$) [40]; $r = 0.71$ [90]</p>	<p>Construct validity: Not found</p> <p>Criterion validity: Not found</p> <p>Content validity: Not found</p> <p>Responsiveness: Not found</p>	<p>Time: 5-10min</p> <p>Therapist training: None</p> <p>Cost and ordering information: Appendix of Adams et al. [40], cost according to the value of the article.</p>
<p>Used in [100]</p>				
<p>Derogatis Sexual Functioning Inventory (Derogatis and Melisaratos, [41])</p>	<p>Self-reported questionnaire of 254 items evaluating current sexual functioning of men and women. The 10 domains assessed are: information, experience, drive, attitude psychological symptoms, affects, gender role definition, fantasy, body image, sexual satisfaction</p>	<p>Test-retest: Good: $r = 0.42$ to 0.96 [41]</p> <p>Intra/inter-rater: Not found</p> <p>Internal consistency: Very good, Cronbach's alpha ranges from 0.56 to 0.97 [41]</p>	<p>Construct validity: Good [41]</p> <p>Criterion validity: Not found</p> <p>Content validity: Not found</p> <p>Responsiveness: Not found</p>	<p>Time: 45-60 min</p> <p>Therapist training: None</p> <p>Cost and ordering information: Distributed exclusively by Clinical Psychometric Research, Inc. (www.derogatis-tests.com)</p>
<p>Used in [100]</p>	<p>Scoring: Scoring formats vary from dichotomic answers to multiple-point Likert scales. Two scores are calculated: 1) The Sexual Functioning Index (total score of the DSFI) and 2) The Global Sexual Satisfaction Index, which reflects subjective perception of sexual behaviour.</p>			
<p>Sexual Inhibition/Sexual Excitation Scale</p>	<p>Self-reported questionnaire assessing sexual responsiveness. The version for men contains 45 items and three factors are measured: propensity for sexual excitation (SES), propensity for sexual inhibition because of the threat of performance failure (SIS1) and propensity for sexual inhibition because of the threat of performance consequences (SIS2). The version for women contains 36 items and has two sections: sexual excitation (SE) factors and sexual inhibitions (SI) factors.</p>	<p>Test-retest: <u>Version for men:</u> $r = 0.73$ for SES, $r = 0.74$ for SIS1 and $r = 0.62$ for SIS2 [101] <u>Version for women:</u> $SE = 0.81$ and $SI = 0.82$ at $p < 0.005$ [102] <u>Version for men and women:</u></p>	<p>Construct validity: <u>Version for men:</u> $r = 0.73$ for SES, $r = 0.74$ for SIS1 and $r = 0.62$ for SIS2 [101] <u>Version for women:</u> $SE = 0.81$ and $SI = 0.82$ ($p < 0.05$) [102] <u>Version for men and women:</u></p>	<p>Time: 5-10min</p> <p>Therapist training: None</p> <p>Cost and ordering information: <u>Version for men:</u></p>
<p><u>Version for men:</u> (Janssen et al. [101])</p>				
<p><u>Version for women:</u></p>				

