Université de Montréal

Améliorer les services de réadaptation sexuelle offerts aux personnes ayant subi un accident vasculaire cérébral par la synthèse et la co-construction des connaissances

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Améliorer les services de réadaptation sexuelle offerts aux personnes ayant subi un accident vasculaire cérébral par la synthèse et la co-construction des connaissances

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Résumé

Introduction : Un accident vasculaire cérébral (AVC) peut entraîner de multiples conséquences sur la participation des personnes dans leurs activités de la vie quotidienne, incluant celles qui sont liées à la sexualité. Toutefois, rares sont les individus ayant subi un AVC qui ont l'opportunité d'aborder la sexualité dans le cadre de leur réadaptation, en lien avec de multiples facteurs liés aux clients (ex., gêne), aux cliniciens (ex., manque perçu de connaissances et d'habiletés) et à l'environnement de réadaptation (ex., surcharge, manque d'outils cliniques). Une revue systématique de la littérature a fait ressortir l'effet prometteur des interventions en réadaptation sexuelle de par les huit études interventionnelles qui y ont été incluses. Toutefois, à notre connaissance, peu d'études ont porté sur la création d'une intervention abordant les multiples barrières à l'offre de services en réadaptation sexuelle post-AVC pouvant être implantée dans un contexte réel de réadaptation.

Objectifs : L'objectif général de cette thèse était de cocréer un programme multifactoriel pour améliorer les services de réadaptation sexuelle post-AVC au Québec avec des cliniciens, des gestionnaires, des individus ayant subi un AVC, ainsi que de leurs partenaires (si applicable).

Méthodes : Cette thèse comprenant trois études a été menée selon une approche de transfert de connaissances intégrée et guidée par les quatre premières étapes de la cartographie des interventions de Bartholomew et al. (2016) en partenariat avec cinq centres de réadaptation post-AVC au Québec. Des méthodes qualitatives et de codesign (ex., adaptation de la méthode LEGO® Serious Play®) ont été utilisées pour répondre aux objectifs. Au total, 20 intervenants, une gestionnaire ainsi que dix individus ayant subi un AVC et partenaires de différentes régions administratives du Québec ont participé à au moins l’une des 11 activités de codesign en ligne qui ont eu lieu d’octobre 2021 à décembre 2022. L’ensemble des activités ont été coanimées, enregistrées et leur contenu a été analysé par thématiques selon le *Theoretical Domains Framework* (TDF), le système *Capability, Motivation, Opportunities and Behaviour* (COM-B) et la Roue du changement de comportement (*Behaviour Change Wheel* (BCW)).

Résultats : La première étude qualitative décrit 12 grands facteurs interreliés influençant l’offre de services en réadaptation sexuelle, situés au niveau des cliniciens et de l’organisation dans laquelle ils travaillent, ainsi que 11 stratégies visant à outiller les intervenants ou à structurer et enrichir l’environnement de réadaptation pour améliorer les services de réadaptation sexuelle (étape 1 de la cartographie des interventions). La deuxième étude présente une revue de la portée sur les méthodes d’évaluation en réadaptation sexuelle post-AVC qui a fait ressortir de nombreuses méthodes pouvant être utilisées par les professionnels de la réadaptation. La troisième étude qualitative présente la démarche de co-création et le programme, son modèle logique, la matrice de changement anticipé ainsi que des suggestions d’indicateurs de retombées, puis des considérations pour son implantation future dans les programmes de réadaptation post-AVC.

Conclusion : Les travaux de recherche composant cette thèse ont permis de faire une synthèse des connaissances sur le sujet de la réadaptation sexuelle post-AVC, de mieux comprendre les facteurs expliquant le manque d’offre de services associés, ainsi que de créer avec les parties prenantes un programme multifactoriel prêt à être implanté dans le futur dans les milieux de réadaptation post-AVC au Québec.

Mots-clés (max 10) : Sexualité, Accident vasculaire cérébral, Cocréation, Réadaptation, Évaluation, Intervention, Cartographie des interventions, *Theoretical Domains Framework*, Roue du changement de comportement.

Abstract

Introduction: A stroke can have multiple consequences on people's participation in their activities of daily living, including those related to sexuality. However, few individuals who have suffered a stroke address sexuality as part of their rehabilitation, in connection with multiple factors related to clients (e.g., embarrassment), clinicians (e.g., lack of perceived knowledge and skills) and the rehabilitation environment (e.g., overload, lack of clinical tools). A systematic review of the literature highlighted the promising effect of sexual rehabilitation interventions through a total of eight intervention studies included in it. However, to our knowledge, few studies have focused on the creation of an intervention addressing the multiple barriers to the offer of post-stroke sexual rehabilitation services that can be implemented in a real rehabilitation context.

Objectives: The general objective of this thesis was to co-create a multifactorial program to improve post-stroke sexual rehabilitation services in Quebec with clinicians, managers, individuals who have suffered a stroke, as well as their partners (if applicable).

Methods: This thesis comprising three studies was conducted according to an integrated knowledge transfer approach and guided by the first four steps of Bartholomew et al. (2016) in partnership with five post-stroke rehabilitation centers in Quebec. Qualitative and codesign methods (e.g., adaptation of the LEGO® Serious Play ® method) were used to meet the objectives. A total of 20 workers, a manager as well as ten individuals who have suffered a stroke and partners from different administrative regions of Quebec participated in at least one of the 11 online codesign activities that took place from October 2021 to December 2022. All the activities were co-facilitated, recorded and their content analyzed by theme according to the Theoretical Domains

Framework (TDF), the Capability, Motivation, Opportunities and Behaviour (COM-B) system and the Behavior Change Wheel (Behaviour Change Wheel (BCW)).

<u>Results:</u> The first qualitative study describes 12 major interrelated factors influencing the offer of sexual rehabilitation services, located at the level of clinicians and the organization in which they work, as well as 11 strategies aimed at equipping interveners or at structuring and enriching rehabilitation environment to improve sexual rehabilitation services (step 1 of intervention mapping). The second study presents a scoping review of assessment methods in post-stroke sexual rehabilitation that highlighted many methods that can be used by rehabilitation professionals. The third qualitative study presents the co-creation process and the program, its logic model, the matrix of anticipated change as well as suggestions for impact indicators, then considerations for its future implementation in post-stroke rehabilitation programs.

<u>Conclusion:</u> The research work making up this thesis has made it possible to synthesize knowledge on the subject of post-stroke sexual rehabilitation, to better understand the factors explaining the lack of supply of associated services, as well as to create with the parties stakeholders a multifactorial program ready to be implemented in the future in post-stroke rehabilitation settings in Quebec.

Keywords (max 10): Sexuality, Stroke, Co-creation, Rehabilitation, Assessment, Intervention, Intervention Mapping, Theoretical Domains Framework, Behaviour Change Wheel.

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AVC : Accident vasculaire cérébral

BCW : Behaviour Change Wheel

BETTER : Bring up, Explain, Tell, Timing, Educate, and Record

CHSLD : Centre d'hébergement de soins de longue durée (CHSLD)

CIF : Classification internationale du fonctionnement, du handicap et de la santé

CISSS : Centre intégré de santé et de services sociaux

CIUSSS : Centre intégré universitaire de santé et de services sociaux

CLSC : Centre local de services communautaires

COM-B : Capability, Opportunity, Motivation and Behaviour

CSFQ-14 : Changes in Sexual Function Questionnaire

DIBQ : Determinants of Implementation Behavior Questionnaire

ECR : Essai clinique randomisé

EX-PLISSIT : Extended – Permission, Limited Information, Specific Suggestions, Intensive Therapy

FSFI : Female Sexual Function Index

IIEF-5 : International Index for Erectile Function (5 items version)

IIEF-15 : International Index for Erectile Function (15 items version)

KCAASS : Knowledge, Comfort, Approach and Attitude towards Sexuality Scale

KT : Knowledge Translation

LGBTQIA+ : Lesbienne, gay, bisexuel·le, trans, queer, intersexe et asexuel·le

LiSat-11 : Life Satisfaction Checklist

MCREO : Modèle canadien du rendement et de l’engagement occupationnel

MDH-PPH : Modèle du développement humain – Processus de production du handicap

PLISSIT : Permission, Limited Information, Specific Suggestions, Intensive Therapy

PRISMA : Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PRISMA-Scr : Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews

SIS : Stroke Impact Scale

TDF : Theoretical Domains Framework

Pour André Auger, qui m'a toujours souhaité bonne chance dans toutes mes entreprises. Tu vas l'avoir ton « docteur » dans ta famille Grand-Papa.

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Je remets cette thèse avec dans mon cœur beaucoup de gratitude envers la vie de m'avoir permis de vivre cette expérience et d'avoir rencontré et côtoyé autant de belles personnes.

À propos

Avant de présenter les travaux de recherche que mes équipes et moi avons menés au cours de cette thèse de doctorat, il importe de mettre en contexte les motivations et les expériences qui m'ont amené à axer mes activités de recherche sur la sexualité, la neurologie et le transfert de connaissances et ce, depuis la période précédant la maîtrise en sciences de la réadaptation (09/2017-08/2019).

Au niveau personnel, j'ai depuis l'adolescence un intérêt portant sur les différentes manières de vivre et d'exprimer sa sexualité. De plus, faisant partie des diversités sexuelles, j'ai eu tôt dans ma vie à me questionner sur ce qu'était pour moi la notion de sexualité, comment je désirais la vivre, quelles étaient mes préférences et mes limites et ce, dans un environnement où j'avais peu de modèles de rôles jusqu'à l'âge adulte. J'ai donc développé graduellement mes connaissances de façon autodidacte sur le sujet de la sexualité durant le secondaire, le CÉGEP ainsi qu'à l'université.

Durant mon parcours au baccalauréat-maîtrise en ergothérapie à l'Université de Sherbrooke, j'ai gardé mon intérêt sur la sexualité « sur la glace », me concentrant sur les notions priorisées par mon programme de formation. J'ai constaté que la sexualité était très peu abordée dans mon curriculum, soit une seule conférence de deux heures au début de la deuxième année de formation, ainsi qu'une vignette d'apprentissage par problèmes (APP) en troisième année portant sur l'intervention en ergothérapie auprès des personnes ayant subi une lésion médullaire. Ma perception de l'exclusion de la sexualité dans le curriculum de formation a d'autant plus été renforcée lorsqu'une personne agissant comme tuteur.rice d'APP m'a indiqué, après que j'aie proposé de formuler un objectif d'intervention en ergothérapie portant sur le vécu de l'intimité et de la sexualité dans un couple dont un des partenaires présentait une lombalgie, « qu'on ne parlerait pas de sexualité en ergothérapie dans cette unité ». Ayant suffisamment de travail à faire pour compléter mes cours tels qu'ils l'étaient conçus sans ajouter la dimension de la sexualité, je me suis concentré sur d'autres aspects de ma formation.

Suite à ma formation en ergothérapie, j'ai failli poursuivre directement au doctorat en sciences de la réadaptation à l'Université de Montréal pour travailler à l'adaptation d'un programme pour faire la prévention secondaire des troubles cognitifs légers chez les personnes âgées, car j'étais intéressé par la recherche, la cognition et contemplais une carrière académique. Toutefois, je me suis retiré quelques semaines avant le début du trimestre pour privilégier une carrière comme intervenant en ergothérapie en réadaptation fonctionnelle intensive, majoritairement auprès d'une clientèle post-AVC, qui a duré plus de cinq ans. Au cours de mes premières années d'intégration dans mon milieu de travail, qui était l'Hôpital de réadaptation Villa Medica, je me suis concentré à améliorer mes connaissances et mes compétences sur la réadaptation sensorimotrice du membre supérieur ainsi que la réadaptation cognitive, qui figuraient parmi les rôles principaux qui étaient attendus de moi dans mon milieu et parmi l'équipe interdisciplinaire.

Après environ deux ans de pratique, j'ai reçu mon premier usager qui m'a posé une question sur la possibilité de retrouver une sexualité satisfaisante à la suite de son AVC. À ce moment, j'ai constaté chez moi le manque de connaissances, la perception de ne pas suffisamment être compétent ni outillé pour répondre aux questions de mon usager. Après avoir bredouillé une réponse où j'orientais cette personne vers son médecin de famille pour recevoir réponse à sa question, je n'étais pas satisfait de moi-même comme professionnel de la santé. J'aurais voulu faire plus, je sentais que comme ergothérapeute je devais en faire plus. Après m'être renseigné, j'ai pu constater que l'AVC, selon la littérature scientifique, pouvait bel et bien influencer la sexualité ET que les ergothérapeutes pouvaient intégrer la sexualité aux domaines qu'ils abordaient dans leur pratique, celle -ci étant composée d'activités dont l'ergothérapeute est expert en son analyse. J'ai également constaté que je n'étais pas le seul intervenant, ergothérapeute ou autre, qui n'intégrait pas, ou très peu, la sexualité à sa pratique. Cette situation a mené chez moi à la prise de conscience d'un écart entre ma pratique, celle de plusieurs autres intervenants, et les services dont les personnes ayant subi un AVC avaient besoin. La réduction de cet écart est pour moi le motivateur de la majorité de mes travaux de recherche jusqu'à présent.

Au départ, je visais à mettre sur pied une équipe spécialisée en réadaptation sexuelle dans mon milieu de travail. C'est également à ce moment que j'ai pris contact pour la première fois avec Pre Annie Rochette, que j'ai ciblé pour sa spécialisation en réadaptation de l'AVC et son rôle de leader du site de transfert de connaissances *InfoAVC/Strokengine*, afin qu'elle m'encadre dans mes projets d'amélioration des services. Après des échanges avec mes gestionnaires qui avaient une grande expérience en réadaptation, ainsi que Pre Rochette, j'ai été orienté vers la création d'outils plus modestes qui pourraient avoir une plus grande portée, dans la visée d'offrir « un peu de services » au plus grand nombre. C'est ainsi que comme clinicien j'ai piloté une équipe qui a élaboré le premier dépliant sur la sexualité post-AVC de l'Hôpital de réadaptation Villa Medica. Voyant tout le travail à faire pour améliorer les services, qui à mes yeux devait provenir de la recherche puisque les milieux cliniques peinaient à répondre à la demande de services pour la clientèle ayant subi un AVC avec leurs ressources actuelles, j'ai décidé d'entreprendre un parcours aux études supérieures. Durant ma maîtrise en sciences de la réadaptation, j'ai dirigé le codéveloppement d'un guide d'entrevue sur la sexualité avec l'Hôpital de réadaptation Villa Medica, sous la supervision d'Annie Rochette et de Frédérique Courtois (Auger, Pituch et al., 2021). Après avoir complété ce projet, une des rétroactions principales des participants à mon étude était que le guide était utile pour entamer un suivi sur la sexualité, mais que les intervenants n'étaient pas outillés pour mener ce suivi à terme, et que sans ces outils ils préféraient ne pas aborder la sexualité dans leur pratique. C'est la motivation qui m'a amené à choisir mon projet de doctorat, qui est décrit dans cette thèse qui porte sur la synthèse et la cocréation des connaissances pour améliorer les services de réadaptation sexuelle post-AVC.

Au total, cinq articles scientifiques sont intégrés à cette thèse, dont deux revues de littérature que j'ai entamées durant ma maîtrise, en parallèle de mon projet principal, et que j'ai complété durant mon doctorat. Je visais à mieux comprendre de quelle manière la sexualité avait été évaluée dans la littérature, et si des interventions réalisées par des professionnels de la réadaptation avaient fait l'objet d'études. Débutant avec la motivation de faire deux revues systématiques, une portant sur l'évaluation et l'autre portant sur l'intervention, ce devis n'a été conservé que pour le sujet des interventions car le nombre d'études portant sur l'évaluation s'approchait de 100 et correspondait mieux à l'angle d'analyse d'une revue de la portée. À terme, ces deux revues de littérature offraient des informations importantes et complémentaires, et j'ai réfléchi longuement à savoir de quelle façon les intégrer dans la thèse. Il faut noter que ces deux revues de littérature assoyaient les bases de connaissances scientifiques pour justifier la création d'initiatives en réadaptation sexuelle, particulièrement un programme multifactoriel. J'aurais donc pu choisir d'intégrer les deux revues de littérature dans le chapitre de recension des écrits de cette thèse, mais je considérais que la revue de la portée portant sur l'évaluation constituait en elle-même un répertoire important de méthodes d'évaluation potentielles qui pouvaient être utilisées par les professionnels de la réadaptation, donc qu'elle serait mieux à sa place parmi les outils (ou composantes) du programme d'amélioration des services de réadaptation sexuelle élaboré dans cette thèse. Toutefois, j'ai choisi de conserver la revue systématique des interventions de réadaptation sexuelle dans la recension des écrits, soit en début de thèse, afin de faire ressortir son message clé qui justifiait la pertinence de toute cette thèse, soit que la réadaptation pouvait avoir un impact bénéfique sur le fonctionnement et la satisfaction sexuelle des personnes ayant subi un AVC. L'intégration de cinq articles en une seule thèse a été un défi cognitif où les pours et les contres de chaque possibilité ont été considérés, et ultimement j'ai utilisé mon privilège d'auteur pour trancher et suivre le fil conducteur qui m'apparaissait le plus cohérent, en espérant une lecture la plus aisée possible.

Il doit finalement être indiqué que les cinq articles scientifiques intégrés à cette thèse ont été modifiés de façon mineure dans le processus de correction de cet ouvrage académique, sans affecter le sens des propos intégrés mais plutôt pour en améliorer la clarté. Ainsi, les versions des articles incluse à cette thèse pourraient différer de façon minime à celle apparaissant dans les journaux dans lesquels ils ont été publiés (n = 4/5) en termes de certaines formulations choisies pour exprimer des idées spécifiques. Toutefois, aucun résultat ni message clé n'a été modifié.

Chapitre 1 – Introduction

L’accident vasculaire cérébral (AVC), une condition de santé affectant soudainement la circulation sanguine au niveau d’une partie du cerveau et lui causant des dommages (Kuriakose & Xiao, 2020), touche plus de 89 000 Canadiens âgés de 20 ans et plus par année (Gouvernement du Canada, 2019). De plus, près de 405 000 Canadiens vivraient avec des séquelles post-AVC à l’heure actuelle (Krueger et al., 2015). L’AVC peut être qualifié de léger (≈ 20% des cas), modéré (≈ 30%) ou grave (≈ 50%) (Muchada et al., 2014) et est susceptible d’affecter la participation des individus dans quelques-unes ou dans l’ensemble de leurs activités selon les séquelles qu’il peut laisser (Seymour & Wolf, 2014; Vincent-Onabajo, 2013). La récupération de l’AVC est, entre autres, liée au temps écoulé suite à l’accident et suit un processus comprenant les phases aiguë, subaiguë et chronique, nonobstant les services que la personne recevra (Bernhardt et al., 2017). Un continuum de services pour les personnes à risque de subir ou ayant subi un AVC a été mis sur pied au Québec pour que les soins prodigués aux personnes ayant subi un AVC soient harmonisés en un « tout intégré » et en mettant ces dernières au centre de l’approche de soins afin que les services offerts soient en conformité avec leurs besoins respectifs. Ce continuum consiste en une trajectoire divisée en six phases : 1) la sensibilisation du public; 2) la prévention primaire de l’AVC; 3) la prise en charge des phases hyperaiguë et aiguë; 4) la réadaptation post-AVC; 5) la réintégration; et 6) le maintien dans la communauté (Ministère de la santé et des services sociaux, 2017). Dans le cadre de cette thèse, sera abordée plus précisément la phase de réadaptation post-AVC, qui vise à favoriser la récupération optimale des personnes ayant subi un AVC en leur offrant des services médicaux et paramédicaux, tels que l’ergothérapie, la physiothérapie et l’orthophonie (Teasell et al., 2020). Bien que les services de réadaptation soient centrés sur la personne, ses besoins et ses objectifs, ces services ne répondent pas nécessairement à l’ensemble des besoins potentiels que les individus ayant subi un AVC peuvent présenter (Chen et al., 2019). En effet, la sexualité et la participation dans les activités qui y sont liées font partie des sujets qui sont peu abordés dans le cadre de la réadaptation post-AVC (Stein et al., 2013). Cette situation est problématique puisque plus de 50% des individus ayant subi un AVC présenteraient des difficultés liées à leur sexualité (Grenier-Genest et al., 2017). De plus, il est recommandé dans les lignes directrices canadiennes en réadaptation de l’AVC que la sexualité soit abordée auprès de chaque individu, durant leur réadaptation ainsi qu’au moment de leur réintégration dans la communauté (Mountain et al., 2020). Il est important de mieux répondre aux besoins des personnes ayant subi un AVC et d’améliorer la qualité des services qui leur sont offerts car les difficultés sexuelles post-AVC ont été associées à un risque accru de dépression et à une plus pauvre qualité de vie (Kim & Kim, 2008; Korpelainen et al., 1999; Park et al., 2015). Plusieurs études ont été réalisées sur le sujet de la sexualité à la suite d’un AVC, mais la plupart ont été réalisées dans une démarche évaluative visant à mieux comprendre soit l’impact de la condition de santé sur cette dimension importante du quotidien (Grenier-Genest et al., 2017), ou bien les facteurs qui amènent les cliniciens à ne pas intégrer la sexualité à leur pratique (Dyer & das Nair, 2013; McGrath et al., 2021; Richards et al., 2016). Peu d’études ont été réalisées pour évaluer l’efficacité de certaines approches d’intervention et/ou la faisabilité d’implanter des méthodes d’évaluation et d’intervention dans la réalité de la réadaptation post-AVC pour améliorer concrètement les services qui sont offerts aux individus (Auger, Grondin, et al., 2021; Auger, Pituch, et al., 2021). Finalement, les quelques études d’intervention réalisées relativement à la sexualité post-AVC se sont limitées à évaluer l’efficacité ou l’implantation d’une seule méthode d’intervention (Auger, Grondin, et al., 2021). Ceci ne prend pas en compte la nature multifactorielle de la sexualité (World Health Organization, 2006) ni l’hétérogénéité des sous-populations touchées, ne met pas à profit l’interdisciplinarité qu’on retrouve en réadaptation post-AVC et ne correspond pas aux meilleures pratiques qui recommandent l’utilisation d’une combinaison de méthodes d'interventions variées pour optimiser la récupération (Teasell et al., 2020). Afin d’améliorer concrètement les services de réadaptation sexuelle post-AVC, il importe de mieux comprendre la situation problématique actuelle qui mène à cette pauvre offre de services et de développer des interventions qui seront acceptables et qui pourront être implantées sur le terrain.

Cette thèse décrit un processus de synthèse et de cocréation des connaissances dans le domaine de la réadaptation sexuelle post-AVC, qui résulte ultimement en la création, à ma connaissance, du premier programme multifactoriel d’amélioration des services de réadaptation sexuelle pour les personnes ayant subi un AVC. La thèse est divisée en neuf chapitres, incluant celui-ci ayant pour but d’introduire le sujet. Le chapitre deux présente la recension des écrits sous-tendant la réalisation de cette thèse, incluant une revue systématique publiée dans la revue *Topics in Stroke Rehabilitation* (Auger, Grondin, et al., 2021). Le chapitre trois décrit les objectifs généraux et spécifiques de la thèse. Le chapitre quatre permet d'exposer les approches méthodologiques utilisées pour l'atteinte des objectifs et inclut un protocole de recherche publié dans la revue *Frontiers in Rehabilitation Sciences* (Auger, Allegue, et al., 2022). Le chapitre cinq est consacré à la présentation d'une étude d'évaluation des besoins et des priorités des parties prenantes en réadaptation post-AVC en ce qui a trait à la réadaptation sexuelle, sous la forme d'un article scientifique qui a été soumis à la revue *Sexuality and Disability* (Auger, Filiatrault, Allegue, Vachon, et al., 2023). Le chapitre six présente une revue de la portée sur les méthodes d'évaluation liées à la sexualité post-AVC pouvant être utilisées par les intervenants en réadaptation post-AVC, sous la forme d'un article scientifique publié dans la revue *Disability and Rehabilitation* (Auger, Aubertin, et al., 2021). Le chapitre sept présente l'étude de cocréation d'un programme d'amélioration des services de réadaptation sexuelle post-AVC, sous la forme d'un article scientifique qui a été soumis à la revue *Disability and Rehabilitation* (Auger, Filiatrault, Allegue, Thomas, et al., 2023). Le chapitre huit consiste en la discussion globale de la thèse, qui permet de ventiler les résultats et de les comparer à l'état des connaissances actuelles de manière complémentaire aux discussions retrouvées dans les cinq articles scientifiques inclus dans la thèse. Finalement, le chapitre neuf est consacré à la conclusion de la thèse, où les idées et retombées principales de la thèse sont relevées et où des orientations pour de futures recherches sont proposées.

Au-delà d'agir comme un ouvrage présenté à des fins académiques, j'ai pour objectif que cette thèse puisse être utilisée autant par les cliniciens, gestionnaires, chercheurs et étudiants dans les domaines de la réadaptation, de la sexualité, de l'AVC, du transfert ou de l'application des connaissances, comme un outil pour les orienter dans leurs propres projets d'implantation clinique et/ou de recherche. Je suis très enthousiaste à l'idée que l'ensemble des connaissances issues des travaux réalisés dans le cadre de cette thèse soit disponible dans un seul document et, je l'espère, utile pour les personnes qui souhaiteront le mettre à profit pour améliorer la qualité des services de réadaptation liés à la sexualité. Les personnes lisant cette thèse sont encouragées à garder en tête que l'ensemble des travaux la composant sont le résultat d'un travail d'équipe acharné et ne sauraient se résoudre à la contribution d'une seule personne. Pour refléter cette collaboration, les phrases seront articulées à la troisième personne ou au « nous » tout au long du document.

Chapitre 2 – Recension des écrits

Ce chapitre présente l'état des connaissances scientifiques sur la situation problématique qui justifie la réalisation de cette thèse. Ainsi, les différents thèmes abordés dans ce chapitre sont : l'accident vasculaire cérébral, la participation suite à un AVC, la sexualité et l'impact de l'AVC sur celle-ci. Ensuite, la réadaptation post-AVC, les facteurs influençant l'offre de de services dans ce domaine, ainsi qu'une revue systématique des études sur les interventions de réadaptation sexuelle sont présentés. À la fin du chapitre, les constats relatifs à l'état des connaissances dans le domaine de la réadaptation sexuelle post-AVC contribuent à justifier les objectifs de la thèse, qui composent le chapitre 3.

L'accident vasculaire cérébral

Un AVC survient lorsque la circulation sanguine est interrompue abruptement au niveau des vaisseaux sanguins du cerveau (Kuriakose & Xiao, 2020). La nature, la localisation et l'étendue de l'AVC font partie de ses caractéristiques qui influenceront l'ampleur des dommages cérébraux et des dysfonctions associées (Hillis et al., 2004; Lindenberg et al., 2010; Zhu et al., 2010). Un AVC peut être de nature ischémique ou hémorragique et leurs proportions représenteraient environ 85% et 15% des cas, respectivement (Kuriakose & Xiao, 2020). Un AVC ischémique résulte du blocage d'un vaisseau sanguin par un caillot, lié soit à une condition embolique (i.e., formation du caillot dans une autre partie du corps et circulation de celui-ci vers le cerveau) ou une condition thrombotique (i.e., formation du caillot de manière graduelle à même le vaisseau sanguin du cerveau par le rétrécissement de sa lumière par l'athérosclérose, l'accumulation de plaques et l'agrégation de plaquettes) (Musuka et al., 2015). L'occlusion du vaisseau sanguin mènera à une hypoxie de la zone cérébrale qu'il dessert, ce qui lui causera un stress important et ultimement la nécrose des tissus et, entre autres, la perte de fonction neuronale, si aucune intervention n'est réalisée (Broughton et al., 2009). Un AVC de nature hémorragique est lié à la rupture d'un vaisseau sanguin et à l'épanchement de sang soit : 1) à l'intérieur même du cerveau (c.-à-d., sous la couche de méninges (1/3) la plus proximale au cerveau – la pie-mère) ou 2) dans l'espace sous-arachnoïdien (c.-à-d., entre les couches proximales et intermédiaires des méninges, soit la pie-mère et l'arachnoïde). L'AVC hémorragique peut causer des effets toxiques sur le système neurovasculaire, mener à une méningite chimique qui risque d'augmenter la pression intracrânienne et/ou à des vasospasmes qui peuvent mener à une ischémie cérébrale. L'ensemble de ces conséquences potentielles suscitent un stress sur les structures cérébrales et peuvent mener à la perte de fonction neuronale (Flaherty et al., 2005). La localisation de l'AVC sera associée à l'hémisphère, à l'artère et aux structures corticales et sous-corticales qui sont affectés. Selon une perspective neuropsychologique, chaque structure cérébrale remplirait une fonction spécifique. Ainsi, des incapacités et autres conséquences (ex., troubles des systèmes sensorimoteurs, cognitifs et/ou langagiers) liées auxdites fonctions de la ou des structures touchées pourraient être observées suite à l'AVC (Jawabri & Sharma, 2021). Par exemple, un AVC affectant le cortex prémoteur de l'hémisphère gauche, responsable de la planification des mouvements, pourrait résulter en des troubles moteurs ou praxiques au niveau de l'hémicorps droit (Heilman, 2021; Park, 2017). Finalement, un AVC de plus grande étendue est susceptible de mener à de plus lourdes conséquences pour la personne, par exemple, une plus grande perte d'autonomie, en comparaison à un AVC touchant une portion plus limitée du cerveau (Farzadfard et al., 2019). L'AVC est donc un trouble neurologique d'origine cardiovasculaire qui affecte principalement les structures du système nerveux central, plus particulièrement le cerveau (Shakir, 2018), et qui peut, directement ou indirectement, influencer le fonctionnement des fonctions organiques des individus qui en subissent un (Geyh et al., 2004; Rathore et al., 2002).

L'AVC affecte différemment les personnes en fonction de leur sexe et de leur genre. Les Instituts de recherche en santé du Canada (2023; https://cihr-irsc.gc.ca/f/48642.html) ont décrit ces termes comme :

- *Sexe : « [...] renvoie à un ensemble d'attributs biologiques retrouvés chez les humains et les animaux. Il est lié principalement à des caractéristiques physiques et physiologiques, par exemple les chromosomes, l'expression génique, les niveaux d'hormones et l'anatomie du système reproducteur. »*
- *Genre : « [...] renvoie aux rôles, aux comportements, aux expressions et aux identités que la société construit pour les hommes, les femmes, les filles, les garçons*

> *et personnes de divers sexes et de genre. Le genre influe sur la perception qu'ont les gens d'eux-mêmes et d'autrui, leur façon d'agir et d'interagir, ainsi que la répartition du pouvoir et des ressources dans la société. »*

Une revue systématique de 98 études a démontré des différences entre les sexes au niveau de l'épidémiologie de l'AVC (Appelros et al., 2009). La méta-analyse des résultats des études portant sur l'incidence de l'AVC a montré que le premier AVC survenait en moyenne à 68,6 ans pour les hommes et à 72,9 ans pour les femmes, ce qui représente une différence moyenne de plus de 4 ans d'âge entre les sexes. Au niveau du type d'AVC lorsqu'il survient, les hommes auraient un risque accru d'AVC ischémique (55% plus élevé) et d'hémorragie intracérébrale (60% plus élevé) et les femmes présenteraient un risque accru d'hémorragie sous-arachnoïdienne (16% plus élevé). Au niveau de la prévalence et de l'incidence, sans égard à l'âge, les hommes auraient 41% plus de risque de subir un AVC au cours de leur vie et l'incidence de l'AVC serait 33% plus élevée que chez les femmes. Finalement, les femmes présenteraient généralement des AVC plus sévères les laissant avec davantage d'incapacités, et leur taux de mortalité post-AVC serait plus élevé en comparaison aux hommes (Appelros et al., 2009).

Les résultats d'Appelros et collaborateurs sont appuyés par deux revues de littérature plus récentes, qui ajoutent également à la compréhension des différences en termes de sexe et de genre par rapport à l'AVC au niveau de ses facteurs de risque, de son évaluation, des interventions et de leurs retombées. Au niveau des facteurs de risque, la présence des conditions de santé suivantes susciterait un risque d'AVC plus élevé chez les femmes que chez les hommes: l'obésité, la fibrillation auriculaire, l'hypertension, le diabète et les migraines. Ceci est d'autant plus préoccupant considérant que les femmes présentent généralement davantage ces facteurs de risque que les hommes selon une revue de littérature (Rexrode et al., 2022). Au niveau des facteurs socioculturels et liés aux habitudes de vie, les femmes seraient plus affectées en termes de risque de subir un AVC par le tabagisme et le fait de présenter un niveau socio-économique plus faible en comparaison aux hommes. De plus, elles seraient plus susceptibles d'être veuves et de vivre seules au moment de la survenue de leur AVC, ce qui les met à risque de se rendre de manière plus tardive à l'urgence et/ou d'appeler à l'aide suite à l'apparition de symptômes (Ospel et al., 2023). Toutefois, la consommation excessive d'alcool serait un facteur de risque d'AVC qui est retrouvé en majorité chez les hommes. Au niveau des services reçus, les femmes seraient à risque plus élevé de recevoir des évaluations incomplètes, par exemple que leur AVC ne soit pas détecté et diagnostiqué adéquatement lors de leur visite à l'urgence (risque > 25% comparé aux hommes) (Rexrode et al., 2022). Finalement, cette même revue de littérature a indiqué que les femmes seraient généralement incluses en moindre proportion aux essais cliniques randomisés et autres études visant à tester l'efficacité d'interventions en lien avec l'AVC et seraient plus à risque de ne pas recevoir le meilleur traitement médical en fonction de leur AVC, ce qui les mettrait à risque plus élevé de présenter des incapacités plus graves suite à leur récupération (Rexrode et al., 2022). Il est donc important de considérer les notions de sexe et de genre dans l'offre de soins et services de santé à une personne ayant subi un AVC considérant qu'ils ont une influence qui leur est spécifique et qui pourra avoir une incidence sur les besoins de réadaptation éventuels. Selon les données les plus récentes et ce, à l'échelle mondiale, 12,2 millions de nouveaux cas d'AVC sont survenus en 2019 et 101 millions de personnes présentaient les conséquences d'un AVC cette année-là (Feigin et al., 2021). Selon cette même étude, la prévalence mondiale de l'AVC, tous types confondus, par tranches de 100 000 personnes était de 1 150 pour les hommes (sexe) et de 1 317 pour les femmes (sexe) (Feigin et al., 2021). Selon une enquête canadienne, 89 540 personnes de 20 ans et plus avaient subi un AVC en 2017 et environ 878 500 Canadiens déclaraient avoir subi un AVC au cours de leur vie (Gouvernement du Canada, 2019). Toutefois, les dernières données canadiennes portant sur le handicap suite à un AVC remontent à une enquête réalisée en 2013, qui a montré que plus de 400 000 Canadiens vivaient des handicaps en lien avec les séquelles de leur AVC (Krueger et al., 2015). La récupération suite à un AVC peut être divisée en plusieurs périodes ou phases (Grefkes & Fink, 2020), qui jusqu'à récemment ne faisaient pas consensus au niveau de leur durée et de leur terminologie, entre autres. Afin de répondre à cet écart dans la science du rétablissement de l'AVC, la Table ronde sur le rétablissement et la réadaptation post-AVC, composée d'une soixantaine d'experts internationaux tant sur les plans scientifiques que cliniques, a été mise sur pied pour arriver à des consensus sur la manière d'élaborer, de mener et de rendre compte de la recherche sur la réadaptation et le rétablissement post-AVC (Bernhardt et al., 2016). Les experts siégeant à cette Table ronde sont arrivés à un consensus pour diviser les périodes de récupération post-AVC selon les phases suivantes : la phase hyper-aiguë représente les 24 premières heures suivant l'AVC; la phase aiguë est liée aux sept jours après l'AVC; la phase subaiguë précoce englobe les trois premiers mois post-AVC; la phase subaiguë tardive inclue la période de quatre à six mois suivant l'AVC; et la phase chronique représente la période excédant six mois post-AVC (Bernhardt et al., 2017).

La récupération de l'AVC est caractérisée par différents mécanismes complémentaires, qui peuvent être résumés par la récupération spontanée et la récupération induite par la thérapie (Cassidy & Cramer, 2017). Suite à la survenue de l'AVC, la majorité des personnes vivront un certain degré d'amélioration des fonctions et de la participation dans les activités qui est uniquement attribuable au temps suivant l'accident, ce qui représente la « récupération spontanée » (Kwakkel et al., 2003). Cette récupération spontanée est induite par l'AVC, qui entraîne au niveau du cerveau une série de réactions mises en évidence par les recherches sur modèles animaux (Carmichael, 2006; Murphy & Corbett, 2009). Ces réactions comprennent : une croissance accrue de synapses et de dendrites (Jones et al., 1996; Zhang et al., 2008), une augmentation des fonctions de remodelage des neurones et de l'angiogenèse (Ding et al., 2008; Seevinck et al., 2010), ainsi qu'une augmentation de l'excitabilité du cerveau (Que et al., 1999; Redecker et al., 2002). Cette série d'effets engendrés par l'AVC est particulièrement présente dans les premiers jours et les premières semaines suivant l'accident. Ces réactions favorisent la protection et la récupération des neurones et sont associées au phénomène de plasticité du cerveau, ou à son caractère adaptable (Overman & Carmichael, 2014), bien qu'elles résultent généralement en une récupération incomplète à elles-seules (Cassidy & Cramer, 2017). Ainsi, la récupération est généralement plus importante dans les trois premiers mois suivant l'AVC (Kwakkel et al., 2003; Nishimura et al., 2007). Toutefois, des améliorations peuvent également être notées à partir du $4^{ème}$ mois de l'AVC et par la suite (Cramer, 2007; Duncan et al., 2011; Korner-Bitensky, 2013), car bien que le cerveau soit revenu à une nouvelle stabilité en ce qui a trait à ses mécanismes endogènes de réparation, des changements sont toujours possibles au niveau de ses structures et de ses fonctions par d'autres mécanismes de récupération (Cassidy & Cramer, 2017). La récupération induite par la thérapie représente le degré de récupération lié à une intervention, qu'elle soit pharmacologique ou non. Ce type de récupération est, entre autres, lié au moment où les traitements sont débutés. Les dernières études recommanderaient que la thérapie soit débutée le plus tôt possible afin d'optimiser la récupération post-AVC (Sawaki et al., 2014; Wolf et al., 2010). De plus, la fréquence, l'intensité et la durée à laquelle les interventions sont offertes sont des facteurs influençant la récupération (Dignam et al., 2015; Dromerick et al., 2009). Les mécanismes neurophysiologiques associés à cette récupération induite par la thérapie seraient particulièrement liés à une augmentation de l'intégrité de la matière blanche (soit les gaines de myéline entourant les axones et qui favorisent la transmission des influx entre les neurones) et à une meilleure activation corticale des zones pour lesquelles une thérapie a été réalisée (Thimm et al., 2006; Yang et al., 2015). La récupération de l'AVC est donc caractérisée à la fois par des mécanismes de récupération spontanée et de récupération induite par la thérapie. La compréhension de ces mécanismes complémentaires est importante car elle permet de mieux saisir de quelle manière les conséquences de l'AVC pourraient évoluer dans les jours, les semaines et les mois suivant l'événement sur les fonctions organiques de la personne, mais également sur la réalisation de ses activités et sa participation en général.

Les soins de l'AVC

La récupération de l'AVC suit un processus autour duquel un continuum de soins et services pour l'AVC a été mis sur pied au Québec (Ministère de la santé et des services sociaux, 2017). Selon ce continuum, certains intervenants seront davantage impliqués dans certaines phases et moins dans d'autres. Parmi les intervenants retrouvés typiquement dans le continuum de soins de l'AVC figurent les professionnels médicaux (médecins spécialistes et de famille, infirmières et préposés aux bénéficiaires), les professionnels paramédicaux (ergothérapeutes, physiothérapeutes, orthophonistes, nutritionnistes, kinésiologues) et les professionnels psychosociaux (travailleuses sociales, psychologues, récréologues) (Teasell et al., 2020). En fonction des différentes phases de récupération, les individus ayant subi un AVC peuvent recevoir des services à domicile ainsi qu'au sein de différents milieux de soins, dont les suivants : les centres hospitaliers, les centres et les hôpitaux de réadaptation, les centres locaux de services communautaires (CLSC) et les centres hospitaliers de soins de longue durée (CHSLD). L'orientation, la trajectoire de soins et l’implication des différents intervenants seront choisies en fonction des besoins de la personne et de sa récupération qui se reflètera dans sa participation dans ses activités de la vie quotidienne (Ministère de la santé et des services sociaux, 2017).

La participation suite à un AVC

L’analyse de la participation dans cette thèse sera articulée en fonction de la Classification internationale du fonctionnement, du handicap et de la santé (CIF) (World Health Organization, 2001) et, plus particulièrement, avec les concepts clés liés à l’AVC (Geyh et al., 2004). La CIF offre une nomenclature et un langage commun pour décrire les composantes de la santé et du bien-être. Selon la CIF, le fonctionnement de la personne (et le handicap) est associé aux domaines des « fonctions organiques et des structures anatomiques » (ou « déficiences »), des « activités » (ou « limitations ») et de la « participation » (ou « restriction ») dans la société. La participation a été définie comme « l’implication d’une personne dans une situation de vie réelle » (World Health Organization, 2001; p. 10). Dans la CIF, l’état de santé (ex., présence d’une maladie), les facteurs personnels (ex., âge, genre, habitudes de vie) et les facteurs environnementaux (ex., soutien et attitudes de l’entourage) font également partie du contexte de la personne et entrent également en interaction avec les domaines présentés précédemment pour favoriser une analyse exhaustive du fonctionnement (World Health Organization, 2001).

L’AVC peut affecter les composantes du fonctionnement et du handicap de la personne, ainsi que ses facteurs contextuels. En se concentrant premièrement sur la personne, l’affection directe des structures du système nerveux par l’AVC et l’influence indirecte de l’AVC sur d’autres structures (ex., liées au mouvement dans le cas d’une hypotonie entraînant une subluxation de la tête de l’humérus), peut affecter plusieurs fonctions organiques de la personne. Celles-ci incluent les fonctions de l’appareil locomoteur et liées au mouvement (Arene & Hidler, 2009; Raghavan, 2015), les fonctions sensorielles et liées à la douleur (Gandhi et al., 2021; Tyson et al., 2008), les fonctions mentales (Kalaria et al., 2016), les fonctions de la voix et de la parole (Dickey et al., 2010; Plowman et al., 2012) ainsi que les fonctions génito-urinaires et reproductives (Grenier-Genest et al., 2017; Tuong et al., 2016). Cette affection de certaines fonctions peut mener à des limitations dans l’ensemble des activités de la vie quotidienne de la personne, dont la communication, la mobilité, les soins (ou l'entretien) personnels, les activités domestiques et les activités et relations avec autrui (Desrosiers, Rochette, et al., 2006; Matos et al., 2014; McCarthy et al., 2020). Ces limitations dans les activités peuvent amener des restrictions dans la participation dans des situations de la vie quotidienne, comme le fait de pouvoir réaliser ses activités quotidiennes dans le domicile occupé avant l'AVC (vs devoir changer d'environnement), de pouvoir occuper un emploi ou de s'engager dans une activité de bénévolat régulière, ou d'entretenir ou développer des relations interpersonnelles et intimes satisfaisantes (D'alisa et al., 2005; de Graaf et al., 2018). Les facteurs contextuels de la personne peuvent influencer et être influencés par le fonctionnement post-AVC. Par exemple, du côté des facteurs environnementaux (et plus particulièrement dans la catégorie des attitudes), une étude transversale menée auprès de 48 personnes ayant subi un AVC a montré que la perception des participants à l'égard du soutien offert par l'environnement social était un bon prédicteur de leur niveau de participation sociale (Foley et al., 2019). Finalement, certains facteurs personnels, tels que l'âge, le sexe, le genre, le niveau socioéconomique, les stratégies d'adaptation, les habitudes de vie et la présence de comorbidités peuvent influencer les retombées de la réadaptation et la participation suite à l'AVC (Chang et al., 2013; Desrosiers, Noreau, et al., 2006; Desrosiers et al., 2002; Visser et al., 2015; Ospel et al., 2023). En résumé, l'AVC peut affecter l'ensemble des domaines liés au fonctionnement et au contexte de la personne. Toutefois, son contexte et tout particulièrement ses facteurs environnementaux peuvent également influencer le processus et les retombées de la réadaptation pour la personne et doivent être pris en compte. La recherche portant sur la récupération et les traitements offerts aux personnes ayant subi un AVC s'est surtout centrée sur la récupération motrice, langagière et cognitive (Cassidy & Cramer, 2017). En effet, une revue systématique de la littérature récente a montré que de 1972 à 2018, un total de 1 410 et de 293 essais cliniques randomisés (ECR), ont été réalisés pour des interventions liées à la motricité et la cognition, respectivement, pour les personnes ayant subi un AVC (McIntyre et al., 2020). Bien que l'AVC puisse avoir un impact sur la sexualité (Grenier-Genest et al., 2017), la recherche portant sur ce sujet est encore à un stade embryonnaire en comparaison aux autres domaines déjà étudiés (Calabrò & Bramanti, 2014; Prior et al., 2019).

La sexualité

La sexualité est un concept vaste et complexe, en ce sens qu'elle englobe plusieurs composantes. Puisque ces termes seront utilisés à plusieurs reprises dans cette thèse, la sexualité, la santé sexuelle, les droits sexuels, les difficultés sexuelles et la réadaptation sexuelle sont définies ci-dessous.

Sexualité : La sexualité est « un aspect central de l'être humain tout au long de la vie qui englobe le sexe, les identités et les rôles de genre, l'orientation sexuelle, l'érotisme, le plaisir, l'intimité et la reproduction. La sexualité est vécue et exprimée dans des pensées, des fantasmes, des désirs, des croyances, des attitudes, des valeurs, des comportements, des pratiques, des rôles et des relations. Bien que la sexualité puisse inclure toutes ces dimensions, toutes ne sont pas toujours vécues ou exprimées. La sexualité est influencée par l'interaction de facteurs biologiques, psychologiques, sociaux, économiques, politiques, culturels, juridiques, historiques, religieux et spirituels » (World Health Organization, 2006; p. 5).

Santé sexuelle : La santé sexuelle est un « état de bien-être physique, émotionnel, mental et social par rapport à la sexualité ; elle ne correspond pas simplement en l'absence de maladie, de dysfonctionnement ou d'infirmité. La santé sexuelle exige une approche positive et respectueuse de la sexualité et des relations sexuelles, ainsi que la possibilité d'avoir des expériences sexuelles agréables et sûres, libres de coercition, de discrimination et de violence. Pour que la santé sexuelle soit atteinte et maintenue, les droits sexuels de toutes les personnes doivent être respectés, protégés et réalisés » (World Health Organization, 2006; p. 5).

Droits sexuels : L'application des droits humains à la sexualité et à la santé sexuelle constitue des droits sexuels. Les droits sexuels protègent les droits de chacun à s'épanouir et à exprimer sa sexualité et à jouir de sa santé sexuelle, dans le respect des droits d'autrui et dans un cadre de protection contre la discrimination (World Health Organization, 2006; p. 5).

Difficultés sexuelles : Les difficultés sexuelles que peut vivre une personne sont le résultat de l'inadéquation entre ses facteurs personnels (ex., fonctions et structures anatomiques), ses facteurs environnementaux (ex., présence de barrières architecturales, présence/absence de soutien social, attitudes de l'entourage) et les tâches et activités qu'elle veut réaliser (ex., déshabillage, hygiène excrétrice, activité sexuelle) qui viennent influencer négativement la participation dans les activités liées à la sexualité (Auger, 2020).

Réadaptation sexuelle : En l'absence de définition officielle, la réadaptation sexuelle a été définie par notre équipe de recherche comme « un ensemble d'interventions conçues pour optimiser le fonctionnement et réduire l'expérience du handicap pour les personnes qui éprouvent des difficultés au niveau de leur sexualité (comprenant le sexe biologique, l'identité de genre, les rôles significatifs, l'orientation et les activités sexuelles, l'érotisme, le plaisir, l'intimité et la reproduction) » (Auger, Filiatrault, Allegue, Thomas, et al., 2023; p. 3).

Intégration des différents termes : Lorsqu'une condition de santé ou une situation de la vie suscite des difficultés sexuelles chez la personne, celle-ci se retrouve plus ou moins apte à prendre part de manière satisfaisante aux différentes activités qui composent sa sexualité, ce qui affecte sa situation de santé sexuelle et la met dans un état de réponse incomplète à ses droits sexuels. La réadaptation sexuelle vise à mitiger la source ou les conséquences des difficultés sexuelles de manière à optimiser la participation dans les activités liées à la sexualité, ce qui favorise la santé sexuelle de la personne et favorise l'exercice de ses droits sexuels.

Au cœur de ces différents termes peuvent être situées les difficultés sexuelles, dont l'identification de la source et/ou de leurs conséquences sont essentielles à l'offre de services de réadaptation sexuelle susceptibles de favoriser la santé sexuelle des personnes. Quelques modèles ont été élaborés pour orienter la prise en compte des différentes difficultés sexuelles causées par une situation de handicap sur la sexualité. Parmi ceux-ci, le modèle de prise en charge des difficultés sexuelles post-AVC de Grenier-Genest et Courtois (2021) et le *Sexual Rehabilitation Framework* (Elliott et al., 2017) ressortent comme pertinents pour orienter les professionnels dans l'exploration des difficultés sexuelles et de leurs conséquences sur la participation liée à la sexualité.