<p>(Graham et al. [102])</p> <p><u>Version for men and women:</u> (Milhausen et al. [42])</p> <hr/> <p>Used in [83]</p>	<p>Scoring: 4-point scales ranging from 1 = “Strongly agree”, 2 = “Agree”, 3 = “Disagree”, 4 = “Strongly disagree”. A lower score at the SES and SE factors indicates a greater propensity for sexual excitation. A lower score at the SIS1, SIS2 and SI factors indicates a greater propensity for sexual inhibition.</p>	<p>r ranges from 0.66 to 0.82 with a mean correlation of 0.76 at $p < 0.005$ [42]</p> <p>Intra/inter-rater: Not found</p> <p>Internal consistency: <u>Version for men:</u> Cronbach's alpha for three samples = 0.89, 0.89 and 0.88 for the SES; 0.81, 0.78 and 0.83 for SIS1; 0.73, 0.69 and 0.75 for SIS2 [101]) <u>Version for women:</u> Cronbach's alpha = 0.70 for SE section and 0.55 for SI section; Pearson correlation between SE and SI = 0.28 ($p < 0.01$), indicating relative independence them [102]</p>	<p>r ranges from 0.66 to 0.82 with a mean correlation of 0.76 ($p < 0.05$) [42]</p> <p>Criterion validity: Not found</p> <p>Content validity: Not found</p> <p>Responsiveness: Not found</p>	<p>Appendix of Janssen et al. [101], cost according to the value of the article.</p>
<p>Eleven Questions about Sexual Functioning (ESF) (Vroege [31])</p> <hr/> <p>Used in [103]</p>	<p>11 item self-reported questionnaire identifying duration and frequency of sexual problems due to health condition. Sexual fantasy, solo sex, desire for sexual contact, actual sexual contact, reduced quality of stiffness/lubrication, reduced duration of stiffness/lubrication, actually having an orgasm, having a postponed orgasm, having a premature orgasm, experiencing pain in genitals and general satisfaction are assessed in the questionnaire.</p>	<p>Test-retest: Not found</p> <p>Intra/inter-rater: Not found</p> <p>Internal consistency: Not found</p>	<p>Construct validity: Not found</p> <p>Criterion validity: Not found</p> <p>Content validity: Not found</p> <p>Responsiveness: Not found</p>	<p>Time: 5-10min</p> <p>Therapist training: None</p> <p>Cost and ordering information: Table 2 of Meesters et al. [104], cost according to the value of the article.</p>
<p>Scoring: 7-point and 5-point Likert scales</p>				

<p>Sexual Self Schema Scale</p> <p><u>Version for women:</u> (Andersen and Cyranowski, [43])</p> <p><u>Version for men:</u> (Andersen, Cyranowski and Espindle, [105])</p>	<p>Self-reported questionnaire measuring cognitions associated with sexual feelings and expressions to assess the "Sexual self-view". The assessment is made by rating 50 trait adjectives for women and 45 for men. Factors evaluated are, for women: Romantic/passionate, Open/direct views of the self and Embarrassment and/or conservatism, and for men: Passionate and loving traits, Powerful and aggressive trait and Open-mindedness and liberal thinking.</p>	<p>Test-retest: <u>Version for women:</u> r = 0.89 (p<0.0001) for 2 weeks and 0.88 (p<0.0001) for 9 weeks [43]</p> <p><u>Version for men:</u> R = 0.81 (p = 0.0001) at 9 weeks [105]</p> <p>Intra/inter-rater: Not found</p>	<p>Construct validity: Not found</p> <p>Criterion validity: Not found</p> <p>Content validity: Not found</p> <p>Responsiveness: Not found</p>	<p>Time: 5-10 min</p> <p>Therapist training: None</p> <p>Cost and ordering information: Version for women is available in the Appendix of Andersen and Cyranowski [43] and the version for men is available in the Appendix B of Andersen et al. [105]. Cost according to the value of the articles.</p>
<p>Used in [23]</p>	<p>Scoring: 7-point Likert-type scale, ranging from 0 ("Not at all descriptive of me") to 6 ("Very much descriptive of me"). For women, the total score is obtained by adding the scores of Factors 1 and 2 and subtracting the score of Factor 3. For men, the total score is the sum of the 3 factors. [106]</p>	<p>Internal consistency: <u>Version for women:</u> Cronbach's alpha = 0.82 for the full scale, 0.81 for Factor 1; 0.77 for factor 2 and 0.66 for Factor 3 [43]</p> <p><u>Version for men:</u> Cronbach's alpha = 0.86 for the total scale; 0.89 for Factor 1; 0.78 for Factor 2; 0.65 for Factor 3 [105]</p>		