Le *Sexual Rehabilitation Framework* (SRF) est un modèle de prise en charge interdisciplinaire des difficultés sexuelles liées à une condition de santé (Elliott et al., 2017). Initialement conçu pour la réadaptation sexuelle des personnes présentant une lésion médullaire, le SRF peut être adapté et utilisé pour toutes clientèles rencontrées en réadaptation. Le SRF propose une nomenclature en huit catégories permettant d'explorer les différents impacts que la condition de santé peut avoir sur la sexualité, soit : 1) le désir et les intérêts sexuels, 2) la fonction sexuelle; 3) la fertilité et la contraception; 4) les facteurs associés à la condition; 5) les conséquences motrices et sensorielles; 6) les conséquences sur la continence; 7) l'image de soi sexuelle et l'estime de soi; et 8) les enjeux liés au couple. Le SRF propose également une répartition des rôles de chaque profession selon chacune de ses catégories, ce qui peut contribuer à encadrer les intervenants et les milieux de réadaptation souhaitant améliorer leurs pratiques ou mieux intégrer la sexualité aux services qu'ils offrent déjà. En tant que professionnel de la réadaptation (et ceci représente mon opinion personnelle et professionnelle), je crois que les catégories du SRF doivent être utilisées avec nuance selon la clientèle en cause. En effet, dans le cas d'un AVC, les facteurs associés à la condition (catégorie #4) qui comprennent entre autres les comorbidités, les traitements médicaux reçus (ex., médication) et leurs effets secondaires, ainsi que les autres impacts de l'AVC, tels que les conséquences sur le fonctionnement cognitif et la communication, peuvent prendre une grande place dans l'explication des difficultés sexuelles, mais ne représenter qu'une des huit catégories. La question des émotions et de l'humeur y est également très peu abordée, bien que ces aspects soient importants à prendre en compte au niveau de la sexualité. De plus, certaines dimensions essentielles ne figurent pas dans le SRF, telle que la santé sexuelle et plus spécifiquement l'utilisation de protection lors des activités sexuelles. Malgré les nuances apportées ci-dessus, le SRF représente tout de même un cadre utile qui peut permettre de mieux guider les intervenants et les chercheurs dans leur compréhension et leur analyse des conséquences que l'AVC ou toute autre condition de santé peut avoir sur la sexualité.

Le modèle de Grenier-Genest et Courtois (2021) suggère d'analyser les conséquences de l'AVC sur la sexualité selon trois niveaux d'impacts, soit les niveaux primaires, secondaires et tertiaires. Ce modèle résulte de l'adaptation de celui de Foley et collaborateurs (1992) qui avaient pour but d'évaluer les conséquences de la sclérose en plaques sur la sexualité. Les impacts primaires représentent les conséquences directes de la lésion ou de la condition de santé sur les structures anatomiques ou les fonctions sexuelles qui sont impliquées dans la réponse sexuelle de la personne. La réponse sexuelle englobe toutes les réactions physiologiques (ex., phénomène d'engorgement sanguin menant à l'érection de ce certains tissus) et psychologiques (ex., désir sexuel) de la personne qui résultent en la complétion d'un cycle sexuel complet, soit le désir, l'excitation, le plateau, l'orgasme et la résolution (Kaplan, 1977; Masters & Johnson, 1966). Les impacts secondaires sont associés à des conséquences de la condition qui affectent des structures anatomiques ou des fonctions autres que sexuelles mais qui peuvent avoir une influence sur la participation dans les activités liées à la sexualité. Par exemple, le handicap lié à une hémiparésie affectant la fonction motrice de la personne agirait comme un impact secondaire de la condition sur la sexualité, dans la mesure où la personne ne serait plus capable de réaliser certaines caresses, d'adopter certaines positions ou d'utiliser certains objets (ex., condoms, bouteille de lubrifiant). Finalement, les impacts tertiaires sont associés aux conséquences psychosociales que la condition peut avoir sur la personne. En effet, les impacts tertiaires peuvent être associés aux aspects psychologiques de la personne, tels que son humeur, sa confiance en soi ou son image corporelle, ainsi qu'à ses interactions avec son environnement social, dont des partenaires actuels ou potentiels. Bien que le modèle de Grenier-Genest et Courtois (2021) a été utile dans mes propres travaux de recherche et dans ma pratique clinique, je considère que la flexibilité du modèle avec ses trois grandes catégories d'impacts peut susciter de l'incertitude chez des utilisateurs étant peu formés et expérimentés en lien avec la réadaptation sexuelle, ce qui pourrait nécessiter un cadre plus précis tel que le SRF pour s'initier à cette pratique.

L'intervenant ou le chercheur doit donc demeurer critique et attentif, peu importe le choix du modèle, par rapport aux aspects qui y sont abordés versus ceux qui y semblent négligés ou même mis de côté. La bonne compréhension des définitions de la sexualité et de certaines de ses autres composantes présentées plus tôt dans la thèse m'apparaissent comme essentielles et complémentaires au choix d'un modèle d'analyse, tels que le SRF (Elliott et al., 2017) ou le modèle de Grenier-Genest et Courtois (2021) pour bien comprendre l'impact d'une condition de santé sur la sexualité.

D'autres modèles moins spécifiques pourraient également être utilisés, tels que la CIF, le Modèle du développement humain – Processus de production du handicap (MDH-

PPH) (Fougeyrollas, 2010; Fougeyrollas et al., 1998) ou le Modèle canadien du rendement et de l'engagement occupationnel (MCREO) (Townsend & Polatajko, 2007). L'essentiel est que l'étudiant, l'intervenant ou le chercheur prenne en compte l'interaction des différents facteurs personnels, environnementaux et occupationnels dans l'évaluation des conséquences de la condition de santé, ou la situation de vie, sur la sexualité (Auger, 2020).

Impacts de l'AVC sur la sexualité

L'AVC peut causer des difficultés sexuelles chez 28 à 75% des personnes qui en subissent un, selon une revue de littérature rassemblant 21 études (Grenier-Genest et al., 2017). Selon l'étude longitudinale d'Azanmasso et collaborateurs (2016) où 67 personnes ayant subi un AVC ont chacune été pairées avec une personne contrôle ayant le même âge et le même sexe, les personnes post-AVC avaient un risque 15 fois plus élevé de présenter des dysfonctions sexuelles et un risque cinq fois plus élevé d'être inactifs sexuellement que les contrôles. Cette étude a également montré les dysfonctions sexuelles que l'AVC pouvait causer selon le sexe. Ainsi, les hommes étaient à risque plus élevé de dysfonction érectile et de trouble de l'éjaculation, qui pouvait soit être précoce ou retardée. Quant à elles, les femmes post-AVC étaient à risque de troubles du désir, de sécheresse vaginale, de troubles de l'orgasme et de dysparenuie (c.-à.-d., douleur ressentie durant et suite aux relations sexuelles) (Azanmasso et al., 2016). De plus, une étude transversale sur le sujet de la sexualité réalisée auprès de 199 personnes ayant subi un AVC a révélé une diminution au niveau : 1) du désir sexuel pour 57% des participants; 2) de l'excitation chez 77% des hommes et 45% des femmes; et 3) de la satisfaction liée aux activités sexuelles chez 49% des participants (Korpelainen et al., 1999). Bien que cette étude date d'il y a plus de vingt ans, elle demeure importante car elle représente l'un des échantillons les plus grands pour une étude portant sur la sexualité post-AVC. De plus, cette étude a montré que les partenaires des participants ayant subi un AVC avaient une diminution du désir et de la satisfaction sexuelle qui était semblable à celle de leurs conjoints, ce qui suggère que l'AVC a un impact sur les deux membres du couple (le cas échéant) et appuie l'importance d'intégrer également les partenaires dans le suivi de réadaptation sexuelle post-AVC (Korpelainen et al., 1999). La fonction sexuelle, liée à la réponse sexuelle, n'est toutefois qu'une des catégories des fonctions liées à la personne qui doivent être considérées pour analyser la participation des personnes dans leurs activités liées à la sexualité, ajoutées aux composantes liées à l'environnement physique et social, ainsi qu'à la participation dans les différentes activités de la vie quotidienne et les rôles significatifs, qui doivent être considérés (Elliott et al., 2017; Fougeyrollas, 2010). Le manque de consensus quant à l'étiologie des difficultés sexuelles en lien avec les caractéristiques de l'AVC renforce la pertinence d'utiliser un modèle d'analyse à multiples niveaux, tels que ceux présentés ci-dessus pour explorer les causes et les conséquences de ces difficultés. En effet, selon une revue de littérature rassemblant 21 études, il y aurait un manque de preuves pour associer les difficultés sexuelles à l'AVC en ce qui a trait à sa localisation spécifique ou à sa latéralité (Grenier-Genest et al., 2017). Un AVC causant des lésions à plusieurs zones cérébrales serait associé à un plus grand risque de difficultés sexuelles (Jung et al., 2008). Ce résultat doit toutefois être interprété avec prudence, puisque selon la revue de Grenier-Genest et collaboratrices (2017), une seule étude a porté sur cette question (Jung et al., 2008). Cette prudence devrait particulièrement être de mise pour les personnes ayant subi un AVC léger, qui affectent généralement une plus petite superficie du cerveau, car celles-ci pourraient tout de même présenter des difficultés sexuelles (Seymour & Wolf, 2014).

Le modèle de Grenier-Genest et Courtois (2021) permet de faire ressortir certains des impacts primaires, secondaires et tertiaires de l'AVC. Sur le plan des impacts primaires, l'AVC peut influencer négativement le désir (Jung et al., 2008; Korpelainen et al., 1999; Thompson & Ryan, 2009) et la fonction excitatrice et orgasmique (Akinpelu et al., 2013; Tamam et al., 2008; Yilmaz et al., 2017), bien que certaines études ont rapporté une sexualité post-AVC hyperactive comportant des risques plus élevés de comportements inappropriés (Brandstater, 1988; Mutarelli et al., 2006). Sur le plan des impacts secondaires, les impacts moteurs, tels que l'hémiparésie et la perte de fonction de la main (Bugnicourt et al., 2014; Seymour & Wolf, 2014; Yilmaz et al., 2015), la douleur (Jung et al., 2008), l'incontinence urinaire (Bekker et al., 2010; Nilsson et al., 2011), les troubles cognitifs (Vikan et al., 2021) et les troubles du langage (Lemieux et al., 2001; Stead & White, 2019) font partie des conséquences de l'AVC qui sont associées à une diminution de la participation aux activités liées à la sexualité. Finalement, les impacts tertiaires de l'AVC, tels que l'anxiété (Bugnicourt et al., 2014), la dépression (Seymour & Wolf, 2014; Yilmaz et al., 2015), la détérioration de l'image corporelle (Thompson & Ryan, 2009) peuvent affecter la sexualité de la personne ayant subi un AVC ainsi que celle des partenaires (Korpelainen et al., 1999). Une revue systématique de la littérature ayant rassemblé les résultats de 43 études qualitatives sur le vécu lié à la sexualité des personnes post-AVC a fait ressortir des similarités et des distinctions entre les personnes de différents sexes (McGrath et al., 2019). Premièrement, la plupart des couples participant aux études avaient rapporté un changement en lien avec leur relation en comparaison à la période précédant l'AVC. En effet, des impacts secondaires de l'AVC tels que les troubles cognitifs, l'aphasie et/ou la fatigue amenaient les couples à devoir répartir différemment ou réaliser différemment les tâches quotidiennes, les rôles et les responsabilités (souvent attribués initialement, selon les auteurs, en fonction des normes sociales attribuées aux rôles de genre) (McGrath et al., 2019). Pour les hommes, il était rapporté des préoccupations quant à la possibilité de réaliser des tâches et rôles exigeants physiquement, ce qui pouvait influencer leur perception d'être capables d'offrir protection et sécurité à leur famille. Pour les femmes, les études ayant porté sur le sujet ont soulevé que les conséquences de l'AVC affectaient leur perception de pouvoir remplir leurs rôles d'épouse, de mère et/ou de ménagère. Pour les deux sexes (les études recensées faisaient rarement la distinction entre le sexe et le genre), cette perturbation dans les rôles affectait l'estime de soi chez les personnes post-AVC et menait généralement à une charge augmentée sur les partenaires. L'impact de l'AVC était également rapporté par les partenaires, et particulièrement chez les femmes, qui rapportaient une déstabilisation dans les rôles lorsqu'ils et lorsqu'elles devaient passer du rôle de partenaire intime à celui de proche-aidant.e (McGrath et al., 2019). Les conséquences de l'AVC démontrent donc pouvoir affecter non seulement le fonctionnement des personnes au niveau de leur sexualité, mais également avoir un impact sur la réalisation des autres tâches significatives qui étaient attribuées aux personnes post-AVC. Ceci peut mener à une déstabilisation des rôles dans le couple qui elle peut mener à des enjeux dans le couple (dimension #8 du SRF), influencer leur intimité et potentiellement leur sexualité, ce qui soulève l'importance de considérer le fonctionnement global des personnes post-AVC et de l'impact de leur perte d'autonomie potentielle sur le partenaire dans l'exploration des difficultés qui pourraient être vécues par les deux membres du couple (ou un nombre plus grand selon la configuration de relation choisie).

En complément des influences primaires, secondaires et tertiaires de l'AVC sur la sexualité, la présence de difficultés sexuelles peut également nuire à d'autres sphères du fonctionnement de la personne. En effet, dans une étude transversale réalisée auprès de 77 personnes Nigériennes ayant subi un AVC, les participants présentant une dysfonction sexuelle avaient des scores significativement plus pauvres aux mesures de dépression et de qualité de vie que ceux n'ayant pas rapporté de dysfonction sexuelle (Akinpelu et al., 2013). Cette relation entre les difficultés sexuelles post-AVC et la dépression et/ou la qualité de vie a également été montrée dans les études transversales de Kim et collaborateurs (2008) et Korpelainen et collaborateurs (1999), réalisées respectivement auprès de 67 et 199 personnes ayant subi un AVC. En résumé, l'AVC est fortement susceptible d'affecter la sexualité des personnes qui en subissent un et cette influence est complexe à analyser considérant : 1) les différents impacts primaires, secondaires ou tertiaires de l'AVC ; et 2) que la manière de vivre sa sexualité est complexe et unique pour chaque personne. Une approche interdisciplinaire et centrée sur la personne est donc à privilégier en réadaptation sexuelle (Moreno et al., 2017), ce qui fait écho aux lignes directrices générales en réadaptation de l'AVC (Teasell et al., 2020), dont les recommandations spécifiquement liées à la sexualité qui sont présentées ci-dessous.

La réadaptation post-AVC

Cette thèse est particulièrement axée sur la « réadaptation de l'AVC », qui a été définie comme un « processus graduel, dynamique et orienté par des objectifs visant à permettre à une personne atteinte d'une déficience liée à un AVC d'atteindre son niveau fonctionnel physique, cognitif, émotionnel, communicatif et social optimal » (traduction libre, Canadian Stroke Best Practices, https://www.strokebestpractices.ca/recommendations/stroke-rehabilitation/definition-and-conisderations). La réadaptation n'est donc pas liée à un établissement en soi, mais est plutôt un processus ponctué de différentes activités qui débutent dès que la condition médicale de la personne est stable, moment où la personne peut établir ses propres objectifs, avec ses proches et ses intervenants pour recouvrer ses fonctions et atteindre une participation optimale (Teasell et al., 2020).

Selon Teasell et collaborateurs (2020), qui ont procédé à la sixième mise à jour des lignes directrices canadiennes en réadaptation de l'AVC, les connaissances scientifiques continuent à avancer dans le domaine, avec une estimation d'environ 2 400 nouveaux essais cliniques randomisés (ECR) réalisés depuis la dernière mise à jour publiée quatre ans plus tôt. Parmi ces ECR, il est estimé que plus de 60% d'entre eux auraient été consacrés à l'étude de la récupération motrice, particulièrement au niveau du membre supérieur ou inférieur parétique ou plégique (Teasell et al., 2020). Bien que cet avancement des connaissances soit important, les autres conséquences de l'AVC sur la personne et sur ses activités, telles que la fatigue (Staub & Bogousslavsky, 2001), le retour au travail (Corr & Wilmer, 2003) et la sexualité sont sous-adressées dans la recherche. Une étude qualitative récente réalisée dans un centre de réadaptation montréalais auprès de 15 intervenants et de cinq clients en réadaptation post-AVC a montré que la priorité en réadaptation subaiguë (majoritairement dans la phase précoce) était donnée aux fonctions, aux tâches et aux activités liées à la sécurité et la survie, dont la marche, la fonction du membre supérieur et l'alimentation, au détriment de celles liées à la qualité de vie, dont les loisirs et la sexualité et ce, tant chez les intervenants que chez les clients (Auger et al., 2020). Bien qu'il puisse être compréhensible que les notions de survie soient abordées en priorité, la problématique est que les fonctions, les tâches et les activités liées à la qualité de vie sont souvent abordées insuffisamment ou pas du tout en réadaptation post-AVC. Une étude transversale sur les besoins répondus ou non par la réadaptation, réalisée auprès de 135 personnes ayant subi un AVC dont la moyenne d'âge était de 52 ans (écart-type : 9,0) a relevé que les quatre besoins non répondus rapportés les plus fréquemment étaient : 1) recevoir de l'information sur l'AVC; 2) l'épanouissement (ou la stimulation) au niveau intellectuel; 3) l'aide à la gestion financière; et 4) le soutien en lien avec les activités qui n'étaient pas liées aux soins personnels (Low et al., 2003). Dans une autre étude transversale réalisée auprès de 799 personnes ayant subi un AVC vivant au Royaume-Unis, 49% des participants avaient un ou plusieurs besoins non répondus par la réadaptation (médiane : 3, étendue de 1 à 13) (McKevitt et al., 2011). Entre autres, parmi les participants qui étaient en couple au moment de l'étude, 145 (42%) ont rapporté avoir expérimenté une diminution de la qualité de leur relation intime depuis l'AVC et 9% auraient souhaité recevoir des services ou de l'information au niveau de la sexualité et de l'intimité (McKevitt et al., 2011). Les résultats des études présentés ci-dessus doivent toutefois être interprétés de manière nuancée, car elles révèlent tout de même que plus de 50% des participants percevaient que leurs besoins avaient été comblés par la réadaptation. Il peut effectivement y avoir une discordance entre les différentes priorités des clients et des intervenants durant la réadaptation (Brown et al., 2014; Talbot et al., 2004; Tistad et al., 2012), mais il pourrait également y avoir de nouveaux besoins qui surviennent chez les personnes ayant subi un AVC suite à leur réadaptation (Kristensen et al., 2016) considérant que plusieurs études qui impliquent des personnes ayant subi un AVC le font dans la phase chronique de la récupération de l'AVC (Chen et al., 2019; Nilsson et al., 2017). Ainsi, la présente critique se veut plutôt un argumentaire pour soutenir l'amélioration de la qualité des services de réadaptation post-AVC portant davantage sur des aspects de qualité de vie, afin de répondre à un plus grand nombre de besoins exprimés par les personnes ayant subi un AVC, incluant ceux liés à la sexualité.

La réadaptation sexuelle post-AVC

Les lignes directrices canadiennes en réadaptation de l'AVC stipulent que la sexualité doit être abordée avec chaque personne qui en est affectée (Mountain et al., 2020). Plus précisément, les lignes directrices recommandent que les personnes ayant subi un AVC et leurs partenaires reçoivent de l'information sur le fait que l'AVC peut influencer leurs relations et leur sexualité. Cette information devrait être offerte durant le suivi de réadaptation post-AVC, dans un format qui respecte les capacités et la littératie de chaque personne et, idéalement, en utilisant des méthodes variées (ex., écrit, verbal). De plus, il est recommandé que les personnes puissent reçoivent, au besoin, de l'éducation en lien avec la manière dont leur AVC pourrait influencer leur sexualité, ainsi que des conseils et des stratégies pour se réengager dans leur sexualité d'une manière qui est satisfaisante. Finalement, les lignes directrices stipulent, pour les personnes ayant subi un AVC ayant des difficultés « persistantes », qu'elles soient orientées vers des professionnels spécialisés en santé sexuelle pour recevoir des traitements plus ciblés (Mountain et al., 2020). La recommandation d'inclure la sexualité aux services offerts aux personnes ayant subi un AVC fait également partie des lignes directrices américaines (Winstein et al., 2016), britanniques (National Institute for Health Care Excellence, 2013) et australiennes (Stroke

Foundation, 2022). Les lignes directrices sont également cohérentes avec les résultats de quelques études portant sur les besoins des personnes ayant subi un AVC en ce qui a trait à la sexualité. En effet, qu'ils aient besoin de recevoir des services en lien avec la sexualité ou non durant leur réadaptation, les personnes ayant subi un AVC participant dans une étude qualitative québécoise ont rapporté qu'ils considéraient pertinent de se faire proposer des services de réadaptation sexuelle par leurs intervenants (Auger et al., 2020). Ceci est corroboré par une autre étude d'implantation menée au Québec auprès de 28 personnes ayant subi un AVC soulignant l'ouverture des participants à se faire proposer des services de réadaptation sexuelle (Auger, Pituch, et al., 2021). De plus, Stein et collaborateurs (2013) ont montré, dans leur étude transversale réalisée auprès de 37 personnes ayant subi un AVC, que 71% d'entre elles considéraient la sexualité comme un sujet important à aborder en réadaptation et que 81% ont rapporté ne pas avoir reçu assez d'information sur le sujet (plus de 90% de ces derniers disaient n'avoir reçu aucune information). Les études portant sur les besoins des personnes ayant subi un AVC avec un échantillon de plus de 30 personnes sont rares. Toutefois, McGrath et collaborateurs (2019) ont réalisé une revue systématique incluant 43 études qualitatives sur le sujet rassemblant un total de 649 personnes ayant subi un AVC (étendue de 1 à 125). La synthèse des résultats de la revue a fait ressortir deux grands thèmes, soit : 1) que les personnes ayant subi un AVC considèrent toujours la sexualité comme un sujet important après un AVC, bien que celle-ci soit différente; et 2) que la sexualité est souvent mise sous silence. Ce deuxième thème est particulièrement important pour la suite de cette thèse. En effet, la revue de littérature a fait ressortir que les personnes ayant subi un AVC considèrent la sexualité comme un sujet tabou, qu'elles ne sont pas confortables et/ou ne savent pas comment en parler avec leur partenaire, et que les intervenants ne soulèvent pas le sujet de la sexualité (McGrath et al., 2019). Cet écart entre les lignes directrices en réadaptation post-AVC et les services qui sont reçus par les usagers est appuyé par plusieurs études sur les pratiques professionnelles par les intervenants de la réadaptation post-AVC. En effet, une revue systématique comprenant 103 études sur les pratiques cliniques des intervenants travaillant auprès d'une clientèle avec des conditions chroniques, telles que l'AVC (n = 2/113 études spécifiques à cette condition de santé), a montré que 85% des intervenants n'intégraient pas la sexualité à leur pratique courante. Ces résultats sont appuyés par une étude transversale internationale plus récente réalisée auprès de 958 intervenants en réadaptation post-AVC, qui a également montré que près de 77% d'entre eux n'abordaient pas la sexualité avec leur clientèle (Low et al., 2022). Il importe de se pencher sur les facteurs qui mènent à cet écart entre les lignes directrices en réadaptation de l'AVC et la faible offre de services en réadaptation sexuelle.

Facteurs influençant l'offre de services de réadaptation sexuelle

De nombreuses études ont été réalisées pour explorer et mieux comprendre les facteurs qui influencent l'offre de services de réadaptation sexuelle par les intervenants (de réadaptation ou autres) à leurs clients, incluant les personnes ayant subi un AVC. Les facteurs personnels des intervenants, tels que la perception d'un manque de connaissances et d'habiletés, le besoin de formation et un certain inconfort lié à la sexualité ont été mis en évidence dans la revue systématique de McGrath et collaborateurs (2021) comprenant 103 études. De plus, selon une autre revue systématique comprenant huit études, certains facteurs sociodémographiques liés aux personnes ayant subi un AVC, tels que la différence d'âge ou de genre entre l'intervenant et la personne post-AVC, les différences langagières et/ou culturelles par rapport aux intervenants, ainsi que la peur de froisser la personne diminuent la propension des intervenants à aborder la sexualité avec eux (Dyer & das Nair, 2013). L'étude qualitative de Richards et collaborateurs (2016), réalisée auprès de dix intervenantes en réadaptation s'identifiant comme femmes n'a toutefois pas fait ressortir les différences de genre parmi les facteurs influençant les pratiques cliniques liées à la sexualité, ce qui soulève l'hypothèse de disparités entre ce que des personnes d'un même genre pourraient considérer comme un facteur d'influence dans leur travail. La revue systématique de McGrath et collaborateurs (2021) a également démontré que, en général, il n'y aurait pas de différence selon le genre parmi les intervenants à savoir si les femmes ou les hommes initieraient plus ou moins souvent d'aborder la sexualité dans leur pratique (Akinci, 2011; Hyland & Mc Grath, 2013; Julien et al., 2010; Kazukauskas & Lam, 2010; Nicolai et al., 2013; Stead et al., 2003). Toutefois, quelques études ont montré que les intervenants hommes rapporteraient une autoévaluation plus élevée de leurs connaissances et de leur niveau d'aise en lien avec la sexualité (Abu Ali et al., 2018; Haboubi & Lincoln, 2003; Low et al., 2022; Salehian et al., 2017; Wilson & Dibble, 1993), et seraient plus susceptibles de se faire poser des questions en lien avec la sexualité par leur clientèle

(Haboubi & Lincoln, 2003; Lewis & Bor, 1994), en comparaison aux intervenantes femmes . Finalement, une étude qualitative réalisée auprès de dix intervenants en réadaptation post-AVC a montré que des facteurs environnementaux, tels que le manque de ressources matérielles (ex., outils cliniques), le pauvre accès à des intervenants spécialisés en sexualité et la surcharge de travail affectent négativement l'intégration de la sexualité aux pratiques cliniques (Richards et al., 2016). Les facteurs affectant les pratiques cliniques des intervenants sont ainsi d'origines multiples. Ainsi, tel que suggéré par McGrath et collaborateurs (2021), la complexité caractérisant les facteurs d'influence des pratiques cliniques liées à la sexualité suggère que ceux-ci devraient être abordés par des interventions complémentaires pour arriver à améliorer les services offerts aux personnes ayant subi un AVC. Considérant que le changement des pratiques est un phénomène complexe (Kelly & Barker, 2016; Rowe et al., 2018), il importe de s'appuyer sur des données probantes afin d'établir si les services de réadaptation sexuelle peuvent effectivement être implantés et/ou mener à une amélioration de la santé sexuelle. Afin de répondre à cet objectif, une revue systématique de la littérature portant sur les interventions en réadaptation sexuelle auprès de la clientèle post-AVC a été réalisée et publiée dans la revue *Topics in Stroke Rehabilitation* et présentée ci-dessous avec des modifications minimes (Auger et al., 2020).