GENERIC TOOLS

<p>Life Satisfaction Checklist (LiSat-9) (Fugl-Meyer, Bränholm and Fugl-Meyer [44])</p>	<p>Checklist of 9 items about life satisfaction with 1 item about sexual life. Explore the degree of satisfaction in activities of daily life (ADL), leisure situations, vocational situations, financial situations, sexual life, partnership relations, family life and contacts with friends and acquaintances.</p>	<p>Test-retest: Kappa = 0.82 for sexual life; p = 0.74 for the mean score [111] (chronic pain population)</p> <p>Intra/inter-rater:</p>	<p>Construct validity: <i>Divergent validity:</i> r = 0.52 with the Mental Health Scale (SF-36) [113]; , r = 0.66 with the Hospital Anxiety and depression scale [114]; r = -0.45 with the Social Dimension of</p>	<p>Time: 10-30 min</p> <p>Therapist training: None</p> <p>Cost and ordering information:</p>
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Used in [107, 108, 109, 110]	<p>Scoring: 6-grade ordinal scale for each item: 1 = “Very dissatisfying”, 2 = “Dissatisfying”, 3 = “Rather dissatisfying”, 4 = “Rather satisfying”, 5 = “Satisfying”, 6 = “Very satisfying”. Cut off: 1-4 = dissatisfied; 5-6 = satisfied</p>	Not found	the Sickness Impact Profile 68 [115]. [112]	Free, available online: https://www.sralab.org/rehabilitation-measures/life-satisfaction-questionnaire-9
		<p>Internal consistency: Chronbach's alpha = 0.75 [112](Spinal cord injury population)</p>	<p>Criterion validity: r = 0.59 [112]</p> <p>Content validity: No floor or ceiling effects [112]</p> <p>Responsiveness: Not found</p>	
Life Satisfaction Checklist (LiSat-11) (Fugl-Meyer, Melin and Fugl-Meyer [116])	Checklist of 11 items about life satisfaction. Can be self-administrated or used as an interview tool. The items can be divided into four themes : closeness (sexual life, partner relationship, family life), health (ability to care for self/ADL, physical health, mental health), spare time (leisure, contact with friends and acquaintances), provision (vocational and financial situations).	<p>Test-retest: For all the items, the kappa coefficient ranged from 0.59 to 0.97 and the percent agreement (PA\leq1) from 89% to 100% for the chronic stroke population. Kappa = 0.84 and PA\leq1 = 91 for sexual life. [122]; ICC = 0.71 [123]</p> <p>Intra/inter-rater: Not found</p> <p>Internal consistency: Good: Cronbach's alpha = 0.89 [123]</p>	<p>Construct validity: Not found</p> <p>Criterion validity: Not found</p> <p>Content validity: Not found</p> <p>Responsiveness: Not found</p>	<p>Time: 5min</p> <p>Therapist training: None</p> <p>Cost and ordering information: Free, available online: https://www.fsfiquestionnaire.com/FSFI%20questionnaire2000.pdf;</p>
Used in [117, 118, 119, 120, 121]	<p>Scoring: Six grade ordinal scales for each item: 1 = “Very dissatisfying”, 2 = “Dissatisfying”, 3 = “Rather dissatisfying”, 4 = “Rather satisfying”, 5 = “Satisfying”, 6 = “Very satisfying”. Cut off : 1-4 = Dissatisfied; 5-6 = Satisfied</p>			
World Health Organization	Self-reported questionnaire of 26 items measuring a health condition’s impact on quality of life in 4 domains: physical health, psychological well being,	<p>Test-retest: Not found</p>	<p>Construct validity: Significant correlations with the Overall Quality of Life score</p>	<p>Time: Less than 5 min</p>

<p>Quality of Life scale abbreviated (WHOQOL-BREF) (WHOQOL group [124])</p>	<p>social relationships and environment satisfaction. Only one direct question about sexuality: "How satisfied are you with your sex life?" and one indirect question: "How satisfied are you with your personal relationships?"</p>	<p>Intra/inter-rater: Not found</p>	<p>ranging from $r = 0.244$ to 0.676 for all domains [124]</p>	<p>Therapist training: None</p>
<p>Used in [82, 125]</p>	<p>Scoring: 5-points Likert scale from 1 ("Very poor", "Very dissatisfied", "Not at all", "An extreme amount or Always") to 5 ("Very good", "Very satisfied", "An extreme amount", "Not at all" or "Never"). A higher score indicates a higher quality of life. The total score is obtained by a manual calculation of individual score. It is possible to convert the total score on a 4-20 scale or on a 0-100 scale.</p>	<p>Internal consistency: Cronbach's alpha = 0.7 for the total sample; = 0.68 for relationship domain [126]; Cronbach's alpha = 0.65-093 [124]</p>	<p>Criterion validity: Not found</p> <p>Content validity: Pearson correlations (< 0.0001) range from 0.46 to 0.67 with 0.45 for sex and 0.57 for personal relationship. No evidence of ceiling or floor effects [126].</p>	<p>Cost and ordering information: Free, available online https://www.who.int/mental_health/media/en/76.pdf</p>
<p>Grid for Measurements of Activity and Participation (G-MAP) (Belio et al. [127])</p>	<p>ICF-derived [129] assessment tool evaluating activity limitation and participation restriction. It consists of a 26 items Grid for Measurements of Activity and Participation which is filled at the end of a semi-structured interview. 6 categories are assessed: Personal care, Domestic life, Interpersonal relationships and interactions (including spouse/partner and sexual relationships), Economic and social productivity, Leisure, Community and civic life.</p>	<p>Test-retest: Not found</p>	<p>Construct validity: Not found</p>	<p>Time: 15-30min</p>
<p>Used in [128]</p>	<p>Scoring: Each item is scored on 3 categories of scales: 1) Severity of activity limitations, from 0 (absence) to 2 (total); 2) Environmental factors; 3) Severity of participation restriction, from 1 (absence) to 3 (total).</p>	<p>Intra/inter-rater: Not found</p>	<p>Criterion validity: Not found</p> <p>Content validity: According to Belio et al. [127], data obtained were in agreement with clinicians and patients representatives' opinions.</p>	<p>Therapist training: None</p>
		<p>Internal consistency: Cronbach's alpha = 0.89 [127]</p>	<p>Responsiveness: Not found</p>	<p>Cost and ordering information: Appendixes 1 and 2 of Belio et al. [127], cost according to the value of the article.</p>

Beck Depression Inventory (Beck et al. [49])	Self-reported questionnaire of 21-question assessing depressive symptoms. The last item is about loss of Libido.	<p>Test-retest: 0,60-0,83 for nonpsychiatric patients and 0,48-0,86 for psychiatric patients for the BDI [130]Instability of the scores over short time intervals [131]</p>	<p>Construct validity: <i>Convergent validity</i> r = 060-0,72 with clinical ratings and 0,73-0,74 with Hamilton Psychiatric Rating Scale for Depression [130]; r = 0.93 (p<0.01) between the BDI and the BDI-II [132];</p>	<p>Time: 5-10min</p>
Used in [8]	<p>Scoring: 4-point scale evaluating the degree of severity of depressive symptom. 0 = “None”, 1 = “Mild”, 2 = “Moderate” and 3 = “Severe”. A higher score indicates greater depressive symptom. The total score is the sum of each score. Cut off scores: 1-10 = normal, 11-16 = mild, 17-20 = borderline clinical depression, 21-30 = moderate, 31-40 = severe, over 40 = extreme.</p>	<p>Intra/inter-rater: Agreement in the rating of depression = 97% of the cases; Interrater : high degree of consistency among interviewers for the mean score [49]</p>	<p><i>Discriminant validity</i> Against anxiety, validity in differentiating between depressed and nondepressed subjects [131]</p>	<p>Therapist training: None</p>
		<p>Internal consistency: All categories have a significant relationship to the total score (p<0.001 except for one category); Pearson coefficient = 0.86 and rose to 0.93 with a Spearman-Brown correction [49]</p>	<p>Criterion validity: Not found</p> <p>Content validity: High, reflects well 6 of the 9 DSM-III criteria [131]</p> <p>Responsiveness: In 85% of the cases the BDI adequately correctly predicted a change in the score in 85% of the cases [49]</p>	<p>Cost and ordering information: Free, available online : https://www.ismanet.org/doctoryourspirit/pdfs/Beck-Depression-Inventory-BDI.pdf</p>
Hamilton Depression Rating Scale (Hamilton [133])	The tool should be use in an unstructured interview conducted by a health care professional. The questionnaire measures the severity of depressive symptoms with 17 items. One question is about genital symptoms, including libido.	<p>Test-retest: Poor [135]</p>	<p>Construct validity: Not found[135]</p>	<p>Time: 15-20 min</p>
Used in [78, 134]	<p>Scoring:</p>	<p>Intra/inter-rater: <i>Interrater:</i> r = 0.84 [133]; Poor [135];</p>	<p>Criterion validity: Not found</p> <p>Content validity:</p>	<p>Therapist training: Yes</p>
			<p>Cost and ordering information:</p>	<p>Cost and ordering information:</p>