Interventions used by Allied Health Professionals in Sexual Rehabilitation After Stroke: a Systematic Review

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Abstract

Background: Although sexuality can be affected post-stroke, few individuals receive sexual rehabilitation because of clinicians' lack of knowledge regarding evidence-based interventions.

Objective: To document and describe the best available evidence supporting interventions that target post-stroke rehabilitation of sexuality.

Methods: This systematic review searched the databases Medline, Embase, Psycinfo, CINAHL, Web of science, PEDRO and OTSeeker up to May 29, 2020. Inclusion criteria were: published studies with a sample composed of ≥ 50% stroke clients and describing an intervention that could be applied by an allied health professional. Data was extracted according to the PRISMA guidelines by two independent reviewers. Interventions were described according to the Template for intervention description and replication checklist.

Results: Among the 2446 articles reviewed, 8 met the inclusion criteria. Two randomized controlled trials (RCT) and one non-RCT showed improvement in sexual functioning and satisfaction following a 30-45-minute structured rehabilitation program. Two other RCT showed significant improvement in sexual functioning with physical therapy oriented towards 1) structured physical and verbal sexual counselling and 2) pelvic floor muscle training. Three studies showed that interdisciplinary sexual rehabilitation improved satisfaction and sexual functioning; implementation of an interview script for clinicians improved the proportion of clients who addressed sexuality from 0 to 80% in 10 months; and two-day couple retreats improved perceived intimacy between couples.

Conclusions: This review highlights promising interventions that could orient future research and improve the access to sexual rehabilitation services for post-stroke, with structured sexual rehabilitation and pelvic floor muscle training being the most strongly supported.

Keywords

Sexuality, stroke, rehabilitation, clinicians, intervention

Introduction

Sexuality is an integral part of people's existence and is related to quality of life (McCabe et al., 2000; Robinson & Molzahn, 2007). According to the World Health Organization, sexuality is defined as "a central aspect of being human throughout life that encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships" (World Health Organization, 2006). Stroke affects sexuality in more than 50% of individuals (Korpelainen et al., 1999) and can lead to many sexual difficulties, such as erectile dysfunction, loss of vaginal lubrication or a decrease in desire (Grenier-Genest et al., 2017). Of the approximately 10 300 000 persons around the world who survive a stroke each year (Strong et al., 2007), more than five million may present sexual difficulties. Few will have the opportunity to address them during their rehabilitation (McGrath et al., 2018) even though this is likely to be among their priorities (Stein et al., 2013). Addressing sexuality is also part of best practices guidelines in stroke rehabilitation in several countries, including Canada (Mountain et al., 2020), Australia (Stroke Foundation, 2019) and the United States (Winstein et al., 2016). Therefore, an important gap can be observed between clients' needs and actual clinical practices in stroke rehabilitation.

Many factors influence clinicians' position on discussing sexuality with clients in their practice, including concern about their own knowledge and skills regarding related interventions, lack of written information (e.g. leaflets, posters) and the absence of specific policies or guidelines on the subject (Dyer & das Nair, 2013). Considering these factors, it can be hypothesized that clinicians are unaware of existing evidence-based interventions that could be used with stroke clients.

Two reviews on the topic of evidence-based intervention in sexual rehabilitation after a stroke have been published recently. A literature review conducted by Grenier-Genest and collaborators (2017) on the subject of stroke and sexual functioning, with the secondary objective of reviewing intervention methods, showed that very few studies have been conducted on sexual rehabilitation interventions. However, the review was limited to a single bibliographic database (c.-à-d., Pubmed). A Cochrane review published in 2020 on interventions for sexual dysfunction following stroke was conducted by Stratton and collaborators (2020). After an extensive search in 18 bibliographic databases, only three papers met their inclusion criteria, notably to be controlled clinical trials. The review may have neglected relevant intervention studies in an earlier stage of development, considering that this is an emerging research topic. Furthermore, since one of the three studies included focused on a pharmacological intervention, there is clearly a lack of knowledge available to inform the practice of allied health professionals such as occupational therapists, physical therapists, nurses or speech-language pathologists.

The aim of this study was to document and describe the best available evidence supporting interventions that target post-stroke rehabilitation of sexuality.

Materials and methods

This study was reported using the Preferred reporting items for systematic review and meta-analysis (PRISMA) protocols, as described by Moher and collaborators (2015). The research team consisted of four occupational therapists, an American Library Association accredited librarian specialized in rehabilitation and a master's student in occupational therapy.

Eligibility criteria

In order to be included in the present review, a study needed to report intervention outcomes regarding sexuality after stroke. The study could use qualitative, quantitative or mixed methods, and participant selection criteria needed to include having experienced a stroke. At least half of the total sample needed to be stroke survivors, although it could include participants with various other conditions if the study met our other criteria. Studies addressing only medical or pharmacological interventions were excluded, as this review focused on sexual rehabilitation interventions offered by allied health professionals. However, methods used by physicians or other medical specialists that had the potential to be used by rehabilitation clinicians (e.g. educational or exercise sessions) were included. Regarding intervention outcomes, only those related to sexuality (e.g. function, satisfaction, behaviors, services) were addressed. Only papers written in English or French were considered.

Search strategy

The search strategy was developed collaboratively with the support of the second author who is a accredited librarian. A combination of keywords and descriptors were searched in MEDLINE, Embase, PsycINFO and CINAHL. Additional searches using only the keywords “Sexuality” and “Stroke” were conducted in Web of Science, PEDro and OTseeker since the search strategy could not be used for these. The articles were also retrieved using references lists and manual searches in relevant journals. 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 showed 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. After duplicates were removed, the first and second authors carried out a blinded selection, based on the inclusion and exclusion criteria. This process involved an initial screening of the title and abstract of each article. Most disagreements between reviewers were resolved by one consensus-based discussion, in some cases followed by consultation with the last author who acted as a third reviewer. To standardize the process after the initial search, the two reviewers analyzed the titles and abstracts from the database CINAHL and compared their results. Once their respective perceptions of the data had been shared and standardized, the two reviewers analyzed the remaining data. A second screening of complete article content was then conducted by the first and last authors. Figure 1 depicts the PRISMA flow chart of this systematic review. Data from the selected articles was then extracted by the first author.

Risk of bias in individual studies

Risk of bias and quality of the intervention studies was not assessed using a standardized method but the studies were ranked using the *Oxford Centre for Evidence-Based Medicine* (OCEBM) levels of evidence (see Table 1 – 4th column). The OCEBM levels of evidence range from one to five, and the closer to one, the stronger the conclusions that can be drawn based on the study findings. The intervention methods were described using the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al., 2014) in Table 2.

Synthesis of results

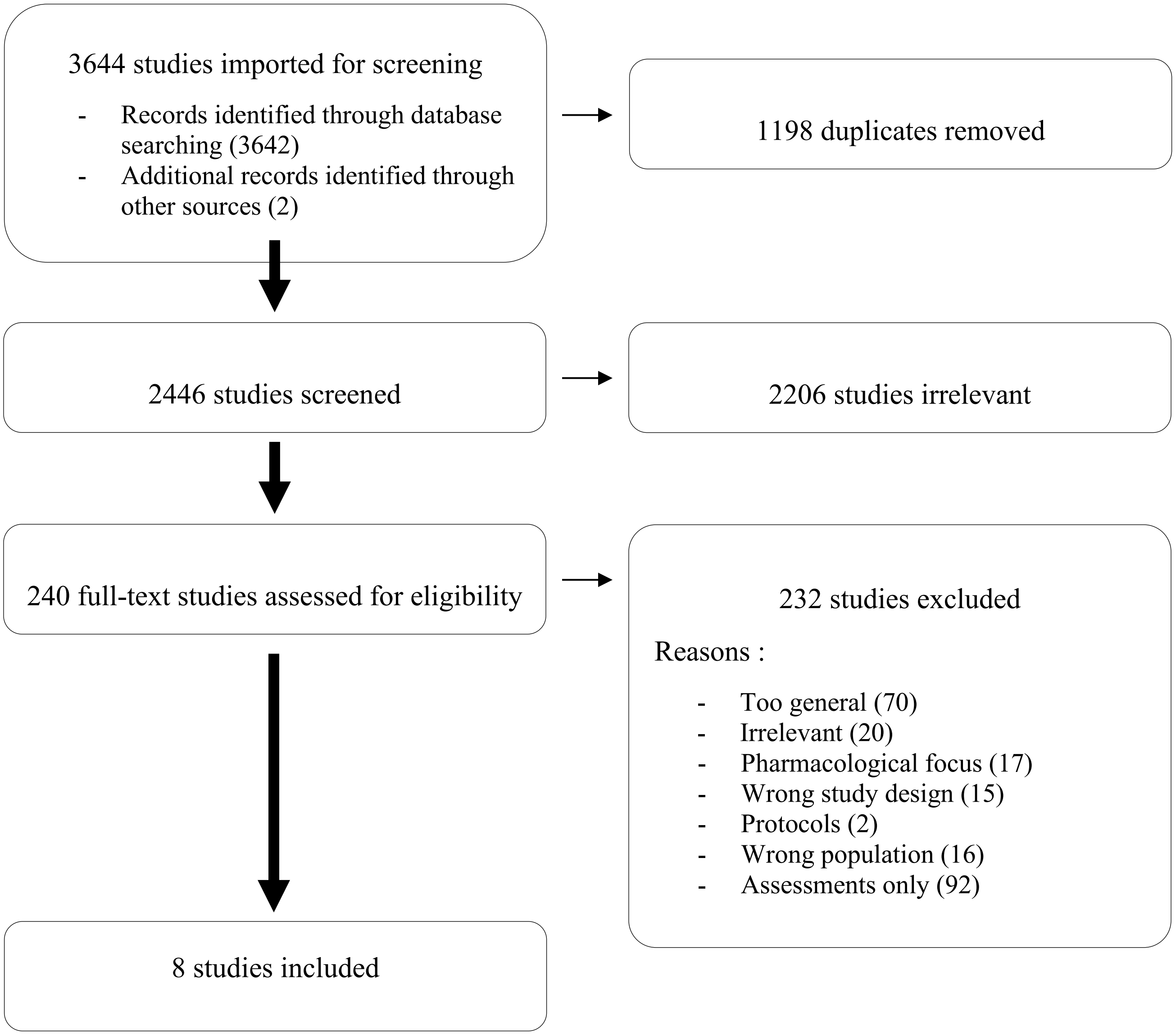
Intervention methods and their outcomes were categorized according to the *Evidence-Based Classification of Occupational Therapy Interventions* (McColl & Law, 2013). When extracting study and intervention characteristics, the first author associated each method to the eight types of interventions described by McColl and Law (2013) targeting either the person (training, education, skill development), the occupation (task adaptation, occupational development) or the environment (environmental modification, support provision, and support enhancement). For each intervention method included in the review, the categories of intervention and the specific types are presented in Table 1 (7th column) in order of importance, the first being the most contributing to the intervention.

Results

Study selection

A total of 2 446 articles remained after duplicates were removed from the initial database search and manual searches (see Figure 1). After irrelevant articles were excluded, eight matched the inclusion criteria. Description and results of each of the studies, including description of the participants, are presented in Table 1, and details about each intervention are presented in Table 2.

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



Risk of bias within studies

Among the intervention studies, four were randomized controlled trials (Ng et al., 2017; Sansom et al., 2015; Tibaek et al., 2015; Vajrala et al., 2019). The others were: a non-randomized controlled trial (Song et al., 2011), a cohort study (Stead & White, 2019), a case study (Thomas, 2016) and a prospective study (Guo et al., 2015). The level of evidence of these studies varied and is reported in Table 1.

Tableau 1. – Characteristics and results of studies that addressed sexual rehabilitation (intervention) after a stroke (n=8) presented in order of the Results section

Author, year	Country	Design	Level of evidence^A	Sample	Intervention	Type of intervention*	Study objectives	Main results
(Song et al., 2011)	South Korea	Non-randomized controlled trial	2b	23 stroke clients (19 males and 4 females) and their partners. EXP group: 12 couples, CTRL group: 11 couples. Mean subjects' age: 57.89 ± 6.59 years. Number of days post-stroke was not provided but clients were recruited during inpatient rehabilitation.	Sexual rehabilitation intervention program	PERSON and OCCUPATION <u>Education</u>, task adaptation	Examine whether a sexual rehabilitation intervention program was effective in terms of sexual knowledge and satisfaction and frequency of sexual activity at 1 month after intervention.	Sexual satisfaction score in the EXP group was significantly higher than that in the CTRL group (23.63 ± 8.20 versus 16.23 ± 11.82, Z = −2.29, p = 0.02); Frequency of sexual activity (e.g. masturbation, oral sex, sexual intercourse) in the EXP group was significantly higher than that in the CTRL group (4.29 ± 2.53/month versus 1.86± 1.61/month, F = 14.77, p < 0.001); Frequency of sexual intercourse in the EXP group was significantly higher than that in the CTRL group (3.31 ± 2.70/month versus 1.18 ± 1.22/month, F = 11.51, p = 0.001); Sexual knowledge was higher in the EXP group but not significantly different from the CTRL group (10.46 ± 2.77 versus 9.32 ± 3.73; Z = −1.19, p = 0.24).
(Sansom et al., 2015)	Australia	Randomized controlled trial	2b	12 participants (10 clients and 2 partners) were randomly assigned to an EXP (n=4 clients) or CTRL (n=6 clients) group. The mean age of participants was 66.3 years (range: 34–88 years), with an equal number of males and females. Most (67%) of the participants were married or had a partner. Number of days post-stroke was not provided but clients were recruited during inpatient rehabilitation.	Structured sexual rehabilitation program	PERSON and OCCUPATION <u>Education</u>, task adaptation	Assess the effectiveness of a structured sexual rehabilitation program combined with the use of written material compared to the use of written material only, and to evaluate the impact of both interventions on sexual and psychological function in an Australian stroke cohort.	There was no significant difference between the EXP and CTRL groups (p = 0.255) in terms of sexual functioning according to the Change in Sexual Functioning Questionnaire (CSFQ-14) (Keller et al., 2006) six weeks after the intervention. There was a trend toward improvement in both groups in sexual functioning.

EXP: Experimental; CTRL: Control; A: According to the Oxford Centre for Evidence-based Medicine – Levels of Evidence (OCEBM; (Howick et al., 2009)); *According to the eight types of intervention in occupational therapy (McColl & Law, 2013): training, education, skill development, task adaptation, occupational development, environmental modification, support provision, and support enhancement; The <u>underlined</u> mode of intervention is considered the major intervention and the other modes are minor

Tableau 1 (continued)

Reference	Country	Design	Level of evidence^A	Sample	Intervention	Type of intervention*	Study objectives	Main results
(Ng et al., 2017)	Australia	Randomized controlled trial	1b	68 stroke survivors were included at baseline: 35 in the EXP group – mean age 62.0 ± 17.3) and 33 in the CTRL group – mean age 66.8 ± 16.7). Number of days post-stroke was not provided but clients were recruited during inpatient rehabilitation.	Individualized sexual rehabilitation program	PERSON and OCCUPATION Education, task adaptation	To assess the effectiveness of a comprehensive structured sexual rehabilitation program compared with written information alone, on sexual and psychological function, and on functional independence and quality of life in a stroke cohort	6 weeks after the intervention, both groups improved sexual functioning and no difference (p = 0.758) was found between the EXP and CTRL groups with the Change in Sexual Function Questionnaire (CSFQ-14) (Keller et al., 2006). At 6 months, the only difference in the sexuality assessment was that CTRL participants had higher scores in the arousal items (p = 0.027).
(Vajrala et al., 2019)	India	Single - blinded randomized controlled trial	1b	40 persons with stroke were divided equally between the EXP and CTRL groups. EXP group/ CTRL group. Age (years)* 40.2 / 42.1; Gender (male/female) EXP : 10/10, CTRL : 12/8; Time post stroke before recruitment* (in Months) 5.85 / 4.5	structured physiotherapy and verbal communication	PERSON and OCCUPATION skill development, Education, training, task adaptation	To investigate the role of structured physiotherapy and verbal communication in improving Physical dimensions and on the Psychological dimensions of sexual health after a stroke	The mean of differences between pre-test and post-test CSFQ-14 in EXP group is 22.7 SD +/-9.65 and that of CTRL group is 3.5 SD +/-5.37 (t = 8.9, p < 0.05), which indicates a significant increase in the sexual health in participants from the EXP group.
(Tibaek et al., 2015)	Denmark	Randomized controlled trial	1b	30 males with lower urinary tract symptoms after stroke. EXP group: 16 male – 68 years-old [57–73]. CTRL group : 15 male - 70 years-old [64–75]. All participants: median age: 68 years; interquartile range: 60–74 years. Time since last stroke: EXP group: 55 days (50-63); CTRL group: 65 days (50-87)	Pelvic floor muscle training	PERSON Training, education	evaluate the effect of pelvic floor muscle training (PFMT) on measured erectile function as an indicator of sexuality in men with LUTS after stroke.	The results showed a significant improvement in the EXP group from pre-test to post-test (p = 0.04), but not in the CTRL group (p = 0.32) according to the International Index for Erectile Function (IIEF-5) (Rosen et al., 1999). There were no significant differences between EXP group and CTRL group either at pre-test (p = 0.97) or at post-test (p = 0.84). At 6-month follow-up, the results showed no significant difference between groups (p = 0.08) or within groups (pre-test versus follow-up; EXP: p = 0.8, CTRL: p = 0.18). However, IIEF-5 sum scores within pre-test and follow-up were lower in the CTRL group (EXP: 15/25; CTRL: 11/25).

EXP: Experimental; CTRL: Control; A: According to the Oxford Centre for Evidence-based Medicine – Levels of Evidence (OCEBM; (Howick et al., 2009)); *According to the eight types of intervention in occupational therapy (McColl & Law, 2013): training, education, skill development, task adaptation, occupational development, environmental modification, support provision, and support enhancement; The underlined mode of intervention is considered the major intervention and the other modes are minor

Tableau 1 (continued)

Reference	Country	Design	Level of evidence[A]	Sample	Intervention	Type of intervention*	Study objectives	Main results
(Thomas, 2016)	United States	Case study	4	a 69-year-old, married, Hispanic heterosexual woman who suffered a right stroke. Outpatient rehabilitation began around 24 days post-stroke.	Interdisciplinary sexual rehabilitation	OCCUPATION, ENVIRONMENT and PERSON Education, skill development, task adaptation, training, environmental modification, support enhancement	Describe the process and outcomes of the client's rehabilitation	After 5 weeks of therapy, the participant met all her objectives. The couple's Canadian Occupational Performance Measure (Law et al., 1994) (performance and satisfaction) went from 4/20 to 11/20, showing a 175% improvement in the total score for intimate activities. Significant changes were also seen on the Quality of Sexual Function (QSF) Scale (Heinemann et al., 2005). The couple's overall score was initially 96/160 and 61/160 at follow-up, demonstrating a 36% reduction at the QSF where a higher score means poorer quality of sexual function. There were no significant changes in the client's scores on the Stroke Impact Scale (Duncan et al., 1999).
(Guo et al., 2015)	Canada	Action research using a Plan-Do-Study-Act methodology	4	Stroke rehabilitation clients and healthcare professionals from an inpatient rehabilitation facility. Age: Not specified	Implementation of procedures for provision of sexuality services.	ENVIRONMENT Support enhancement, environmental modification	To provide all stroke clients in inpatient rehabilitation with the opportunity to discuss sexual health concerns with healthcare providers	At baseline (1-3 months), 0% of clients addressed sexuality. At the end of the implementation period (10 month), the monthly proportion of stroke clients who had addressed sexuality during their rehabilitation was 80%. 100% was attained at 9 months.
(Stead & White, 2019)	United States	Cohort study	4	11 Couples with one partner who has aphasia. Sample included people who were between 5 months to 19 years post-stroke	the Aphasia Couples Retreat	PERSON and ENVIRONMENT Education, skill development, support provision, support enhancement	Describe the intervention and report preliminary outcomes (not clearly stated in the article)	Post-retreat surveys indicated that, overall, participants reported feeling refreshed and with a better connection to their partners.

EXP: Experimental; CTRL: Control; A: According to the Oxford Centre for Evidence-based Medicine – Levels of Evidence (OCEBM; (Howick et al., 2009)); *According to the eight types of intervention in occupational therapy (McColl & Law, 2013): training, education, skill development, task adaptation, occupational development, environmental modification, support provision, and support enhancement; The underlined mode of intervention is considered the major intervention and the other modes are minor.

Synthesis of results

Among the intervention studies, four presented the impact of a structured sexual rehabilitation program (Ng et al., 2017; Sansom et al., 2015; Song et al., 2011; Vajrala et al., 2019), one a case of interdisciplinary sexual rehabilitation (Thomas, 2016), one the implementation of a systematic sexuality-related discussion (Guo et al., 2015) and two the impact of a specific intervention, i.e. pelvic floor muscle training (Tibaek et al., 2015) and a retreat for couples in which one is aphasic (Stead & White, 2019).

Two randomized controlled trials (RCT) (Ng et al., 2017; Sansom et al., 2015) and one non-randomized controlled trial (Song et al., 2011) assessed the effect of a sexual rehabilitation program consisting of one 30-45 minute session with a clinician offering sexual counselling and education targeting a stroke clientele. The program followed the sexological intervention model PLISSIT (Annon, 1976), which stands for Permission, Limited Information, Specific Suggestions, Intensive Treatment and offers guidelines to clinicians in addressing sexuality in their practice. Sample sizes varied between studies from very small (n=4/group) to moderate (n=38/group). The sexual rehabilitation program was compared to offering written documentation regarding sexuality after a stroke (Ng et al., 2017; Sansom et al., 2015) or no intervention in Song and collaborators' (2011) study. The two RCT led to improved sexual function between baseline and six weeks post-intervention as measured by the Change in Sexual Function Questionnaire (CSFQ-14) (Keller et al., 2006) but no between-group difference was found (Ng: $p = 0.758$; Sansom: $p = 0.255$). A significant difference between experimental and control participants was observed in the study by Song and collaborators (2011) for sexual satisfaction ($p = 0.02$), frequency of sexual activity ($p < 0.001$) and frequency of sexual intercourse ($p = 0.001$) one month after the intervention.

In the randomized controlled trial by Vajrala and collaborators (2019), a physical therapist provided skill development (e.g. transfer and bed mobility) and physical training contextualized to sexuality combined with verbal counselling based on the PLISSIT model (Annon, 1976) to 20 stroke clients in inpatient rehabilitation for one hour per day over a two-week period. Compared to the 20 control participants who received the usual rehabilitation services, sexual functioning improved significantly ($t = 8.9$, $p < 0.05$) in the experimental group six months after the intervention.

The twelve-week program of pelvic floor muscle training (PFMT) for men conducted by Tibaek and collaborators (2015) combined weekly group sessions and daily individual exercise. This program led to a statistically significant improvement ($p = 0.04$) in erectile function for the 16 men in the experimental group, from a median score of 18/25 [5-24] to 20/25 [5-25], both of which can be qualified as "mild erectile dysfunction" according to the International Index of Erectile Function – 5 (Rosen et al., 1999).

Thomas (2016) described the case of a woman who underwent interdisciplinary sexual rehabilitation in an outpatient setting. While the article focused on describing the occupational therapy intervention, as well as the contribution of physical therapy, speech therapy, psychology and medicine, the results showed that the woman attained all her occupational therapy objectives related to sexuality and intimacy and that her score improved on the Canadian Occupational Performance Measure (Law et al., 1994) (pre: 4/20; post: 11/20; 175% improvement) and the Quality of Sexual Function Scale (Heinemann et al., 2005) (pre: 96/160; post: 61/160; 36% change), which indicates an improvement in the perceived quality of sexual function considering that this scale uses a scoring system where higher scores mean poorer quality.