	<p>Each item is rated using a scale from 0 to 2 or from 0 to 4. The 0 indicates that the symptom is absent. A higher score indicates a higher degree of symptoms.</p> <p>A total score of 0-7 is considered normal, 8-16 suggest mild depression, 17-23 moderate depression and over 24 severe depression. The maximum score is 52.</p>	<p>Internal consistency: Adequate, range from 0.46 to 0.97, with ≥ 0.70 in 10 studies [135].</p>	<p>Not found</p> <p>Responsiveness: Not found</p>	<p>Free, available online : https://dcf.psychiatry.ufl.edu/files/2011/05/HAMILTON-DEPRESSION.pdf</p>
<p>Social Functioning Examination (SFE) (Starr, Robinson and Price [52])</p> <hr/> <p>Used in [136]</p>	<p>28 items semi-structured interview assessing social functioning. Questions 1 to 10 are about closeness, independence, compatibility, sexual adjustment and satisfaction with the significant other.</p> <p>Scoring: 3-point scale about sexual satisfaction. 0 = "Normal", 1 = "Moderately dissatisfied", 2 = "Severely dissatisfied".</p>	<p>Test-retest: High, for the total score $r = 0.90$ ($p < 0.01$) [137]</p> <p>Intra/inter-rater: High, interrater: $r = 0.92$ ($p < 0.01$) [137]</p> <p>Internal consistency: Not found</p>	<p>Construct validity: Correlation coefficient with the Social Ties Checklist is $r = 0.65$ ($p < 0.01$) and with the Hollingshead social class is $r = 0.41$ ($p < 0.05$) [137]; No significant correlation with the Hamilton depression scale [48] and the Mini-Mental State Examination [138] [52]</p> <p>Criterion validity: Not found</p> <p>Content validity: Not found</p> <p>Responsiveness: Not found</p>	<p>Time: 10-30 min</p> <p>Therapist training: None</p> <p>Cost and ordering information: Tables 2 and 3 of Starr et al. [137] and Table 3 of Starr et al. [52]. Cost according to the value of the articles.</p>
<p>Psychological Adjustment to Illness Scale (PAIS) (Morrow, Chiarello and Derogatis [139])</p>	<p>45 questions semi-structured interview to measure adjustment to a medical illness. It can be administered to the patient or the partner. The tool is divided into 7 domains: 1) Health care orientation, 2) Vocational environment, 3) Domestic environment, 4) Sexual relationship, 5) Extended family relationships, 6) Social environment and 7) Psychological distress.</p>	<p>Test-retest: Not found</p> <p>Intra/inter-rater: <i>Inter-rater:</i> $r = 0.83$ for the total score and 0.81 for the sexual</p>	<p>Construct validity: For 5 of the 7 domains ranges from $r = 0.34$ to 0.47 ($p < 0.05$) with 0.47 for sexual relationships. For 2 domains, $r = 0.08$ and 0.22 [139]; Partially established [141]</p>	<p>Time: 20-30min</p> <p>Therapist training: Yes</p> <p>Cost and ordering information:</p>

Used in [140]	The domain "Sexual relationship" assess quality and frequency of sexual activities, sexual interest, sexual satisfaction, sexual dysfunction, and interpersonal conflict. Scoring: 4-point scale. A higher score indicates a higher impairment.	relationship domain (Morrow et al. [139]); Internal consistency: "the reliability coefficient ranged from $r = 0.82$ to $r = 0.33$ on subtests." (Weissman et al.[141]); High, Cronbach's alpha ranges in mean from 0.60 to 0.90 for the 7 domains with 3 different populations [142]	Criterion validity: Strong [139]; Partially established [141] Content validity: Not found Responsiveness: Not found	Distributed exclusively by Clinical Psychometric Research, Inc. (www.derogatis-tests.com)
Post-Stroke Checklist (Philp et al. [143]) Used in [144]	15 item checklist to identify long-term problems following a stroke. One item assesses intimate relationships in the latest version of Turner et al.[145]. Scoring: Yes or No choices	Test-retest: Not found Intra/inter-rater: Not found Internal consistency: Not found	Construct validity: Not found Criterion validity: Not found Content validity: Not found Responsiveness: Not found	Time: 5-10min Therapist training: None Cost and ordering information: Philp et al. [143]. The 15 items are listed in Table 4 of Turner et al. [145].
Maudsley Marital Questionnaire (MMQ-rs) (Arrindell, Boelens and Lambert [51]) Used in [103]	Self-reported questionnaire about marital functioning containing 20 items. It is composed of three scales: marital (M), sexual (S) and general life adjustment (GL). The sexual scales assess frequency and satisfaction of intercourses and feeling during contact with partner.	Test-retest: Appropriate: $r = 0.60-0.90$ [51] Intra/inter-rater: Not found	Construct validity: Significantly intercorrelation of the 3 scales: M-S $r = 0.60$, M-GL $r = 0.46$, S-GL $r = 0.33$ at $p < 0.001$ (Joseph et al.[146]) Correlation with global desirability scale = 0.27	Time: 5-10min Therapist training: None Cost and ordering information:

	<p>Scoring: 9-point Likert scale, from 0 = “No dissatisfaction” to 8 = “Great dissatisfaction”. Total score ranges from 0 to 80. A higher score indicates greater dissatisfaction. A score higher than 25 indicates that patients experience limitation. A score higher than 36 indicates severe limitation.</p>	<p>Internal consistency: Cronbach's alpha = 0.90 for the M scale, 0.80 for the S scale and 0.66 for GL scale [146]; Cronbach’s alpha for husbands and wives = 0.87 (M scale), 0.82 (S scale), 0.63 (GL scale) for distressed group and 0.88 (M), 0.64 (S) and 0.60 (GL) for normal group; Cronbach's alpha = 0.90 for M, 0.61 for S and 0.73 for GL at retest [51]</p>	<p>(p=0.001) for M, 0.09 (p<0.05) for S and 0.25 (p<0.05) for GL [51];</p> <p>Criterion validity: Not found</p> <p>Content validity: Not found</p> <p>Responsiveness: Not found</p>	<p>Appendix of Arrindell, Boelens and Lambert [51], cost according to the value of the article.</p>
<p>Assessment of Life Habits (LIFE-H) (Fougeyrollas et al. [53])</p> <p>Used in [147]</p>	<p>Self-reported questionnaire assessing the 12 domains of life habits proposed by the handicap creation process. The first 6 domains are the activities of daily living: nutrition, fitness, personal care, communication, residence, mobility. The last 6 are social roles: responsibility, family relations, interpersonal relations (including sexual and affective relations), community, education, employment, recreation. Available in a long and short form.</p> <p>Scoring: The participant indicates the level of difficulty and the type of assistance. Those two elements are then combined and rated on a 0 to 9 descriptive scale. The total score is the sum of each score divided by the number of items. The subject also rates the level of</p>	<p>Test-retest: Long form: ICC = 0.73 for children and 0.74 for adult; Short form: ICC= 0.67 for children and 0.83 for adult [53]</p> <p>Intra/inter-rater: Inter-rater reliability: " highly reliable (ICC ≤ 0.89) [148]</p> <p>Internal consistency: Not found</p>	<p>Construct validity: <i>Discriminant validity</i> Good [149]</p> <p><i>Convergent validity</i> Moderately correlated (r = 0.70) with the SMAF, no significant association for the “Interpersonal relationships” domain [149]</p> <p>Criterion validity: Not found</p> <p>Content validity:</p>	<p>Time: 20-40 min for the short form. 20-120min for the long form</p> <p>Therapist training: None</p> <p>Cost and ordering information: Can be obtained by emailing the International Network on the Disability Creation Process (iNDCP) at ripph@irdpq.qc.ca. The cost is 288.00\$ for 3 years.</p>

satisfaction on a 5 grades scale from “Very satisfied”
to “Very dissatisfied”.

A consensus of experts
concluded that the tool covered
the major part of life habits and
that it could be used to evaluate
handicap situations. [53]

Responsiveness:

Not found

ICC: Intraclass correlation coefficient; Data presented is related to the English version of the test, unless when specified.

**Psychometric properties established by the original study are presented and when stroke data were not found, data for other populations were included for informative purpose.