The study by Guo and collaborators (2015) was carried out in collaboration with occupational therapists and speech language therapists in a rehabilitation hospital. The systematic use of a standardized script for interviews and a teaching session on sexuality led to an important improvement in the proportion of clients who had the opportunity to address sexuality issues (i.e. from 0 to 80% in ten months).

In the cohort study by Stead and White (2019), 11 couples, each with one aphasic person, completed a survey after attending a weekend retreat aimed at promoting each couple's recovery and reconnection. Qualitative results of this study showed that participants felt supported, and left feeling rested and more connected to their partner.

Tableau 2. – Description of the sexual rehabilitation interventions using the Template for Intervention Description and Replication (TIDIeR) checklist (Hoffmann et al., 2014)

(Song et al., 2011) - Sexual rehabilitation intervention program

Why	**What – material**	**What - procedure**	**Who provided**	**How**
Sexual rehabilitation after stroke	A 35-page booklet was also distributed to participants. Produced by the research team, contact info: wschang@inha.ac.kr.	Topics addressed with participants were divided in 5 subjects: 1) information on common sexual problems and major causes of changes in sexual life after stroke, 2) general information regarding a healthy sexual life, 3) counseling on fears regarding post-stroke sexual life, 4) tips and specific strategies to minimize post-stroke sexual dysfunction, and 5) frequently asked questions and answers regarding post-stroke sexuality.	The first author of the study (HoSook Song) offered the program. The context suggests that he has a nursing background.	The program was offered to the stroke client and the partner the day before discharge.

Where	**When and how much**	**Tailoring**	**Modifications**	**How well: actual**
Counseling in a small conference room. The article suggests that it was only presented to one couple at a time.	The day before discharge from inpatient rehabilitation. One session of 40-50 minutes.	Not specified	Development followed programs for spinal cord injury, lumbar disc and stroke. Beta version of the program was revised by nursing experts and was further modified after feedback from two clients.	A total of 46 subjects (12 couples in the EXP group and 11 couples in the CTRL group) were included and completed the program. 7 couples dropped out for no specified reason.

(Sansom et al., 2015) – Structured sexual rehabilitation program

Why	**What – material**	**What - procedure**	**Who provided**	**How**
Sexual rehabilitation in order to have an impact on sexual and psychological function.	A fact sheet by the Australian Stroke Foundation (2012) to both EXP and CTRL groups.	EXP group: A one-session sexual rehabilitation intervention, inpatient or outpatient. Partners could be involved. The program included: information regarding common changes in sexuality post-stroke; counselling on fears regarding post-stroke sexuality; challenging stereotypical views on sexuality and satisfaction; tips and strategies to minimize post-stroke sexual dysfunction; reviewing medication that may affect sexuality; managing urinary incontinence.	The intervention was conducted by a rehabilitation physician, with additional input from occupational therapists, physiotherapists and/or psychologists as required.	Provided in a single private session.

Where	**When and how much**	**Tailoring**	**Modifications**	**How well: actual**
Inpatient or outpatient in an Australian hospital	The intervention consisted of one session of 30 minutes. All participants but one in the EXP group received the intervention toward the end of their inpatient stay; one participant chose to receive intervention as an outpatient. For CTRL group, it was not clarified when the material was provided.	Programs were tailored to each individual's needs and were based on the PLISSIT model (Annon, 1976). Content was similar to the sexual rehabilitation program by Song et al. (2011)	Not specified	All clients in the intervention group received counselling from the rehabilitation physician only, with no further allied health input.

EXP: Experimental; CTRL: Control.

Tableau 2 (continued)

(Ng et al., 2017) – Structured sexual rehabilitation program

Why	What – material	What - procedure	Who provided	How
Sexual rehabilitation after stroke	Written educational material produced by the Australian Stroke Foundation (2012).	The program consisted of a single 30-min individualized session with the offer of additional input from professionals in occupational therapy, physiotherapy and or psychology as required. Sexual partners of participants were invited to participate in the sessions with the consent of the participant where possible/available. Content of the program followed another study (Sansom et al., 2015).	The intervention was provided by one of the two physicians of the clinical setting (7 years of experience in delivering sexual rehabilitation)	Individual therapy session.
Where	**When and how much**	**Tailoring**	**Modifications**	**How well: actual**
In inpatient setting	The educational material was provided at the time of recruitment. A meeting was then set with the EXP participants for a single 30-minute individual session with the physician, early enough during rehabilitation to enable consultation with other professionals prior to discharge if needed.	Programs were individually tailored and based on the PLISSIT model (Annon, 1976).	Not specified	Of the 68 participants at baseline, five in the EXP group and three in the CTRL group dropped out at the 6-week follow-up and a further five participants in the EXP group and four in the CTRL group dropped out at 6 months, leaving 51 in total (25 in the EXP group, 26 in the CTRL group). Participants in the EXP group tended to largely listen and/or read the written information provided at the time of recruitment and asked no questions during the 30-min individual session they received. Participants in the CTRL group only read the information provided and none requested any additional information.

(Vajrala et al., 2019) – Structured sexual rehabilitation program

Why	What – material	What - procedure	Who provided	How
Improving physical dimensions of sexual health and verbal communication among stroke survivors	Therapeutic bed, bolsters.	The EXP group followed an individualized sexual rehabilitation program daily, which included counselling in the form of verbal communication, training bed mobility, active and passive movement physiotherapy, sexual positioning and transferring activities in and out of bed. The physiotherapist used pictorial illustrations to demonstrate various alternative sexual positions to enable adaptation to the motor skills of the patient. Patients were given Verbal counseling on Sexual Health After discharge, were provided with pictorial and written instructions about sexual positioning, oral sex, and various exercises, and was advised to continue at home. The control group was given conventional physical therapy rehabilitation.	Training was given under the direct supervision of a trained physiotherapist.	The individualized sexual rehabilitation program was given in person.
Where	**When and how much**	**Tailoring**	**Modifications**	**How well: actual**
Hospital setting	1-hour individualized sexual rehabilitation program daily; for a	Verbal counselling was tailored according to the PLISSIT model (Annon, 1976)	Not specified	Little information about attendance is included in the article, however the calculated effect size

period of 2 weeks during the hospital stay.	suggests that every participant completed the study.

EXP: Experimental; CTRL: Control.

Tableau 2 (continued)

(Tibaek et al., 2015) – Pelvic floor muscle training

Why	What – material	What - procedure	Who provided	How
Rehabilitation of erectile dysfunction and LUTS after stroke	Not specified	The program was composed of a theoretical introduction session, followed by pelvic floor muscle group treatments, combined with exercises at home.	A specialized physiotherapist in pelvic floor muscle therapy	Group sessions (animated by a physical therapist) and individual exercises at home.

Where	When and how much	Tailoring	Modifications	How well: actual
Not specified	One 60-min group session per week, with 3 to 6 participants. Exercises at home 1-2 times per day. 12-week program	The training program was a modified version of a standard program for group treatment of stress incontinence (Bø et al., 1990; Tibaek et al., 2005).	Not specified	The 30 participants, 15 in each group, with a median age of 68 (interquartile range 60–74), completed the study. At follow-up, one participant from the CG was lost for follow-up. Attendance in group -treatment sessions ≥ 8/12 sessions. No adverse events were reported.

(Thomas, 2016) – Interdisciplinary sexual rehabilitation

Why	What – material	What - procedure	Who provided	How
For the couple to return to their roles as intimate partners	Not specified	The occupational therapist started the follow-up regarding sexuality – the client was provided with educational materials, teaching and reassurance regarding sexual activity post-stroke. After assessments, decisions were made with the patient to make referrals to speech therapy, physical therapy, psychology and the physician. The OT then established long and short term objectives with the patient and pursued the follow-up. Every professional worked in a multidisciplinary fashion and confidential information was only shared when needed.	Occupational therapist, physical therapist, speech-language therapist, psychologist, physician	Occupational therapy interventions were mostly done with the partner present and included: education (i.e. ways of expressing sexuality), bodily sensations mapping, homework assignments, spasticity management, positioning, transfer and bed mobility training, scheduling daily activities, including sexual activities and couple activities, respite/caregiving resources references for the partner, environmental adaptations and assistive devices (provision and education), education on energy conservation; The ST focused on promoting the woman's communication of her wants and needs to her husband, using traditional and alternative methods; The PT worked on pelvic floor strengthening to address the incontinency issues.; The PSY addressed the role conflict issues in the couple and provided more in-depth sexual counseling.; The physician prescribed an antispasmodic medication to reduce spasticity and education on potential side effects.

Where	When and how much	Tailoring	Modifications	How well: actual
Outpatient stroke rehabilitation settings	Week 1: OT addresses sexuality; Weeks 3-4: discussion about sexuality with Mrs and husband; Weeks 5-9 (total of 5 weeks): sexual rehabilitation in OT and other disciplines. The participant had OT 1x/week	Using the PLISSIT model (Annon, 1976), the interventions followed participant preference	Not specified	After 5 weeks of therapy, the participant attained all her objectives. No mention of missed sessions in the article suggests good attendance.

EXP: Experimental; CTRL: Control.

Tableau 2 (continued)

(Guo et al., 2015) – Implementation of procedures for provision of sexuality services

Why	What – material	What - procedure	Who provided	How
Giving stroke clients an opportunity to have a conversation about sexuality with a rehabilitation clinician	The clinicians used a checklist to keep track of issues that they address with clients during their rehabilitation stay. Sexuality was added to the checklist (reminder mechanism); a standardized script to address sexuality was followed.	Prior to the study, interviews were held with clinical team members and five discharged clients. Based on the barriers identified, standardization and reminders were selected as initial options for change concepts. The occupational therapists proposed that discussions about sexual health concerns could take place during their intake assessments. The occupational therapists used the checklist and the script in their practice. A visual conversation-support tool for sexual health that mirrored the standardized script was also created to facilitate the conversation with aphasic clients.	Occupational therapists in general and speech language therapists if clients had aphasia.	Clients were interviewed by clinicians in the rehabilitation facility. Collaboration process between investigators and stakeholders was not clarified, but the article suggests a mix of in-person meetings and remote follow-ups.

Where	When and how much	Tailoring	Modifications	How well: actual
In the rehabilitation hospital	The study gathered data for ten months, including the first three that formed the baseline. Therefore, the active implementation of the project lasted seven months.	The intervention was implemented in collaboration with stakeholders. The tailoring was proposed by OT and speech therapists during collaborative work with the investigators.	Not specified	Proportion of clients having discussed sexuality: Months 1-3 (baseline): 0%; 4th: 50%; 5th: 75%; 6th: 55%; 7th: 55%; 8th: 75%; 9th: 100%; 10th: 80%.

(Stead & White, 2019) – the Aphasia Couples Retreat

Why	What – material	What - procedure	Who provided	How
Support couples with one partner who has aphasia in their recovery and reconnection	Documents and schedules were created by the research team	Aphasia Couples Retreat. Some of the topics explored included: Changing roles and the effect on the identity of individuals and the couple; How to revive former interests and find new activities to share together; How aphasia and related conditions affect intimacy and relationships.	An interdisciplinary team of occupational therapists, speech–language pathologists, neuropsychologists, nurses, and Aphasia Network staff. Each couple is paired with an interdisciplinary student team of one speech–language pathology and one occupational therapy graduate student to support them throughout the weekend in both communication and mobility needs.	The retreat has a maximum capacity of 15 couples, including 2 peer mentor couples. Approximately 40% (7 out of 18 hrs) of the weekend is spent in small or large group sessions addressing individualized issues related to marriage, aphasia, and adjustment. The other portions are spent engaging in group meals, social times, leisure activities, and rest.

Where	When and how much	Tailoring	Modifications	How well: actual
Retreat in the local community	Once a year, over a weekend, for a total amount of 18 hours.	The Aphasia Couples Retreat follows the Ex-PLISSIT model (Davis & Taylor, 2006) during group and individual sessions. All activities during the weekend are adapted for aphasia (e.g. visual schedules and supports, individual assistive devices)	Not specified	Little information about attendance is included in the article. However, 11 couples completed the post-retreat questionnaire, indicating that at least that many couples attended the weekend.

EXP: Experimental; CTRL: Control.

Additional analysis

Among the eight intervention methods included in the review, six mainly targeted the person, one the occupation and one the environment (see Table 1). Interventions were multimodal for six studies (Ng et al., 2017; Sansom et al., 2015; Song et al., 2011; Stead & White, 2019; Thomas, 2016; Vajrala et al., 2019), one was only oriented towards the person (Tibaek et al., 2015) and one only towards the environment (Guo et al., 2015). Education was the type of intervention most importantly present in five of the eight intervention methods, with training, support enhancement and skill development each predominating in only one study. The intervention described by Thomas (2016) was the only one that addressed the person, the occupation and the environment, and covered six different modes of intervention.

Discussion

The aim of this study was to document and describe the best available evidence supporting interventions that target post-stroke rehabilitation of sexuality that can be offered by an allied health professional. A total of eight intervention studies relevant for allied health professional practice met the criteria for inclusion in this review. Most interventions (n= 6/8) were mainly focused on the person. Structured sexual rehabilitation programs (Ng et al., 2017; Sansom et al., 2015; Song et al., 2011; Vajrala et al., 2019) based on the PLISSIT model (Annon, 1976) and pelvic floor muscle training (Tibaek et al., 2015) were the most supported by evidence and are actually the most promising interventions for use by allied health professionals. Such programs were not typically meant to be offered by a single profession, with certain providers being physicians or nurses (Ng et al., 2017; Sansom et al., 2015; Song et al., 2011). Two other studies highlighted the contribution of physical therapists to sexual rehabilitation, not only in regard to pelvic floor muscle training (Tibaek et al., 2015) but also for training clients in specific physical abilities required for sexual activities (e.g. bed mobility, positioning) and sexual counseling (Vajrala et al., 2019). However, the outcome of pelvic floor muscle training among women who have sustained a stroke is unclear, as the only relevant study (Tibaek et al., 2005) was specifically oriented towards men. These five studies also show the impact of providing appropriate informative documentation on clients' sexual functioning. In fact, in two of these studies (Ng et al., 2017; Sansom et al., 2015), the control group received the same written documentation as the experimental group, but without participating in the sexual rehabilitation program. The fact that both groups showed improvement regarding sexuality, and that no significant between-group difference was found, supports the relevance of providing written documentation to the stroke clientele. This would also meet clients' preferences, as Stein and collaborators' (2013) cross-sectional study showed that among the 38 participants who sustained a stroke, informative printed material was the most (33.3%) and second-most (37.5%) preferred method of receiving information about sexuality. The last study describing an intervention oriented towards the person presented couples retreats (Stead & White, 2019), which could be promising psychosocial interventions for persons who have sustained a stroke, and their partners, once they reintegrate the community, in the chronic phase of stroke. Therefore, even though the evidence supporting these interventions is limited, interdisciplinary sexual rehabilitation, physical rehabilitation focusing on sexuality and couples' retreats appear to lead to meaningful results for the stroke clientele's sexuality. They are promising methods that would require further investigation of their impact and that could eventually be more widely implemented in stroke rehabilitation.

Although of a lower level of evidence (Howick et al., 2009), the two other studies included in this review can inform future research and implementation of better practices in clinical settings. In fact, Guo and collaborators' (2015) study was the only one oriented exclusively towards the environment, and showed that a collaborative approach between research and clinical settings such as action-research have a high potential to lead to concrete changes in the provision of services related to sexuality. These methods could be relevant for the future implementation of the higher-level interventions described earlier, especially the structured sexual rehabilitation programs. Thomas' (2016) study was the most multimodal intervention and the only one mainly focused on occupation, although the person and the environment were given some consideration. This focus on activities is very likely related to the fact that the article primarily described occupational therapy interventions, whose contribution to sexual rehabilitation has been presented elsewhere (Auger, 2019). In her case study, Thomas (2016) highlighted the privileged position of occupational therapists for properly addressing sexuality. This also concurs with the choice of rehabilitation clinicians in Guo and collaborators' (2015) study, in which occupational therapists were asked to initiate a conversation about sexuality with each client. Interdisciplinary sexual rehabilitation tailored to the specific needs of the client, with the occupational therapist as case manager, showed great potential to lead to significant improvements for the clientele in Thomas' (2016) case study, and supports the assumption that sexual rehabilitation after an acquired brain injury should be interdisciplinary (Moreno et al., 2017).

When combining the results of each of the studies presented here, interventions should be tailored to the stage of sexual rehabilitation. In acute care, written documentation should be prioritized, as clients can be overwhelmed in the days and weeks immediately following a stroke (McGrath et al., 2019). Documentation such as informative pamphlets should also be offered in the rehabilitation setting (Stein et al., 2013). Inpatient rehabilitation could offer a structured program, during the week preceding discharge, a one-time session 30-45 minutes individual consultation based on the PLISSIT model (Annon, 1976; Ng et al., 2017; Sansom et al., 2015; Song et al., 2011). Outpatient rehabilitation could also offer structured sexual rehabilitation programs, combined with more diversified interdisciplinary support (Thomas, 2016), including pelvic floor muscle training (Tibaek et al., 2015) and skill development and sexual counseling (Vajrala et al., 2019) for clients to achieve the sexual activities they wish to engage in. For community care, one-time interventions such as an annual retreat could promote couples' well-being and foster intimacy between them. However, sexual rehabilitation interventions after a stroke should not only be focused on persons in a relationship but also on the individuals and their personal objectives regarding sexuality.

Strengths and Limitations

Among the strengths of this systematic review is the fact that it was conducted following the PRISMA guidelines (Moher et al., 2015). Moreover, the research team included an ALA accredited librarian who was involved in the entire process and ensured the development of an extensive search strategy. Finally, blinded data collection, as well as data extraction according to the OCEBM (Howick et al., 2009) and the TIDIeR (Hoffmann et al., 2014), attest to the quality of data reported and its usefulness for clinical and research purposes.

This review also has certain limitations. The potential bias in each of the studies analyzed affects the quality of this review. By including level 4 studies such as a case study, this review risks a certain bias, as the cost of conducting an exhaustive literature review that included a wide range of research designs.

In conclusion, this systematic review presented evidence-supported interventions, and their outcomes, that target rehabilitation of sexuality after a stroke. It highlighted approaches that could be applied and implemented immediately by allied health professionals in their practice with a stroke clientele. It also showed that most research conducted until now has been oriented towards interventions that target the person post-stroke, but that multimodal interventions and approaches focusing on the environment could also yield meaningful results. This review confirms the importance of conducting further research in the field of sexual rehabilitation following a stroke with a focus not only on the person as they regain skills, but also on their environments (e.g. caregivers), thereby including relatives and healthcare settings, and involving workers in the full range of allied health professions.

Declaration of interest statement

The authors report no conflict of interest.

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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 behavio* 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

Interventions de réadaptation sexuelle post-AVC additionnelles

En ajout aux huit études présentées dans la revue systématique présentée ci-dessus, deux études d'intervention additionnelles publiées plus récemment sont présentées dans la prochaine section. Premièrement, l'étude d'implantation d'Auger et collaborateurs (2021) a montré qu'il était faisable d'intégrer le guide d'entrevue sur la sexualité (GES), un outil facilitant l'entrevue visant à explorer le besoin de services de réadaptation sexuelle chez les personnes ayant subi un AVC, à la pratique clinique des intervenants en réadaptation post-AVC. De plus, dans le cadre de la période d'implantation du GES qui a duré quatre mois, 28 usagers ont reçu l'opportunité d'aborder la sexualité dans le cadre de leur réadaptation post-AVC, ce qui représente une augmentation significative considérant que l'ensemble des participants ayant participé à l'étude ont rapporté, pour la période précédant l'implantation, n'avoir « jamais » ou « rarement » abordé la sexualité dans leur pratique clinique (Auger, Pituch, et al., 2021). Cette étude appuie donc les résultats de Guo et collaborateurs (2015) qui ont également montré qu'il était possible d'améliorer la proportion de clients suivis en réadaptation post-AVC se voyant offrir l'opportunité d'intégrer la sexualité aux domaines couverts par leur réadaptation, par l'implantation d'un guide d'entrevue en lien avec la sexualité. Deuxièmement, l'essai clinique randomisé de Lu et collaborateurs (2012) réalisé auprès de 114 hommes post-AVC d'origine chinoise et âgés de 23 à 45 ans a montré que le traitement de 50 mg oral de Sertralin en raison d'une dose par jour a diminué les symptômes d'éjaculation précoce chez les participants après trois mois de traitement pharmacologique. Cette étude était la seule parmi les trois essais cliniques randomisés inclus à une revue systématique Cochrane portant sur les interventions visant à traiter les dysfonctions sexuelles post-AVC (Stratton et al., 2020) qui ne figurait pas dans la revue systématique réalisée dans le cadre de cette thèse (présentée ci-dessus). Puisque les médecins, les pharmaciens et les infirmières font partie des professionnels pouvant composer l'équipe interdisciplinaire de réadaptation post-AVC et du lectorat potentiel de cette thèse, l'intégration d'interventions pharmacologiques aux différentes interventions visant la réadaptation sexuelle et/ou l'amélioration de la santé sexuelle post-AVC apparaissait comme pertinente à rapporter ici.

En résumé, à la lumière de la synthèse des 10 études présentées ci-dessus, certaines interventions de réadaptation sexuelle apparaissent comme efficaces ou prometteuses pour améliorer certains aspects de la santé sexuelle (ex., qualité de la fonction érectile, satisfaction sexuelle) des personnes ayant subi un AVC et il semble faisable d'implanter de nouvelles méthodes d'évaluation et d'intervention dans la réadaptation post-AVC pour améliorer la qualité des services de réadaptation sexuelle.

Au-delà des études d'intervention en réadaptation sexuelle, des modèles existent pour guider la prise en charge des difficultés sexuelles par les professionnels de la santé, tels que le modèle *Permission, Limited Information, Specific Suggestions, Intenstive Treatment* (PLISSIT) (Annon, 1976), le modèle *Extended* (EX)-*PLISSIT* (Davis & Taylor, 2006) et le modèle *Bring up, Explain, Tell, Timing, Educate, and Record* (BETTER) (Quinn & Happell, 2012). Bien qu'ils comportent quelques différences mineures, ces modèles de prise en charge encouragent les intervenants à prendre l'initiative d'aborder la sexualité avec leurs clients, à leur offrir l'information dont ils ont besoin et de leur proposer des interventions en fonction des difficultés sexuelles qu'ils auront détectées (Grenier-Genest et al., 2017). Ces modèles sont susceptibles d'être trop généraux pour mener à eux seuls à un changement de pratique car les intervenants ont rapporté avoir besoin de conseils et suggestions précises sur les pratiques à adopter, par exemple quels outils utiliser, et quand (Auger, Pituch, et al., 2021). Toutefois, ces modèles sont pertinents pour orienter l'évaluation des composantes et interventions d'un programme visant à améliorer la prise en charge des difficultés sexuelles (Tuncer & Oskay Ü, 2022).

Pour conclure, considérant que l'AVC affecte plus de 90 000 Canadiens par année, que plus de 50% d'entre eux présentent des difficultés sexuelles post-AVC et que l'offre de services de réadaptation sexuelle actuelle ne réponde pas aux lignes directrices bien que les données probantes disponibles soutiennent son efficacité, il est important d'élaborer une intervention multifactorielle qui mènera à une bonification de l'offre de services de réadaptation sexuelle en réadaptation post-AVC pour les personnes qui en ont besoin.

Chapitre 3 – Objectifs de recherche

L'objectif général de cette thèse était de cocréer avec des parties prenantes de la réadaptation post-AVC (personnes ayant subi un AVC, partenaires, intervenants, gestionnaires, chercheurs) un programme multifactoriel pour améliorer les services de réadaptation sexuelle offerts en réadaptation post-AVC. Plus spécifiquement, cet objectif général se décline en cinq objectifs spécifiques, soit :

1) Comprendre les facteurs influençant l'offre de services de réadaptation sexuelle post-AVC par les intervenants au Québec;
2) Explorer des stratégies qui pourraient être mises en œuvre pour améliorer les services de réadaptation sexuelle post-AVC;
3) Identifier les retombées principales, les objectifs de performance, les déterminants et les objectifs de changement du programme;
4) Identifier des méthodes et des stratégies fondées sur la théorie et les données probantes, à considérer dans la création des interventions du programme;
5) Mettre en œuvre une démarche structurée de co-création du programme et de ses composantes.

Ces objectifs ont été légèrement ajustés et reformulés en cours de projet en comparaison à ceux figurant dans le protocole présenté au chapitre 4, afin de représenter avec plus de fidélité ce qui a été réalisé dans les articles 3 à 5 présentés aux chapitres 5, 6 et 7.

Chapitre 4 – Méthodes

Ce chapitre est principalement constitué d'un protocole publié dans la revue *Frontiers in Rehabilitation Sciences* (Auger, Allegue, et al., 2022), avec des modifications minimes pour le bien de la thèse. Dans le protocole figurent la présentation des méthodes utilisées ainsi que la justification de leur choix. Ainsi, sont exposés : la cartographie des interventions (Bartholomew et al., 2016), le devis de recherche, les modèles théoriques, la population à l'étude, l'échantillonnage et le recrutement, le déroulement des différentes étapes du projet et les méthodes de co-design utilisées, la collecte de données, l'analyse de données et les considérations éthiques. Une brève discussion sur la pertinence des méthodes et leur potentiel pour répondre aux objectifs de recherche est ensuite présentée.

Co-designing a program to improve post-stroke sexual rehabilitation: the promise of innovative methods

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Abstract

Introduction: Most people who sustain a stroke are likely to experience sexual difficulties during their recovery. However, few people get the opportunity to address sexuality during their rehabilitation because of factors related to the organization (e.g., culture), managers (e.g., lack of resources), clinicians (e.g., perceived lack of knowledge, skills, and comfort), and clients (e.g., taboo). A multifactorial program tailored to stakeholders' needs with various complementary interventions is needed to lead to a change of practice in post-stroke sexual rehabilitation.

Objective: To co-design with stakeholders (i.e., people with stroke, partners, clinicians, managers and researchers) a theory-driven multifactorial program to improve post-stroke sexual rehabilitation services.

Methods: This qualitative study will be conducted in four steps using an Intervention Mapping approach and a co-design methodology divided into four phases: 1) exploration; 2) co-design; 3) validation; and 4) development. Persons with stroke, partners, clinicians and managers from five distinct stroke rehabilitation centres in the province of Quebec (Canada), and researchers will be recruited to either participate in an advisory committee or working groups throughout the study. A combination of contributions from three different types of groups (advisory group, Lego® groups, work groups) will be used for data collection. Qualitative data analysis will first be realized by two independent reviewers using the Theoretical Domains Framework, and preliminary results of analysis will be validated with the advisory and working groups.

Conclusion: This study will lead to the co-design of the first theory-driven program intended to optimize post-stroke sexual rehabilitation services.

Keywords

Sexuality; Stroke; Rehabilitation; Co-design; Implementation; Intervention Mapping;

Introduction

Stroke is the second leading cause of disability around the world (Katan & Luft, 2018) and can result in various consequences impacting the person, their environment, and their activities (Geyh et al., 2004). Persons with stroke are likely to experience restricted participation in meaningful activities and roles because of impairments, such as hemiplegia, aphasia, cognitive impairments, or mood disorders (Desrosiers et al., 2006; Teasell et al., 2020). These impairments may require a variety of activity adaptations and environmental modifications to maintain or improve participation (Rochette, Desrosiers, Bravo, Tribble, & Bourget, 2007; Rochette, Desrosiers, & Noreau, 2001). Persons with stroke report that balance and walking difficulties, fatigue, upper limb dysfunction, and speech difficulties are among the main priorities that must be addressed in rehabilitation (Auger, Pituch, Filiatrault, Courtois, & Rochette, 2020; Rudberg et al., 2021). Sexuality is among other priority domains for persons with stroke (Auger, Pituch, et al., 2020; McGrath, Lever, McCluskey, & Power, 2019b) and is part of the International Classification of Functioning, Disability and Health (ICF) core set for stroke as a relevant domain to be addressed (Geyh et al., 2004).

Sexuality after a stroke

According to the World Health Organization, sexuality is "a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction" (World Health Organization, 2006). Stroke can lead to multiple difficulties related to sexuality, either because of the location and/or severity of the cerebral lesion or in relation to consequences of the stroke (Grenier-Genest & Courtois, 2021; Grenier-Genest, Gerard, & Courtois, 2017). In fact, more than 50% of persons with stroke are likely to experience difficulties influencing their participation and satisfaction related to sexual activities and their partners' (Akinpelu, Osose, Odole, & Odunaiya, 2013; Korpelainen, Nieminen, & Myllyla, 1999; Tamam, Tamam, Akil, Yasan, & Tamam, 2008).

However, few persons with stroke get the opportunity to address sexuality during their rehabilitation (Richards, Dean, Burgess, & Caird, 2016; Stein, Hillinger, Clancy, & Bishop, 2013) even though past studies showed that a lack of access to sexuality-related services could put them at risk of depression and poor quality of life (Kim, 2008; Korpelainen et al., 1999). There are interrelated factors, both individual and organizational, that contribute to this situation (Auger, Pituch, Filiatrault, Courtois, & Rochette, 2021; McGrath, Low, Power, McCluskey, & Lever, 2021). The perceived lack of knowledge and skills of clinicians, as well as personal discomfort and misconceptions related to sexuality are among the most reported barriers (Dyer & das Nair, 2013; Hyland & Mc Grath, 2013; Richards et al., 2016). For example, clinicians expect clients to raise sexuality-related issues when needed (Richards et al., 2016), while clients that perceive sexuality as a taboo subject expect health professionals to address the subject first (McGrath et al., 2019b).

To overcome sexual difficulties, Canadian (Mountain et al., 2020), American (Winstein et al., 2016), and Australian (Stroke Foundation, 2019) stroke guidelines recommend addressing sexuality during rehabilitation. A recent systematic review showed that post-stroke sexual rehabilitation interventions could significantly improve individuals' sexual functioning and sexual satisfaction (Auger, Grondin, et al., 2020). Moreover, considering the various factors influencing sexuality, an interdisciplinary approach to sexual rehabilitation is recommended (Elliott, Hocaloski, & Carlson, 2017; Moreno, Gan, & Zasler, 2017). The findings from a recent Australian study conducted with diverse stroke rehabilitation stakeholders (i.e., persons with stroke, partners, clinicians, and researchers) highlighted priority subjects and intervention methods that should be integrated regarding sexuality in post-stroke rehabilitation, such as strategies to resume sexual activities and communication between persons with stroke and their partner or clinicians (McGrath, Lever, McCluskey, & Power, 2019a). However, to our knowledge, no studies have addressed key considerations (e.g. "by who?", "when?", "how?") regarding the development and application of these intervention methods, or solutions, for use in clinical practice and research. Therefore, because of the important incidence of stroke worldwide, the high prevalence of sexual difficulties post-stroke and their significant impact on the quality of life of persons with stroke, it is crucial to generate evidence-based solutions tailored to stakeholders' needs while considering barriers related to the inclusion of sexuality in rehabilitation services.

Sexual rehabilitation and theories for change of practice

Considering the multiple barriers experienced by people with stroke, clinicians, and other stakeholders in relation to post-stroke sexual rehabilitation, it appears important to develop complex, or multifactorial, interventions that can improve the implementation of clinical practice guidelines recommendations. For example, a recent systematic review of 114 studies on inclusion of sexuality in the care of people with disability or chronic illness by McGrath and collaborators (2021) included seven studies specifically dedicated to training of clinicians. The synthesis of these results showed that clinicians may benefit from training on sexual rehabilitation, ideally through an interdisciplinary approach, to improve their self-reported knowledge, attitude, comfort with sexuality and self-reported frequency of addressing sexuality. However, this kind of single stand-alone training can only partially address the multiple barriers influencing the provision of sexual rehabilitation, as individual and environmental factors respectively influence behaviour and should be considered when planning interventions to change practice (Michie, van Stralen, & West, 2011). Therefore, focusing only on clinicians' lack of knowledge and skills may prove to be insufficient in leading to significant change in clinical practice.

Intervention Mapping for improving sexual rehabilitation services

This study is being conducted to address the concerns of five participating organizations regarding the lack of services related to post-stroke sexuality. Considering that changes in provision of sexual rehabilitation is complex, multiple interventions simultaneously targeting people with stroke, partners, clinicians, and clinical managers are needed to support the development and delivery of better services related to sexuality post-stroke.

To date, two studies have aimed to improve the provision of post-stroke sexual rehabilitation with a focus on changing clinicians' behaviours by creating and implementing sexuality interview guides (Auger et al., 2021; Guo et al., 2015). The effectiveness of these implementation studies was mixed, and they did not assess the sustainability of practice changes post-implementation. This is on concordance with McGrath and collaborators (2021)'s conclusion that multifactorial implementation programs were needed to lead to an effective change in the provision of sexual rehabilitation services.

Intervention Mapping is a structured process that aims to optimize a practice (e.g., non-provision vs provision of sexual rehabilitation services) by identifying the behaviours underlying the practice and acting upon the factors (i.e., determinants) that influence the behaviour (Bartholomew et al., 2016; Bartholomew, Parcel, & Kok, 1998). According to a systematic review of 17 studies (Durks et al., 2017), Intervention Mapping has shown to be an effective process in guiding the development of methods and programs aimed at changing practices, such as adherence to clinical guidelines (Rutten et al., 2014), assessment and treatment of risk factors (Schmid, Andersen, Kent, Williams, & Damush, 2010), and provision of educational support (Sassen et al., 2012). To our knowledge, Intervention Mapping has never been used to guide the development of programs and interventions designed to improve sexual rehabilitation for any health condition. In fact, very few studies have been conducted on sexual rehabilitation post-stroke, and most focused only on assessing the effects of one specific intervention method, such as pelvic floor muscle training (Auger, Grondin, et al., 2020). Therefore, there is a need for a complex intervention addressing the multiple challenges faced in stroke rehabilitation regarding sexuality. Because of its structured process and the evidence supporting its effectiveness in past studies, Intervention Mapping has the potential to successfully guide multiple stakeholders' needs assessment and subsequent development of a multifactorial program that targets the main determinants, ultimately improving clinical practice related to post-stroke sexual rehabilitation.

Main objectives

The general aim of this study is to co-design with stakeholders (namely: persons with stroke, partners, clinicians, managers, and researchers) a theory-driven program to improve post-stroke sexual rehabilitation services. The specific objectives of this study are to:

1) Describe the factors that influence the actual provision of sexual rehabilitation services in post-stroke rehabilitation from the perspective of various stakeholders.
2) Identify stakeholders' priorities and needs regarding sexual rehabilitation services and develop a preliminary theory-driven program.
3) Identify the behaviour change strategies that can be used to address the prioritized factors and describe their expected action mechanisms.
4) Develop and test the behaviour change strategies that will target the identified determinants.

Materials and Methods

Design

This qualitative study is guided by an Intervention Mapping approach (Bartholomew et al., 2016) and co-design methods (Morales, Rousseau, & Passini, 2012). This innovative combination of two approaches and methods has to our knowledge never been studied, but shows promise in leading to better results in the future. Although it is recommended to include stakeholders in each step of the Intervention Mapping approach, it does not provide clear guidelines regarding how and when to include them during the research process. Therefore, combining this approach with evidence-based co-design methods has a greater potential to lead to a deeper, more relevant, integration of stakeholders in the research process, and to develop creative and applicable strategies to improve post-stroke sexual rehabilitation services. The qualitative methods used in this study were reported in concordance with most of the Consolidated criteria for reporting qualitative studies (COREQ) (Tong, Sainsbury, & Craig, 2007).

The Intervention Mapping approach (Bartholomew et al., 2016) will orient the study process by addressing the corresponding objective (e.g., Step 1 for objective 1) through four steps: 1) needs assessment; 2) preparing matrices of change objectives; 3) selecting theory-informed intervention methods and practical strategies; and 4) producing program.. The Intervention Mapping Approach will therefore guide the process to better understand stakeholders' needs and orient the creation of the matrices of change objectives and the indicators that will be established to assess the upcoming program's impact and outcomes once it will be developed.

The co-design methodology has evolved in recent years, into a paradigm whereby various stakeholders work towards the same objective throughout the research process. The aim of co-design is for the entire team to focus on one challenge to better understand it and to work collaboratively towards finding creative solutions to resolve or improve it (Hussain & Sanders, 2012; Hyysalo et al., 2014; Nimkulrat, Groth, Tomico, & Valle-Noronha, 2020; Trischler, Pervan, Kelly, & Scott, 2018). The co-design methodology that will be used in this study follows four phases: 1) exploration; 2) co-design; 3) validation; and 4) development (Morales et al., 2012). The exploration phase aims at gaining a deeper understanding of the situation that needs to be changed by exploring the stakeholders' perspectives, experiences, and needs. The co-design phase implies the active collaboration between stakeholders and the researchers to generate innovative ideas for elaborating potential solutions that could solve the problems related to the situation. The validation phase consists of presenting the innovative ideas and potential solutions to selected experts to validate some aspects, such as their relevance and feasibility. Finally, the development phase consists of transforming the agreed upon solutions from the validation phase into concrete strategies that could be tested in the future.

To consider a variety of perspectives, persons with stroke, partners, clinicians, managers, and researchers will participate actively in the research process and/or development of the program by taking either part in an advisory group, Lego® groups, or work groups at different stages of the project. The perspectives of persons with stroke and partners will be considered by using three different strategies. First, a review of the literature regarding persons with stroke and partners' priorities and needs related to post-stroke rehabilitation and sexuality will be realized. Second, a person who received post-stroke rehabilitation and the partner of a person with stroke will be involved in the advisory group. Finally, two work groups will be conducted with post-stroke individuals and partners. Clinicians and managers will participate in the Lego® or work groups, and a subset will be included in the advisory group. Researchers will be included in the advisory group. Participation methods for each of the three groups, along with the study timeline and related deliverables, are presented in Table 3.

Tableau 3. – Course of the study and related deliverables according to the co-design methodology by Morales, Rousseau and Passini (2012) and the Intervention Mapping approach (Bartholomew et al., 2016)

Types of participants*	Co-design phases					
	Introduction	**Exploration**	**Co-design**	**Validation**	**Development**	**Pretest****
Advisory group (person with stroke, partner, clinicians, manager, researchers)	X		X		X	
Lego® groups (clinicians)		X	X			
Work groups (1) persons with stroke and partners, 2) clinicians, 3) managers)			X	X		X
Deliverables	Definition of the challenge and general objective of the program	Concrete/deep understanding of participants' needs, experiences, and potential solutions	Preliminary program, matrix of change, and choice of behaviour change strategies	Improved and official program, matrices of change, and behaviour change strategies	Development of preliminary behaviour change interventions and complete description according to the TIDIeR checklist (Hoffmann et al., 2014)	Improved and official selection of behaviour change interventions for the program

*Participants' characteristics and affiliations could not be provided at the time of submission of this manuscript since recruiting was ongoing.

**The pretest phase was separated from the development phase for clarity, although Morales et al. (2012) combines them.

TIDIeR: Template for Intervention Description and Replication.

Theoretical Frameworks

We will draw from a well-known determinant framework, the Theoretical Domain Framework (TDF), and on the International Classification of Functioning, Disability and Health (ICF) core set for stroke (Geyh et al., 2004) to guide data collection and analysis at each step of the study. The TDF was developed using 33 theories related to behaviour change (Cane, O'Connor, & Michie, 2012) and is composed of 14 distinct domains: 1) knowledge; 2) skills; 3) social/professional role and identity; 4) beliefs about capabilities; 5) optimism; 6) beliefs about consequences; 7) reinforcement; 8) intentions; 9) goals; 10) memory, attention, and decision processes; 11) environmental context and resources; 12) social influences; 13) emotions; and 14) behavioural regulation. These domains help implementation teams better understand what factors, or determinants, are likely to positively or negatively affect practice behaviours (Cane et al., 2012). The ICF core set for stroke will be used to deepen data collection and analysis as it has been suggested that the TDF lacks exhaustivity regarding certain key domains such as environmental factors (Atkins et al., 2017). Although all the factors of the ICF will be addressed in this study in conjunction with the TDF, an emphasis will be put on the environmental factors, more specifically "Products and technology", "Natural environment and human-made changes to environment", "Support and relationships", "Attitudes" and "Services, systems and policies" (World Health Organization, 2001). Moreover, the interrelation between different levels of environment (i.e. micro, meso, macro) will be considered (Bolíbar, 2016).

Population

Persons with stroke, partners, clinicians and managers will be recruited from five different stroke rehabilitation centres among three large cities, namely Montreal (n = 3), Laval (n = 1), and Quebec City (n = 1) in the province of Quebec (Canada). These rehabilitation centres offer services to people who sustained a stroke in the subacute (< 3 months post-stroke) or chronic phases (> 6 months post-stroke) of stroke recovery (Kiran, 2012). More specifically, participating rehabilitation centres offer up to four types of stroke rehabilitation programs: 1) inpatient intensive rehabilitation; 2) early supported discharge; 3) outpatient rehabilitation; and 4) community-oriented rehabilitation. Each of the participating stroke rehabilitation programs offers services in an interdisciplinary approach. Only one out of the five programs has access to sexology services. To be eligible to participate in the study, persons with stroke will have to be in the chronic phase and have experienced most of the phases of post-stroke rehabilitation. It will be suggested to eligible persons with stroke that their partner participate in the study. Other potential partners that may be interested in participating in the study will have to be in a relationship with a person with a stroke in the chronic phase. Eligible researchers will have expertise in stroke rehabilitation, sexuality, implementation, or behaviour change research.

Sample and Recruitment

Persons with stroke, partners, clinicians and managers will be recruited from participating stroke rehabilitation centres. Researchers will be recruited via the research team's professional networks. An effort will be made to recruit persons with stroke that present, or partners, that have an experience with, post-stroke cognitive or communication impairments. For each step of the study, different groups of participants will be required: an advisory group, two Lego® groups, and three work groups.

The advisory group will be composed of one person with stroke, one partner, four clinicians from varied disciplines, one coordinator, one manager and four researchers. The advisory group will orient the general course of the study and be actively involved in the co-design phase (i.e., creation of the preliminary program) and in the development phase (i.e., creation of the behaviour change strategies).

The Lego® groups (n = 2) will each rally five clinicians from varied disciplines and rehabilitation centres. One group will be composed of clinicians from inpatient or early supported discharge, and the other group will include clinicians from outpatient or community-oriented rehabilitation. Therefore, for each participating rehabilitation centre, one clinician corresponding to each Lego® group will be selected (total of 10 participants in Lego® groups, 2 per rehabilitation centre). This division between each group is related to the substantial difference between the needs of the clientele and clinicians' respective work contexts. Participants in the Lego® groups will be recruited by convenience to optimize heterogeneity by varying the disciplines included in each of them.

The three work groups will be composed of A) up to 20 clinicians from various disciplines and B) up to 15 managers and coordinators, equally representing each of the participating rehabilitation centres (i.e., n ≤ 4 clinicians and n ≤ 3 managers/coordinators per rehabilitation centre) and C) up to 12 persons with stroke and partners. The work groups will take part in the validation phase (i.e., improving the preliminary program and orienting the choice of behaviour change strategies) and in the pretest phase, aimed at improving the preliminary behaviour change strategies. Considering their different perspectives, the three work groups will operate separately to facilitate discussion and ensure that participants are comfortable sharing information. This methodological choice is related to the pretest of the co-design methods that was conducted with a group of five-graduate students that was done online via two meetings of two-hours each where a need assessment and ideation of solutions to improve graduate students' experience in their studies was done using the adapted version of the Lego® Serious Play® method (Frick, Tardini, & Cantoni, 2013).

Course of the study and co-design methods

The course of the study is summarized in Table 3. Although the co-design methodology (Morales et al., 2012) describe above will guide the whole process of the study, the activities of the Lego® groups will be conducted using an adapted version of the Lego® Serious Play® method (Frick, Tardini, & Cantoni, 2013) in phase 1 (exploration).

Using Lego® as a projective method to optimize in-depth group discussions, participants in the Lego® groups will build a model representing their answer to the question asked by the facilitators. Participants will also reflect together to raise a better understanding of the challenging situation and potential solutions. Given that participants in each group will be in different locations, the Lego® Serious Play® activities will be conducted online via *Zoom Pro* and each participant will receive a Lego® Serious Play® Starter kit. This adapted online version of the Lego® Serious Play® method was pretested in the context of this study and shown to be feasible with five graduate students in another project.

The three other phases (i.e., co-design, validation, and development) will be conducted using iterations between preparatory work by the research team and presentation to the group associated with each phase (advisory, Lego® of work groups) and collecting participants' feedback for improvement.

Data collection

Participants in every group (i.e., advisory group, Lego® groups, work groups) will provide sociodemographic information, such as age, gender, occupation, and professional experience (if applicable). Every group activity will be conducted online, recorded digitally, and co-animated by two experienced facilitators. In the Lego® groups, pictures of the Lego® models that participants will create will be stored by the research team. During group activities, the two facilitators will use guides tailored to each activity's specific purpose (see deliverables in Table 3). The facilitators for group activities will be trained to use the TDF and will keep a list of the 14 domains so that they make adjustments in real time; this will also require ongoing analysis to ensure each domain is adequately explored. The recordings of every group activity will be transcribed verbatim. Verbatim and pictures will be transferred into the NVivo software for analysis. Facilitators of group activities will write their perceptions and reflections in a logbook during data collection and analysis.

Data analysis

The verbatim from each group activity will be analyzed by two independent evaluators using semi-deductive thematic analysis (Paillé & Mucchielli, 2016). First, multiple readings of the verbatim will be done to obtain a better understanding of the content. Each verbatim and pictures will be coded using a preliminary coding scheme based upon the TDF domains and the ICF core set for stroke (Geyh et al., 2004) . Moreover, additional codes (Geyh et al., 2004) directly related to verbatim's content could be added to be as representative as possible of the discussion. The codes will then be organized by categories, themes, and sub-themes when needed using semi-deductive analysis (Paillé & Mucchielli, 2016). Moreover, data will be triangulated between 1) group activities' verbatim, 2) pictures (when applicable), and 3) the team's logbook. The data analysis will highlight the most dominant factors from each of the group activity. Consistent with the co-design paradigm, the advisory and work groups will be consulted when needed. The choice of behaviour change strategies will be oriented using the Behaviour Change Wheel (Michie et al., 2011), and a theory-based taxonomy will be used to guide the detailed development of each strategy (Kok et al., 2016). Moreover, the development and description of the concrete application of each strategy will be realized according to the Template for Intervention Description and Replication (TIDIeR) scale (Hoffmann et al., 2014), which will promote the exhaustive consideration and description of relevant elements (e.g. level of environment, stakeholders, material) for an optimal application of the strategies and future replication.

Ethical considerations

This study was approved (#MP-50-2022-1277) by the research ethics board of the research centre where the first, second, fourth and last author are affiliated. To be included in the study, each potential participant will have to read and sign an informed consent. Participants will be free to withdraw from the study at any time.

Discussion

This study will be conducted in collaboration with five Canadian post-stroke rehabilitation centres, using innovative methods combining the Intervention Mapping approach, co-design methodologies, and a rigorous theoretical framework. First, these methods will allow for a better understanding of the challenging situation regarding the lack of post-stroke sexual rehabilitation, according to the experience of persons with stroke, partners, clinicians, managers, and researchers. Secondly, these methods will orient the production of a multifactorial program with tools and strategies aiming to improve sexual rehabilitation. The program will likely be more relevant and useful for persons with stroke, partners, clinicians, managers, and organizations since stakeholders will actively participate in each phase of the study (Instituts de recherche en santé du Canada, 2016). We believe that the methods presented in this paper may not only be useful for guiding rehabilitation practice among a stroke population but could also provide valuable insights to improve rehabilitation services delivered to other clienteles such as spinal cord injury, traumatic brain injury and multiple sclerosis. Finally, by involving various stakeholders in using innovative and participatory approaches underpinned by robust theoretical frameworks, this study can contribute to implementation science (Bauer, Damschroder, Hagedorn, Smith, & Kilbourne, 2015).

Strengths and limitations

This protocol is characterized by numerous methodological strengths. First, the data collection methods using an adapted version Lego® Serious Play® method has been successfully pretested with five postgraduate students in preparation of this study. Secondly, by combining in-depth (i.e., adapted version of the Lego® Serious Play® method) and exhaustive (i.e., group discussions and collaborative reflections and work) data collection methods with each relevant group of stakeholders, namely persons with stroke, partners, clinicians and managers, results will be more likely to provide an accurate representation of participants' perceptions and experiences. Finally, the methods answer to the scientificity criteria in qualitative research (Drapeau, 2004) and were described in concordance with the COREQ to promote an exhaustive and transparent description (Tong et al., 2007). In fact, the analysis informed by robust frameworks, triangulation of data, and the ongoing analysis validation with the research team and the advisory and work groups will enhance the credibility and dependability of the results (Drapeau, 2004). Moreover, the variety of participants in the sample regarding stakeholders' type (e.g. persons with stroke, clinician) and location (i.e. three different regions in Quebec, Canada) will promote transferability of our results to other stroke rehabilitation settings.

The methods included in this protocol also have certain limitations. First, the sample of participants included in this qualitative study could limit the transferability of the results as they may not be representative of all the stakeholders in their category. In fact, since participants will be recruited in stroke rehabilitation settings, results are likely to be contextualized to this specific reality and may not be representative of stakeholders from other contexts of care, such as acute settings and community-based services. This could especially limit the transferability of results regarding the experiences, priorities and needs of persons with stroke and partners. However, a thorough consideration of the literature regarding people with stroke and their partners will be used in the assessment of needs and the program's development to complement the participants' contribution in each step of the study. Moreover, the inclusion of five different stroke rehabilitation centres from various geographic locations and various disciplines of clinicians will mitigate the impact of specific organizational or professional cultures. Nevertheless, the results will be contextualized to Quebec's healthcare system context and the stroke population. Therefore, results will need to be interpreted with caution in the context of other settings or populations. Secondly, the fact that data collection will be realized remotely may hinder participants' involvement during activities and limit the depth of data collected. However, the presence of trained facilitators in every group and the variety of data collection methods will foster participants' involvement and ensure rich and in-depth discussions during data collection.