***According to the COSMIN checklist [20]

Table 2: Sexual domains covered in each assessment method according to the International Classification of Function and Disability Core Set for Stroke [6]

	Sexual functions				Intimate relationships			Environment	Sub-total (/8)	Other aspects
	Arousal	Preparatory	Orgasmic	Satisfaction	Individual sex	Romantic	Sexual	Immediate family		
Standardized tests	Canadian occupational performance measure (COPM) [26, 27]			X			X		2	Importance of sexuality
	Stroke Impact Scale [24]								0	Relationships in general (family/friends) or social activities
	Quality of Life Index - Stroke version [25]			X		X			2	Importance of sex life and partner
	International Index of Erectile Function – 5 (IIEF-5) [34]		X	X					2	
	International Index of Erectile Function – 15 (IIEF-15) [35]	X	X	X	X				4	
	Female Sexual Function Index (FSFI) [36]	X	X	X	X				4	Pain
	Change in Sexual Functioning Questionnaire Short Form (CSFQ-14) [30]	X	X	X	X	X		X	6	
	Hudson’s Index of Sexual Satisfaction (ISS) [37]				X		X	X	3	
	Arizona Sexual Experience Scale (ASEX) [38]	X	X	X	X				4	
	Kflner [Cologne] Evaluation of Erectile Dysfunction (KEED) [150]	X	X	X	X			X	5	

Quality of Sexual Function Scale [28]	X	X	X	X	X	X	X	X	X	8	Urogen/sexual complaints
Sexual Beliefs and Information Questionnaire (SBIQ) [40]										0	Beliefs and knowledge
Derogatis Sexual Functioning Inventory [41]	X			X						2	Knowledge, attitudes, psychological symptoms, affects, gender role definition, fantasy, body image
Sexual Inhibition/Sexual Excitation Scale [42]	X									1	Sexual inhibition
Eleven Questions about Sexual Functioning (ESF) [31]	X	X	X	X	X			X		6	Duration and frequency of sexuality issues in relation to the health condition, pain in genitals, sexual fantasies
Sexual Self Schema Scale [151, 152]	X									1	Perceptions of self as sexual
Life Satisfaction Checklist (LiSat-9) [44]				X			X			2	
Life Satisfaction Checklist (LiSat-11) [45]				X			X			2	
World Health Organization Quality of Life scale (WHOQOL-BREF) [46]				X						1	
Grid for measurements of activity and participation (G-MAP) [50]				X			X	X		3	Attitudes
Beck Depression Inventory [153]	X									1	
Hamilton Depression Rating Scale [48]	X									1	
Social Functioning Examination (SFE) [52]							X	X		2	

	Psychological Adjustment to Illness Scale (PAIS) [54]	X			X		X	X	X	5	Sexual dysfunction
	Post-Stroke Checklist [47]							X		1	
	Maudsley Marital Questionnaire (MMQ-rs) [51]			X	X		X	X		4	Related psychophysical effects
	Assessment of Life Habits (LIFE-H) [53]						X	X		2	
	Sub-total	13	8	8	18	3	10	12	2		
Questionnaires	Monga, Lawson et Inglis [58]	X	X	X	X			X		5	Enjoyment/pleasure
	McCall and Hosenfel [154]				X	X		X		3	
	Korpelainen et al. [4]	X	X	X	X			X		5	Attitudes, fear of impotence, fear of another stroke, ability to discuss sexuality with partner, unwillingness to participate in sexuality
	Korpelainen et al. [155]	X	X	X	X			X		5	
	Jung [73]	X			X			X		3	Conditions preventing intercourse, methods used to improve sexual function, sexual information, fears of sexual intercourse after stroke, need for sexual treatment
	Sjogren and Fugl-Meyer [156]							X		1	
	Humphrey [157]							X		1	
	Giaquinto et al. [32]	X	X	X	X			X	X	6	Positioning, drug use
	Edmans [158]							X		1	Needs and preferences for sexuality related services
	de Freitas et al. [159]	X	X	X	X					4	
	Choi-Know and Kim [160]	X	X						X	3	
	Cheung [161]	X	X	X	X				X	5	Importance of sexuality, fear of impotence, fear of a recurrent stroke, beliefs of stroke affecting sexuality, ability to discuss sexuality with partner, unwillingness to engage in sexuality
Berry et al. [162]							X		1		