Current study status

The recruitment of participants has been initiated.

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Bien que la majorité des méthodes décrites dans ce protocole aient été utilisées telles que décrites, certains ajustements ont été faits au fur et à mesure des différentes itérations inhérentes au travail de cocréation. Entre autres, deux modèles théoriques additionnels ont été utilisés dans les études #3 et #5 de cette thèse : le système *Capability, Opportunity, Motivation and Behaviour* (COM-B) et la Roue du changement de comportement, tous deux issus de l'étude de Michie et collaborateurs (2011). De plus, le troisième groupe composant l'effort de co-design, le « groupe de travail », n'a finalement été axé que sur les personnes ayant subi un AVC et des partenaires et a été renommé « groupe de validation » dans l'article 5. Ce choix a été fait considérant que les intervenants avaient été suffisamment impliqués dans le comité aviseur et les groupes LEGO®. Le détail des méthodes utilisées pour chaque étude est spécifiquement décrit dans chacun des articles inclus à cette thèse. Toutefois, afin de favoriser la clarté et la compréhension des lecteurs quant aux différents modèles théoriques utilisés, des informations complémentaires à celles décrites dans les articles sont présentées ci-dessous. Finalement, en ajout aux considérations éthiques décrites dans les articles 2, 3 et 5, le certificat d'approbation du Comité d'éthique de la recherche du Centre de recherche interdisciplinaire en réadaptation (CRIR) du Montréal métropolitain est disponible à l'Annexe 1.

La cartographie des interventions (Bartholomew et al., 2016)

En complément à la présentation et aux justifications figurant dans le protocole, dans le tableau 4 figurent une présentation sommaire des six étapes de la cartographie des interventions (Bartholomew et al., 2016) ainsi que les différentes tâches et livrables associés à chacune. Rappelons que les étapes 5 et 6 n'ont pas fait l'objet d'études dans le cadre de cette thèse, mais sont utilisées dans la discussion.

Tableau 4. – Les étapes de la cartographie des interventions (Bartholomew et al., 2016)*

Étapes	**Description**
1. Évaluation des besoins	• Planifier l'évaluation des besoins avec le modèle PRECEDE-PROCEED** (Green & Kreuter, 2005) • Évaluer les aspects de santé, de qualité de vie, les comportements et l'environnement • Évaluer les capacités de la population cible • Établir les objectifs du programme (retombées prévues)
2. Élaboration des matrices	• Établir les changements attendus au niveau des comportements et de l'environnement • Préciser les objectifs de performance • Préciser les déterminants • Créer les matrices associées aux objectifs de changement
3. Choix des méthodes basées sur la théorie et des stratégies	• Réviser les conceptions préliminaires du programme avec des membres de la population cible • Identifier les modèles théoriques • Choisir les méthodes utilisées dans le programme • Sélectionner ou élaborer les stratégies • S'assurer que les stratégies correspondent aux objectifs de changement
4. Élaboration du programme	• Consulter des membres de la population cible et les personnes qui l'implanteront

	- Élaborer la portée du programme, sa séquence, ses thèmes et la liste du matériel et des outils nécessaires - Développer des documents et des protocoles - Faire une revue du matériel disponible - Développer du matériel - Pré-tester les matériaux du programme auprès d'un groupe de la population cible et revoir l'ensemble des processus de production du matériel
5. Plans d'adoption et d'implantation	- Identifier les personnes adoptant et utilisant le programme - Préciser les objectifs de performance au niveau de l'adoption, de l'implantation et de la pérennisation - Préciser les déterminants de ces objectifs de performance et élaborer les matrices - Sélectionner les méthodes et les stratégies - Élaborer des interventions pour influencer l'utilisation du programme
6. Plan d'évaluation	- Décrire le programme - Décrire les hypothèses de retombées et d'effets du programme - Créer des questions en fonction des matrices - Créer des questions en fonction du processus - Développer des indicateurs et des méthodes de collecte de données, incluant des outils de mesure - Préciser le devis utilisé pour l'évaluation

**Traduction libre de la Figure 1.2. *Intervention Mapping* de Bartholomew et al. (2016), p.16

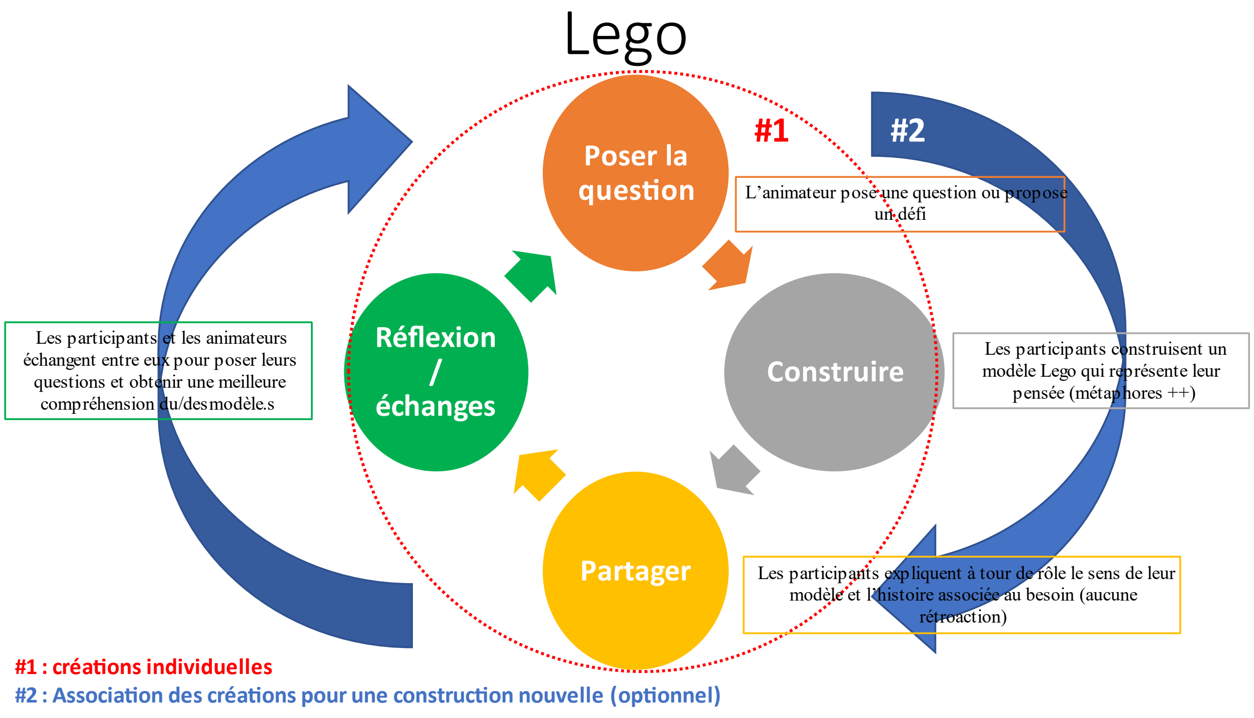
**Le modèle PRECEDE-PROCEED* permet d'orienter la création d'un modèle logique selon 4 niveaux : les déterminants, les facteurs comportementaux et environnementaux, le problème de santé et l'impact sur la qualité de vie (Green & Kreuter, 2005).

Le modèle de co-design de Morales et al. (2012)

Morales et collaborateurs (2012) ont conçu un modèle de co-design fondé sur celui de Sanders et Williams (2001), reconnu dans la littérature sur le sujet. Le modèle de Morales et collaborateurs (2012) pousse les limites de la co-conception jusqu'au développement de la solution concrète. Le modèle comprend quatre étapes : l'exploration, la co-conception, la validation et le développement. En résumé : l'exploration vise l'acquisition d'une meilleure compréhension de la problématique et des idées des participants; la co-conception vise l'élaboration d'un prototype de solution; la validation consiste à confronter le prototype aux avis d'experts dans le domaine dans le but d'évaluer sa faisabilité, de l'améliorer ou de le rejeter; le développement vise à créer les premières versions de la solution afin de la tester auprès des parties prenantes (Morales et al., 2012).

La méthode du LEGO® Serious Play® (Frick et al., 2013)

La figure 2 produite par Louis-Pierre Auger vulgarise les différentes étapes réalisées lors d'une activité de co-design mettant en œuvre la méthode LEGO® Serious Play® (Frick et al., 2013).



L'animateur pose une question ou propose un défi

Les participants construisent un modèle Lego qui représente leur pensée (métaphores ++)

Les participants expliquent à tour de rôle le sens de leur modèle et l'histoire associée au besoin (aucune rétroaction)

Les participants et les animateurs échangent entre eux pour poser leurs questions et obtenir une meilleure compréhension du/des modèle.s

#1 : créations individuelles

#2 : Association des créations pour une construction nouvelle (optionnel)

Figure 2. – Vulgarisation produite par L.-P. Auger du processus de la méthode de co-design Lego® Serious Play® (Frick et al., 2013).

Le Theoretical Domains Framework (Cane et al., 2012)

En complément aux informations figurant dans le protocole sur le TDF, sont présentées ci-dessous les définitions pour chacun des 14 déterminants composant le modèle théorique dans le tableau 5.

Tableau 5. – Les domaines du Theoretical Domains Framework (Cane et al., 2012) et leurs définitions

Domaine	**Définition**
Connaissances	La conscience de l'existence de quelque chose
Compétences	Une capacité ou une compétence acquise par la pratique
Rôle et identité professionnelle/sociale	Un ensemble de comportements et de qualités personnelles affichés par un individu dans un cadre social ou professionnel
Croyances par rapport aux capacités	Acceptation du caractère véridique, de la réalité ou de la validité d'une capacité ou d'un talent qu'une personne peut utiliser de manière constructive
Optimisme	La confiance que les choses se passeront pour le mieux ou que les objectifs souhaités seront atteints
Croyances par rapport aux conséquences	Acceptation du caractère véridique, de la réalité ou de la validité des résultats auxquels mènera un comportement dans une situation donnée
Renforcement	Augmenter la probabilité d'une réponse en organisant une relation dépendante, ou une contingence, entre la réponse et un stimulus donné
Intention	Une décision consciente d'accomplir un comportement ou une volonté d'agir d'une certaine manière
Buts	Représentations mentales des résultats ou des états finaux qu'un individu souhaite atteindre
Processus mnésiques, attentionnels et décisionnels	La capacité à conserver des informations, à se concentrer de manière sélective sur les aspects de l'environnement et à choisir entre deux ou plusieurs alternatives
Contexte environnemental et les ressources	Toute circonstance de la situation ou de l'environnement d'une personne qui décourage ou encourage le développement de compétences et d'aptitudes, l'indépendance, la compétence sociale et le comportement adaptatif
Influences sociales	Les processus interpersonnels qui peuvent amener les individus à changer leurs pensées, sentiments ou comportements
Émotions	Un modèle de réaction complexe, impliquant des éléments expérientiels, comportementaux et physiologiques, par lequel l'individu tente de traiter une question ou un événement personnellement significatif

Régulation du comportement	Tout ce qui vise à gérer ou à modifier des actions objectivement observées ou mesurées

Traduction libre de Cane et al. (2012), p. 13-14

Le système COM-B (Michie et al., 2011)

Le système *Capability, Opportunity, Motivation and Behaviour* (COM-B) de Michie et collaborateurs (2011) permet d'étudier les facteurs influençant le comportement selon les composantes des capacités, des motivations et des opportunités. Les capacités englobent les capacités physiques (ex., fonctions motrices) et psychologiques (ex., connaissances, habiletés) pour pouvoir réaliser un comportement. Les motivations représentent les processus mentaux qui orientent et amènent la personne à consacrer plus ou moins d'énergie dans ses comportements. Les motivations selon Michie et collaborateurs (2011) comprennent autant les processus mentaux conscients que ceux qui sont automatiques. Les opportunités, dans ce système, sont les facteurs externes à l'individu (c.-à-d., facteurs environnementaux), qui influencent positivement ou négativement la possibilité de réaliser le comportement. De la manière dont le système COM-B a été conceptualisé, A) les capacités, les motivations et les opportunités et B) les comportements pourraient s'influencer mutuellement. Par exemple, avoir les capacités suffisantes peut encourager la réalisation d'un comportement et la répétition d'un comportement peut influencer positivement les capacités associées. De plus, les capacités et les opportunités pourraient influencer les motivations, mais cette influence ne serait pas bidirectionnelle (c.-à-d., les motivations ne pourraient pas influencer les capacités ou les opportunités) (Michie et al., 2011).

La roue du changement de comportement (Michie et al., 2011)

La roue du changement de comportement est le résultat de la combinaison de 19 modèles théoriques et représente un outil circulaire à trois couches. La couche proximale est le système COM-B qui supporte la compréhension des facteurs influençant le comportement, la couche intermédiaire englobe neuf types d'interventions pour influencer les comportements et la couche distale comprend sept différentes politiques dont la fonction est de favoriser la mise en place des interventions. Le tableau 6 présente une définition de chacune des interventions et politiques de la roue du changement de comportement (Michie et al., 2011).

Tableau 6. – Définition des interventions et des politiques de la roue du changement de comportement (Michie et al., 2011)

Interventions	
Éducation	Améliorer les connaissances ou la compréhension
Persuasion	Utiliser la communication pour induire des sentiments positifs ou négatifs ou stimuler l'activation
Incitation	Créer l'attente d'une récompense
Coercition	Créer l'attente d'une punition ou d'un coût
Formation	Transmettre des habiletés
Restriction	Utiliser des règles pour réduire la possibilité de s'engager dans le comportement cible (ou pour augmenter le comportement cible en réduisant la possibilité de s'engager dans des comportements associés)
Restructuration de l'environnement	Modifier le contexte physique ou social
Modelage	Fournir un exemple à suivre
Habilitation	Augmenter les moyens/réduire les obstacles pour augmenter les capacités ou les opportunités
Politiques	
Communication et marketing	Utiliser les médias imprimés, électroniques, téléphoniques ou audiovisuels
Lignes directrices	Créer des documents qui recommandent ou imposent la pratique. Cela inclut toutes les modifications apportées à la prestation de services
Politiques fiscales	Utiliser la fiscalité pour réduire ou augmenter le coût financier
Réglementation	Établir des règles ou des principes de comportement ou de pratique
Législation	Créer ou modifier des lois
Planification environnementale/sociale	Élaborer et/ou contrôler l'environnement physique ou social
Prestation de services	Offrir un service

Traduction libre de Michie et al. (2011), p. 7

Chapitre 5 – Évaluation des besoins et priorités des parties prenantes de la réadaptation post-AVC en lien avec la réadaptation sexuelle

Dans ce chapitre est présenté le troisième article inclus à cette thèse, publié dans le journal *Sexuality and Disability* (Auger, Filiatrault, Allegue, Vachon, et al., 2023), comprenant des modifications légères issues du processus de révision de la thèse. Cet article représente l'étape 1 d'évaluation des besoins de la cartographie des interventions (Bartholomew et al., 2016) et répond aux deux premiers objectifs spécifiques de la thèse : 1) Comprendre les facteurs influençant l'offre de services de réadaptation sexuelle post-AVC par les intervenants au Québec; et 2) Explorer des stratégies qui pourraient être mises en œuvre pour améliorer les services de réadaptation sexuelle post-AVC.

Sexual rehabilitation after a stroke: a multi-site qualitative study about influencing factors and strategies to improve services

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Abstract

This study aimed to better understand the factors influencing the provision of sexuality-related post-stroke rehabilitation services by clinicians on different sites and to explore strategies to improve post-stroke rehabilitation services with stakeholders. A qualitative study with co-design methods was conducted with 20 clinicians from five post-stroke rehabilitation centers in Canada, 1 manager and 1 patient-partner. Participants either took part in a focus group or in sessions of an adapted version of the LEGO Serious Play method to explore influencing factors and strategies of improvement in relation to post-stroke sexual rehabilitation services. Thematic analysis was conducted semi-deductively using the Theoretical Domains Framework (TDF), the Capability, Opportunity, Motivation and Behaviour (COM-B) system and the Behaviour Change Wheel (BCW). A total of twenty factors pertaining either to the categories of Capability (n = 8; e.g., Sexual rehabilitation procedural knowledge), Motivation (n = 4; e.g., Professional boundaries) or Opportunity (n = 8; e.g., Workload) were perceived as influencing provision of sexual rehabilitation services by participants. A theoretical model was conceptualized. Strategies (n = 10) were categorized in concordance with the BCW as Training (n = 1), Enablement (n = 5) or Environmental restructuring (n = 4). This study showed that factors influencing provision of post-stroke rehabilitation services were numerous and interrelated, and that various strategies aiming either clinicians or the rehabilitation environment would be relevant to improve services. This study will help guide the design and implementation of future interventions studies aiming at improving post-stroke sexual rehabilitation services.

Key words: Sexuality, stroke, rehabilitation, co-design, Lego Serious Play, services, Canada

Declaration: The authors confirm that they have no conflicts of interest to declare.

Introduction

Around the globe, more than 110 million people live with the consequences of a stroke, including around 500 000 in Canada only (Canadian Chronic Disease Surveillance System, 2019; Katan & Luft, 2018). Stroke is a major cause of disability worldwide (Katan & Luft, 2018), as it can restrict participation in all activities of daily living (Ribeiro de Souza et al., 2022; Vincent-Onabajo, 2013). Stroke results in impairments (e.g., hemiparesis, cognitive impairment, aphasia), which can affect ones interactions with their environment (e.g., physical barriers, burden on caregivers) and restrict satisfactory participation in daily activities including sexuality (Nilsson et al., 2017).

Those living with the effects of stroke need quality services that are in alignment with stroke rehabilitation guidelines including specific recommendations on sexuality with the aim to promote their recovery and participation. Sexuality has been defined by the World Health Organization as "…a central aspect of being human throughout life [that] encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships" (World Health Organization, 2006, p.5).

Stroke rehabilitation guidelines from several countries recommend that sexuality be addressed as part of stroke rehabilitation (Mountain et al., 2020; Stroke Foundation, 2022; Winstein et al., 2016). Although up to 78% of people who sustained a stroke present sexual difficulties (Grenier-Genest et al., 2017) and that sexuality is an important concern for post-stroke individuals (Auger et al., 2020), less than 20% have the opportunity to address sexuality as part of their rehabilitation, from acute care to their return in the community (Guo et al., 2015; Low et al., 2022; Stein et al., 2013). Moreover, studies have shown that few clinicians include sexuality in their regular practice, even when they consider sexuality to be an important aspect of living (Richards et al., 2016; Young et al., 2020). Considering that sexual difficulties and dissatisfaction have been related to higher risks of depression and lower quality of life (Kim & Kim, 2008; Korpelainen et al., 1999), this gap between recommendations and actual practices needs to be addressed by improving the quality of sexual rehabilitation services for people who sustained a stroke.

Recently, Grenier-Genest and Courtois (2021) adapted a three-level model for sexual post-stroke rehabilitation, initially created for individuals presenting multiple sclerosis (Foley & Iverson, 1992). The aim is to deepen our understanding of the multiple impacts that a stroke can have on sexuality. According to this model, sexuality can be affected by the primary (e.g., severity of the stroke), secondary (e.g., incontinence, shoulder pain, fatigue) and tertiary impacts (e.g., anxiety, depression, change in partner's role) (Grenier-Genest & Courtois, 2021) effects of stroke. It is thus imperative that patients are provided evidence-based sexuality rehabilitation. A recent systematic review (Auger, Grondin, et al., 2021) found benefits of carrying out sexual rehabilitation using an interdisciplinary approach for people who sustained a stroke, which included specific skills development (Vajrala et al., 2021), pelvic floor muscle training (Tibaek et al., 2015) and education (Ng et al., 2017; Sansom et al., 2015). Moreover, this review suggested a need for more robust studies in the field of sexual rehabilitation, considering that only four randomized controlled trials were found in the literature (Auger, Grondin, et al., 2021).

However, despite all that is known regarding the importance of addressing sexuality in stroke rehabilitation, multiple barriers such as a perceived lack of knowledge and skills and/or comfort on the subject matter, fear of opening a can of worms and insufficient resources may prevent clinicians from integrating sexuality in their practice (Dyer & das Nair, 2013; Hyland & Mc Grath, 2013; Richards et al., 2016). Moreover, past studies have shown that barriers at the organizational (e.g., resources) and systems (e.g., policies) levels can negatively affect compliance with guidelines, whether related to sexuality or to any other topic (Thomas et al., 2021). Nonetheless, these studies on the factors that influence sexuality-related clinical practices did not improve services in stroke rehabilitation context (Banks & Pearson, 2004; Low et al., 2022; Richards et al., 2016; Sjögren, 1983).

To our knowledge, only two implementation studies of sexuality-related services in stroke rehabilitation have been conducted to date (Auger, Pituch, et al., 2021; Guo et al., 2015). This scarcity of research in this area could be linked to previous studies having insufficiently described the nature of the barriers encountered by clinicians and other stakeholders involved in stroke rehabilitation and suboptimal operationalization of recommendations in practice. There is a need to better understand the breadth of factors that influence provision of post-stroke sexual rehabilitation services so that evidence-informed interventions can be developed, implemented and tested. Ultimately this could lead to positive and lasting changes in the delivery of sexual rehabilitation services to people living with the devastating effects of stroke.

Objectives

This study aimed to: 1) understand the factors influencing the provision of sexuality-related post-stroke rehabilitation services by clinicians in the province of Quebec, Canada; and 2) explore strategies to improve post-stroke rehabilitation services with stakeholders (clinicians, managers and an individual who experienced post-stroke rehabilitation services).

Materials and methods

Design:

This qualitative descriptive study (Kim et al., 2017) is the first part of a larger project aiming to co-design a multifactorial program for improving the provision of post-stroke sexual rehabilitation services using the six steps of the intervention mapping approach developed by Bartholomew et al. (2016). In the present study, attention was given to the first step of the Intervention Mapping, namely to "Conduct a needs assessment or problem analysis"; the focus was on both aspects of step 1: The first objective focused on understanding the factors leading to the lack of sexual rehabilitation services (i.e., problem analysis). The second objective explored stakeholders' needs and perceptions regarding sexual rehabilitation service provision (i.e., needs assessment).

The methods used in this study and the rationale for their use will be succinctly described below. More details are provided in the published research protocol paper (Auger et al., 2022). The description of this qualitative study was based on the Consolidated criteria for reporting qualitative research - COREQ (Tong et al., 2007).

Overarching approach and theoretical framework:

This study was conducted using an integrated knowledge translation approach (IKT). The main premise of IKT is that by including representatives of key stakeholder groups throughout the study is more likely to produce relevant and actionable results by end users (Gagliardi et al., 2015; Kothari & Wathen, 2017).

We opted to use co-design methods as these can 1) promote mutual understanding among stakeholders participating in the research project and 2) facilitate collaborative work. Co-design methodology promotes conversations and collaborative and creative thinking between participants (Morales et al., 2012), and allows for exploration of alternative strategies such as projective methods or visual means (Sanders, 1999; Sanders & William, 2001; Stappers & Sanders, 2005). Data collection and analysis consisted of using a combination of co-design methods, including an adapted version of the LEGO® Serious Play® method (Auger et al., 2022; Frick et al., 2013). The LEGO® Serious Play® method (Frick et al., 2013) consists in asking participants to create a LEGO® model that represents their answer to a question or problem that has been posed to them. The time spent creating the model, presenting it to the rest of the group and exchanging regarding the different models is expected to lead to deeper conversations and better understanding between participants (Frick et al., 2013). This was designed to provide a more holistic understanding of the facilitators and barriers to implementation of sexuality-oriented services, and therefore led to realistic strategies to address the identified barriers.

We used the Theoretical Domains Framework (TDF) to orient the collection and analysis of the qualitative data (Cane et al., 2012; Michie et al., 2005). The TDF was created by combining 33 theories and empirically tested and can support the analysis of the individual and environmental factors that influence behaviour change. The factors are organised into 14 domains: Knowledge, Skills, Social/Professional Role and Identity, Beliefs about Capabilities, Optimism, Beliefs about Consequences, Reinforcement, Intentions, Goals, Memory, Attention and Decision Processes, Environmental Context and Resources, Social Influences, Emotions, and Behavioural Regulation.

Finally, the Capability, Opportunity, Motivation and Behaviour (COM-B) system and the Behaviour Change Wheel (BCW) (Michie et al., 2011) have been respectively used to categorize the domains and related influencing factors and to categorize strategies. The COM-B system supports the understanding of behaviour (herein, sexual rehabilitation practices) by considering the mindful and automatic individual-level influences (Capability and Motivation) and those stemming from their environment (Opportunity). It can be used in conjunction with the TDF (Atkins et al., 2017) to study behavior change and to design interventions to promote uptake of best practices (Michie et al., 2011). Throughout the study, the components of the COM-B system (Michie et al., 2011) will be presented in the following order for coherence between individual and environmental factors: Capability, Motivation and Opportunity. The BCW suggests nine categories of intervention: Education, Persuasion, Incentivization, Coercion, Training, Enablement, Modelling, Environmental Restructuring and Restrictions (Michie et al., 2011).