	Akinpelu et al. [163]	X	X	X	X			X		5	Fear of impotence, fear of another stroke, ability to discuss sexuality, unwillingness to engage in sexuality, importance of sexuality
	Agarwal and Jain [164]	X						X		2	
	Song et al. [100]							X		1	
	Kim [5]					X		X		2	
	Dusenbury and al. [165]							X		1	
	Na and al. [166]						X			1	Fear of rejection by the partner, premorbid sexual dysfunction
	Habot et al [167]				X			X		2	
	Epprecht et al. [81]							X		1	Past sexual experiences
	Stead and White [168]						X		X	2	
	Howes et al. [169]	X								1	Appearance of sexual organs
	Bugnicourt [170]	X	X	X	X					4	
	Sub-total	12	9	8	11	2	5	17	1		
Structured interviews	Boldrini et al. [171]		X	X	X			X	X	5	Overall feelings about sexual life after stroke
	Aloni et al. [172]	X	X	X	X			X		5	
	Aloni et al. [173]	X	X	X						3	Menstrual cycle
	Tamam [174]	X	X	X	X			X		5	Fear of impotence, fear of another stroke, ability to discuss sexuality with spouse, unwillingness to participate in sexual activity
	Aloni et al. [175]	X	X	X						3	
	Sjogren, 1981 [176]		X	X				X		3	Frequency of sexual difficulties
	Sjogren et al. [177]		X	X			X	X	X	5	Couple's communication regarding sexuality, partners' reactions to the other's advances, partner's interest in the post-stroke individual, sexual stigmatism
	Sjogren, 1983 [178]	X	X	X				X		4	Shown interest in partner, thought of mutual sexuality
	Fugl-Meyer and Jaasko [179]							X		1	Couple's communication
	Coslett et al. [180]	X						X		2	
	Buzzelli et al.[181]	X			X			X		3	Importance of sexuality, frustrations, medications taken
	Bray et al.[182]	X	X	X						3	Menstruation, importance of sexual functioning
	Allsup-Jackson, 1981 [183]		X	X				X		3	
		Sub-total	8	10	10	4	0	1	10	2	

Semi-structured interview	Yilmaz et al. [184]								0	General changes in sex life since stroke, support received by clinicians regarding sexuality		
	Thomas [22]							X	1	Perceptions regarding sexual difficulties		
	Schmitz and Finkelstein [185]						X		1	Questions other post-stroke individuals may ask themselves regarding sexuality, support and services offered regarding sexuality and related appreciation		
	Nilsson et al. [186]								0	Description of changes regarding sexuality, professional support received regarding sexuality and related preferences		
	Mitchel-Pedersen, 1994 [29]	X	X		X	X	X	X	X	7	Bodily sexual sensations (zones and intensity), pain during intercourse, couple's communication regarding sexuality, fears or concerns regarding sexuality, sexual interest; search for services regarding sexuality and related preferences	
	Millenbruch [23]				X		X	X		3	Health conditions and medication affecting sexuality, functional impact of stroke and impact on sexuality, quality of life, description of sexuality pre-post stroke, efforts for resuming/maintaining sexuality, perception of self as a sexual being, professional services searched and received	
	McCarthy and Bauer [187]							1	1	2	Stroke's impact on the person, on the partner and on the couple's life	
	Lever and Pryor [188]							1		1	Identity as a woman	
	Lemieux et al. [33]	1	1	1	1				1	1	6	Emotional lability, importance of sexuality, fears, clinician addressing sexuality
	Carod et al. [189]	1	1		1						3	
	Kattari [190]				1						1	Couple's communication about sexuality, confidence
	Hawton [191]	1	1	1						1	4	Couple's communication about sexuality
	Goddess et al. [192]	1								1	2	
	Beal and Millenbruch [193]									1	1	
	McCormick et al. [194]									1	1	Performance anxiety, acceptance of changes, sexual conditioning
	McCarthy et al. [195]								1	1	2	Factors challenging the relationship
	Pryor and Lever [196]								1		1	General questions regarding intimacy and relations
	Sub-total	5	4	2	5	1	7	7	5			
Total (n)	38	31	28	38	6	23	46	10	220			
Total (%)	17.3	14.1	12.7	17.3	2.7	10.5	20.9	4.5	100			

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart of articles selection process