Sampling and recruitment

To gather a variety of perspectives, we recruited stakeholders representing clinical practice, management, coordination of clinical services, and people with lived experience from the five largest organizations providing stroke rehabilitation services in the province of Quebec (Canada), which acted as partner organizations.

To be included in the study, participants had to be a practicing healthcare professional (in any profession); a coordinator of clinical services; managers with a minimum of one year of experience in stroke rehabilitation (either inpatient rehabilitation, early supported discharge or outpatient rehabilitation). The person who sustained a stroke needed to be at least 1-year post-stroke, to have experienced inpatient and outpatient stroke rehabilitation and to be able to participate in group discussions. Clinicians were recruited via an email sent by their manager. The manager, coordinators and person with lived experience of stroke rehabilitation were recruited through the research team’s professional network. Once participants agreed to participate in the study, they were assigned to the Advisory group or to one of the two LEGO® groups.

Data collection

All data collection activities were conducted in groups, via Zoom and with two experienced facilitators. Advisory group meetings were conducted using focus group methodology to obtain an overview of the factors that influence sexual rehabilitation and the possible strategies that can be implemented to support evidence based sexual rehabilitation (Fontana, 2000). To orient the discussions, the facilitators used an interview guide based on the 14 domains of the TDF (Cane et al., 2012) and began with the following overarching question : “What do you think explains why sexuality is poorly addressed in stroke rehabilitation?”.

The two LEGO® groups were conducted using the same activities, summarized in Table 7 and described in detail elsewhere (Auger et al., 2022). The discussions in each group were recorded and transcribed verbatim. Participants in the LEGO® groups were asked to take pictures of their LEGO® models after each activity and to send them to the research team. Each verbatim was uploaded on the *QDA Miner* software to support analysis.

Tableau 7. – Activities realized in the groups using an adapted version of the LEGO® Serious Play®

Session	Activity	Assignment
1	LEGO® ideation* - Familiarization	“Build a LEGO® model representing a house”
	LEGO® ideation - Barriers	“Build a LEGO® model representing the main barrier, or barriers, influencing integration of sexuality in stroke rehabilitation”
2	LEGO® ideation - Strategies	“Build a LEGO® model representing the main strategies that would improve integration of sexuality in stroke rehabilitation”
	Group discussion – Training**	“Tell us about what you would like, or require, from a professional training on sexuality for stroke rehabilitation”

*Participants who took part in the activity: 1) were given a question to answer, 2) built a LEGO® model, 3) presented their model, and 4) exchanged with other participants about every model.

**A portion of the second session of the LEGO® groups was dedicated specifically to a group discussion regarding a professional training on sexuality since it was the main request of partner organizations at the onset of the project.

Data analysis

Transcripts were analyzed using a combination of deductive and inductive thematic analyses (Paillé & Mucchielli, 2021) anchored in the TDF (Cane et al., 2012). After listening to the recording, the first and second authors created a coding grid based upon the 14 determinants of the TDF (Cane et al., 2012) and sorted the strategies according to the BCW (Michie et al., 2011). New themes could also have been created for data that may not have aligned with the TDF domains or categories of intervention of the BCW. The two coders then independently coded the Advisory group transcripts (represented 20% of the total data). Both coders shared their understanding of the emerging themes and related codes to reach consensus and better standardize further coding of the remaining transcripts by the first author. The themes were sorted hierarchically by categories, themes and sub-themes (when applicable) and were presented in tables for clarity. Pictures of certain LEGO® models with the description generated by the person that created them were presented for each objective to demonstrate the depth of the reflections carried out. The analyses and preliminary findings were shared iteratively with the research team for discussion.

The first author kept a logbook throughout the research project to collect his thoughts and make explicit his progressive understanding of the assumptions that characterize the problem being investigated. The data analysis was conducted and presented in concordance with the criteria of the COREQ (Tong et al., 2007).

Ethical considerations

This study was approved by the Research Ethics Board of the research center to whom the first author is affiliated (#MP-2022-1277). To take part in the study, each participant provided an informed consent by signing an information and consent form. They were free to withdraw from the study at any time.

Results

Participants' description

Participants were between 29 to 65 years of age and of female gender. The sample included 16 clinicians (four physical therapists (n = 4), three occupational therapists (n =

3), three nurses (n = 3), two social workers (n = 2), one psychologist specialized in sexuality (n = 1), one neuropsychologist (n = 1), one speech language pathologist (n = 1) and one specialized educator (n = 1); one manager (n = 1), one patient-partner (at the time of participation to the study, the patient-partner was 7 years post-stroke and had experienced inpatient and outpatient stroke rehabilitation), and four researchers with expertise in knowledge translation, implementation science, professional practice, qualitative research and/or sexuality.

Participants who were clinicians or managers had 1 to 30 years of experience in stroke rehabilitation. Participants worked in inpatient rehabilitation (n = 13), in outpatient rehabilitation (n = 7) and in early supported discharge (n = 3), which included certain participants that were implicated in more than one program. Participants' sociodemographic and professional characteristics are described in detail in Table 8.

Tableau 8. – Participants' sociodemographic and professional characteristics

Participant ID	Sociodemographic data					
	Age	**Gender**	**Professional discipline**	**Stroke program**	**Years of experience**	**Affiliation***
Advisory Group						
1	29	Female	Occupational therapist	Outpatient	4	1
2	65	Female	Psychologist specialized in sexuality	Outpatient, Inpatient, Research	8	1, Université du Québec à Montréal
3	29	Female	Nurse	Early supported discharge	4	2
4	38	Female	Physical therapist	Inpatient	14	3
5	53	Female	Nurse	Inpatient	18	5
6	36	Female	Neuropsychologist	Inpatient, Early supported discharge, Outpatient	7	4
7	60	Female	Manager	Inpatient, Early supported discharge, Outpatient	30	1
8	37	Female	Expert patient	NA[a]	NA	NA
9	55	Female	Research coordinator and occupational therapist	NA	NA	1
10		Female	Occupational therapist	Research		Université de Montréal
11	51	Female	Occupational therapist	Research	26	Université de Montréal
12	52	Female	Occupational therapist	Research	30	McGill University
LEGO® Group 1						
13	38	Female	Occupational therapist	Inpatient	16	1
14		Female	Physical therapist	Inpatient, outpatient		3
15	34	Female	Occupational therapist	Inpatient	9	2
16	45	Female	Social worker	Inpatient	7	5

17	34	Female	Speech language pathologist	Inpatient	2	4
LEGO® Group 2						
18	39	Female	Physical therapist	Outpatient	8	3
19	43	Female	Physical therapist	Outpatient	14	2
20	56	Female	Specialist educator	Inpatient	7	5
21	60	Female	Nurse	Inpatient	20	4
22	40	Female	Social worker	Inpatient	5.5	1

*For confidentiality purpose, the identification of the partner organization to which each participant is affiliated has been associated to a number.

[a]NA: Not applicable.

Objective 1: Factors influencing the provision of sexuality-related rehabilitation services

The factors (n = 20) influencing the integration of sexuality in stroke rehabilitation were separated between three categories of the COM-B system (Michie et al., 2011): “Capability”, “Motivation” and “Opportunity” and were associated to one of the 14 domains of the TDF (Cane et al., 2012). “Capability” included eight (n = 8) specific factors which pertained either to “Knowledge”, “Skills”, “Attention, memory and decision processes”, or “Behavioural regulation”. “Motivation” included four (n = 4) specific factors related to “Beliefs about capabilities”, “Professional role and identity”, “Emotions” and “Goals”. The category “Opportunity” pertained eight (n = 8) factors that were related either to the domains “Social influences” or “Environmental context and resources”. The categories, domains and factors are detailed in Table 9, and a theoretical model showing interactions between the TDF domains that included influencing factors for provision of sexual rehabilitation services, founded on the COM-B, is presented in Figure 3. Finally, a LEGO® modes depicting some of the influencing factors is presented in Figure 4.

Tableau 9. – Factors perceived as influencing clinicians in the provision of sexuality-related rehabilitation services categorized using the Capability, Opportunity, Motivation and Behaviour (COM-B) system (Michie et al., 2011) and the Theoretical domains Framework (TDF) (Cane et al., 2012).

TDF domains	Factors	Description	Verbatim
CAPABILITY			
Knowledge	- Basic sexual rehabilitation knowledge - Advanced sexual rehabilitation knowledge - Sexual rehabilitation procedural knowledge	- Sufficient knowledge on sexual anatomy and sexual response. - Knowledge gaps regarding sexual diversity, sexual trauma and how services should be adapted in these contexts. - Lack of knowledge regarding what, how and when to address sexuality in an appropriate way.	Our need is to be equipped about how to address the subject [sexuality]. So it's not really the subject of sexuality with a post-stroke [individual] but … at the level of intervention. (P22 – Social worker) We talked about it quickly, but to be aware of the reality of the LGBTQ [Lesbian, Gay, Bisexual, Trans and Queer] community and to victims of sexual trauma in the way to address sexuality and to train clinicians minimally. (P11 - Researcher)
Skills	- Screening skills - Assessment skills - Intervention skills	- Lack of skills to provide sexual rehabilitation services - Sexuality-related training not part of initial university curricula. - Poor procedural knowledge of the "How-to" regarding sexual rehabilitation, especially in relation to assessment and intervention (i.e., what, how, when) for persons with stroke who confirmed their need to address sexuality.	The knowledge, the tools, the techniques, that we never had. Well, personally, I have never been trained [about sexuality]. (P20 – Specialized educator)
Memory, attention, and decision processes	- Integration in standard clinical tools	- Forgetfulness because sexuality is absent from the disciplinary assessment charts and the	We will question the presence of dizziness, headaches, bla bla, but I have nothing that remind me to question systematically on that [sexuality]. (P18 – Physical therapist).

		interdisciplinary intervention plans that are provided by their organization.	
Behavioural regulation	- Routine stroke practice habits	- Stroke rehabilitation was considered to impose a fast pace on clinicians and impact what they thought important, or forgot to address.	Time is limited […] it's always "the quicker we can give a discharge, that clients be independent", and then we admit another [client] … anyway. (P21 – Nurse)
MOTIVATION			
Beliefs about capabilities	- Self-efficacy related to sexual rehabilitation	- Feeling of being "unequipped" regarding sexual rehabilitation. - Lack of confidence related to poor procedural knowledge. - Various level of confidence among participants for having a conversation about sexuality and screening for the need to address sexuality but generally deemed sufficient.	Me, I am not able … I don't feel equipped to answer that [sexuality issues]. (P20 – Specialized educator) If I address the question [sexuality], I open the door, but after, I don't know what to do […] I could tell some ideas of solutions, but I have not been trained about that. (P6 - Neuropsychologist)
Professional role and identity	- Professional boundaries	- Uncertainty or ignorance about professional roles in sexual rehabilitation. - Fear to exceed the limits of their professional scope of expertise (e.g., when to stop) led to avoidance of the subject of sexuality by clinicians. - Concerns about having to play the role of a sex therapist or having to engage in couples' therapy.	Sometimes I wonder, as speech language pathologists, can we [address sexuality]? Our [professional] order gives us many guidelines about what we can do but […] that [sexuality], do I have the right to address it too? What are the guidelines? (P17 – Speech language pathologist) Me, I am not trained in couples therapy. So, I know that it is not everyone who is single, and that we can also talk about sexuality and all that […] it's more often the social worker who will see

			the patients with their partner. (P6 - Neuropsychologist) There are things that we can easily do by ourselves sometimes. I would like to prove to people that, ok, we don't necessarily have to sex specialists to solve our patients' problems regarding sexuality. (P21 – Nurse)
Emotions	- Comfort	- Participants shared that they would be comfortable addressing sexuality if they felt competent doing so. - The taboo aspect of sexuality was raised often, participants describing sexuality as a subject difficult to address, delicate, in clinical practice. - Not being able to provide services themselves (i.e., disciplinary intervention), not knowing where to refer their clients when needed or referring their clients to an inaccessible service for them because of costs or waiting lists were sources of discomfort.	Me, I work at clients' homes. However, since I'm not trained [in sexuality], not being comfortable and not equipped, I used to refer to a colleague more trained. But if I was trained, if I was comfortable with it [sexuality], that would be a different story. (P20 – Specialized educator) Of course there are people who are uncomfortable talking about sexuality, end of the line. It's ok, it's their right. But it's really the feeling of being unequipped. (P2 – Psychologist) I would just be worried that everybody address the subject with certain clients for whom it is [sexuality] already sensitive and that it just becomes too much. (P15 – Occupational therapist)
Goals	- Goal priority	- Sexual rehabilitation is considered important to address after a stroke. - Participants showed ambivalence about the priority given to sexuality by	There are so many other priorities [to choose between]. Everyone is so overloaded with other tasks and subjects to address with patients. (P6 – Neuropsychologist)

		patients especially during inpatient rehabilitation. - Participants often said that they were perhaps not aware of the real needs and priorities of their clients and that it was up to them to choose what was their priorities.	But it is sure that we are therapists, and in my own book, it is walking and transfers [priorities]. But it doesn't mean that for my patient it will necessarily be that. So I think that we have to be careful not to take anything for granted […] because there are lots of things that they [clients] don't tell us and that, finally, that were their priorities. (P4 – Physical therapist) Well, no, I don't remember that it [sexuality] was really addressed [during inpatient rehabilitation]. I must say that me neither, I didn't think about it. I found it more important to get everything I could get from the physical therapy and occupational therapy side. (P8 – Patient-partner)
OPPORTUNITY			
Social influences	- Support from specialized resources	- The absence of, or lack of access to, clinicians specialized in sexuality in the work environment, either for acting as a contact-person or for referrals, was reported as an important barrier. - Sex therapists, physical therapists specialized in pelvic floor muscle training and colleagues in their own disciplines that were skilled and knowledgeable about sexuality were perceived as needed. - Having positions available, recruiting and/or retaining sex therapists in	[…] In the [healthcare] system, when speaking about shortage, sex therapists are on top of the list. (P7 – Manager) We had sex therapists at the institute a long time ago, but now we don't, they disappeared from the [public healthcare] system. So the subject [of sexuality] just finished by dying you know. (P16 – Social worker) Before we had a physical therapist specialized in pelvic floor muscle training, but we don't have one now. And that was really an access point to

		employment was a problem for partner organizations.	discuss about that [sexuality]. (P14 – Physical therapist)
	- Interdisciplinarity - Lack of access to interdisciplinary outpatient services	- Interdisciplinarity and the level of access to other professionals was perceived as important to provide appropriate sexual rehabilitation services. - Services provided by an interdisciplinary team are more accessible to clients in inpatient rehabilitation and early supported discharge, in comparison to outpatient rehabilitation.	I wanted to add that interdisciplinarity is very important. In fact, me, what I try to do in speech therapy, it's often to go with the occupational therapist, the physical therapist, if I have a very aphasic person, and I will help to pass, I don't know, an assessment tool. (P17 – Speech language pathologist) For us… it's sure that the two first clinicians are the OT and the PT … for social workers, speech language pathologists and psychologists, there are waiting lists, even in inpatient [rehabilitation]. (P15 – Occupational therapist)
Environmental context and resources	- Workload	- Stroke rehabilitation was reported as a work setting where pressure to perform was important. - Shortened duration of stay, increase in the severity and/or number of cases treated at a time and long waiting lists were among the factors shared by participants to explain their feeling of being overwhelmed in their work. - This overload in carrying out usual tasks acted as a barrier to integrating new tasks such as those related to sexual rehabilitation by clinicians.	We have to think about who are the clinicians that will need to be trained [to use a new tool related to sexuality]. What do they already do? I'm not saying it's a bad thing, it would really standardize practice, but it's still adding up a task for clinicians who already have many. (P3 – Nurse)

	- Amount of professional resources - Dedicated financial resources	- The possibility to buy equipment, hire human resources and provide professional training in relation to sexuality influenced the perceived feasibility of improving services in sexual rehabilitation.	I think that my crew has done all the training that were available, which is not a lot. But the challenge is really when talking about the lack of specialized support, and it's not because of the money. There are not a lot of sex therapists, and the ones we had, well, sadly they don't stay in rehabilitation for long because it pays less. It's much more profitable to be in the private [sector]. (P7 – Manager)
	- Environment allowing for privacy	- Availability for a private and/or closed environment were characteristics that made working environments more or less proper to address sexuality. - Participants also considered that clients did not have the necessary privacy to experience their sexuality in their room when in inpatient setting.	[The occupational therapy gym] It's a big room where there can be 5 or 6 clients in intervention [with clinicians]. It's not there that they will address sexuality. It's not likely. (P20 – Specialized educator) To be able to discuss [sexuality] with the patient, we would need to remove everything that is… the sight of other people in the gym. (P14 – Physical therapist) The irony is that, in speech therapy, we have our office. Because we were talking about confidentiality earlier. We're very confidential, but it [sexuality] doesn't come out with us. (P17 – Speech language pathologist)
	- Availability of sexual rehabilitation tools and material	- Participants reported an important lack of assessment and intervention tools to support them in their practice, which	

		prevented them from addressing sexuality. - Few of the available educational tools, such as pamphlets, booklets and posters on topics of stroke rehabilitation addressed sexuality.	We have nothing related to sexuality, we have papers dating from the 40s, we have nothing to give our patients. (P19 – Physical therapist)

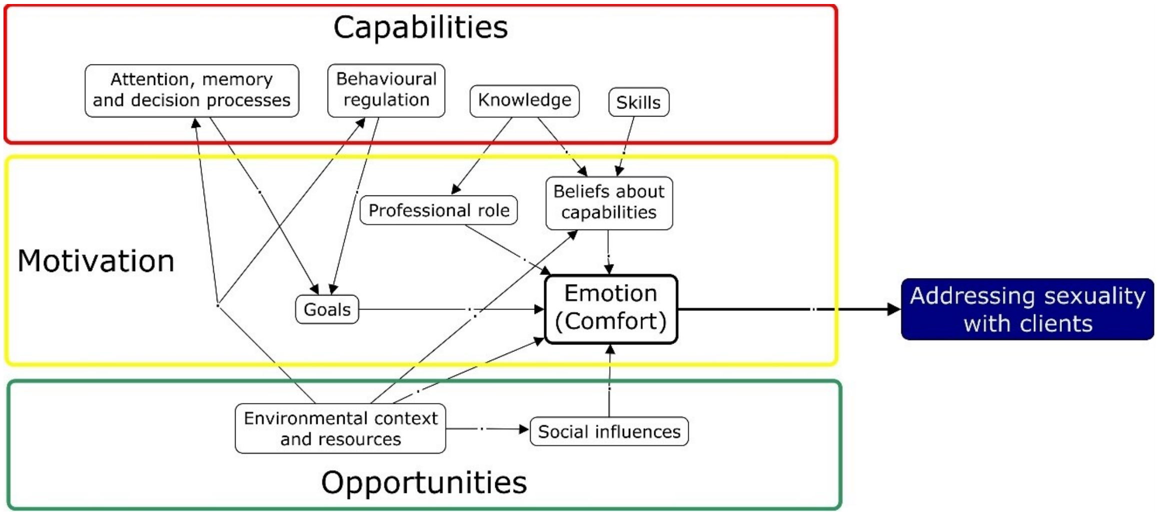

Figure 3. – **A theoretical model that presents the domains perceived as influencing provision of sexual rehabilitation services combining the Theoretical domains Framework (Cane et al., 2012) and the Capability, Motivation, Opportunity and Behaviour (COM-B) system (Michie et al., 2011).**

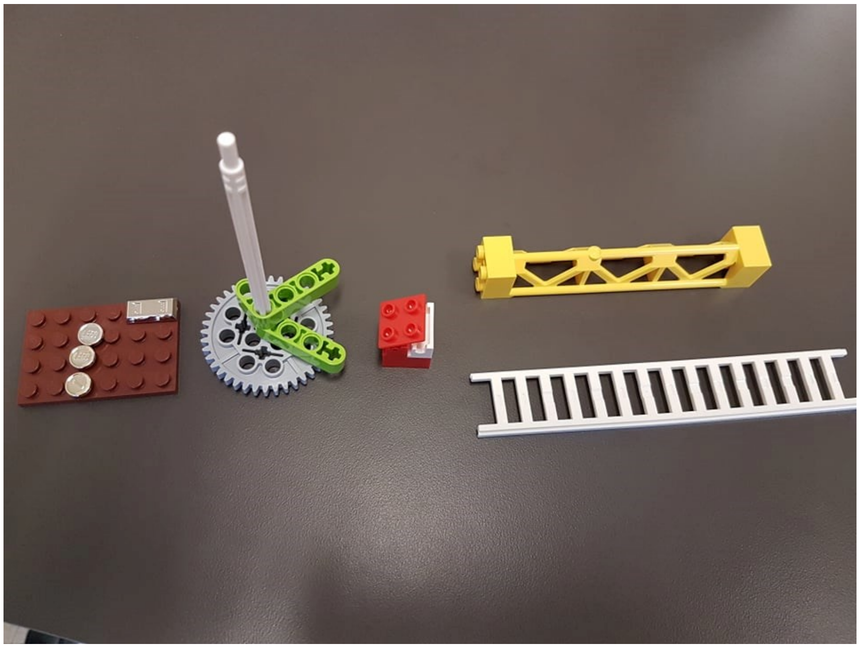

Figure 4. – **Participant 18's LEGO® model representing barriers to address sexuality in her clinical practice.**

Paraphrasing of participant 18's discourse. From left to right: The brown rectangle represents a disciplinary assessment canvas that does not include sexuality. The gear wheel represents a clock and signifies time, or lack of, and work overload where time dedicated to each client is reduced because of waiting lists. The red cube represents a Pandora box, where clinicians uncover clients' complex sexuality issues that they do not feel they can help them with, which brings discomfort and restrain from discussing sexuality. The yellow structure and the white ladder represent bridges that are not related to anything, and signify clinicians' unanswered need of being related to a specialist to support them, or refer their clients to, when they address sexuality.

Objective 2: Strategies to improve post-stroke sexual rehabilitation

A total of ten strategies to improve sexual rehabilitation services were expressed by participants, which were organized according to the main category of intervention of the BCW (Michie et al., 2011) that they were related to: “Training”, “Enablement” and “Environmental restructuring”. The category “Training” included the strategy “Sexual rehabilitation training”. The category “Enablement” included five strategies: “Inventory of professional roles”, “Integrating sexuality via existing tools and procedures”, “Adding new sexuality-related tools”, “Post-stroke sexuality knowledge translation toolkit” and “Access to a contact-person”. The category “Environmental restructuring” included four strategies: “Clarifying the nature of recommended sexual rehabilitation services”, “Access to environment ensuring privacy”, “Access to referral options” and “Slowing down stroke rehabilitation”. Although each strategy was associated to a main category of intervention of the BCW, they could include components of other categories of intervention. For example, the strategy “Sexual rehabilitation training” is likely to include components of education, persuasion and/or modeling. The strategies are described in detail in Table 10, and a model created by a participant, depicting some of the strategies, is presented in Figure 5.

Tableau 10. – Ten strategies to improve post-stroke sexual rehabilitation organized with the main category of intervention of the Behaviour Change Wheel (Michie et al., 2011)

Strategy	Description	Verbatim
Training		
1) Sexual rehabilitation training	All participant agreed that a training was needed for clinicians. Participants also suggested that different levels of training be offered so that clinicians could choose the extent to which they want to be trained according to their level of comfort and motivation regarding sexuality.	It would be interesting […] that all clinicians receive a general training. What does that include [sexuality]? What do we address as a team? What are the general problems with sexuality after a stroke? In the whole spectrum of the person, so, interpersonal, language, cognitive, physical, a little of everything. What could make that we are more comfortable addressing it [sexuality] (P13 – Occupational therapist) a training in two sessions which are still spaced out in time by 2 to 4 weeks where you have like homework, where you have to put into practice what you saw the first time, then after that to review at the second session, then build on it. […]If it's just one session, you think about it for a week and then after that, it's over. (P15 – Occupational therapist)
Enablement		
2) Inventory of professional roles	A way of describing clearly, sharing and formalizing the professional roles of the various clinicians of the interdisciplinary team would foster the appropriation of their own disciplinary role and their colleagues', therefore promoting more fluid teamwork.	[…] That each [clinician] can address it if the patient of course wants to talk about sexuality. But according to their own... their own expertise, therefore, the neuropsychologists can address more the emotional side […] and the speech therapist can bring more the language side, and communication with the spouse or communication in general […] OT and PT, we are going to discuss more […] positioning or technical aids. Or the techniques also to be taken as a little more OT and PT, which is a little more concrete. (P13 – Occupational therapist)
3) Integrating sexuality via	Adding the topic of sexuality to existing disciplinary or interdisciplinary assessment canvas was suggested. This	Me, I feel that if I had that [sexuality] written down [in her assessment chart], and I only had to answer yes or no, and

existing tools and procedures	could act as a reminder to address sexuality for clinicians. Moreover, adding sexuality in procedures common to the entire stroke clientele, such as interdisciplinary intervention plan workshops or giving the responsibility to a specific discipline, may systematize addressing sexuality. Since sexuality may be difficult to address in group workshops, participants suggested that the clinician targeted to discuss sexuality with the client could be systematically designated.	ask my patients if they have difficulties or if they want to talk about it [sexuality], I would be open to that. (P15 – Occupational therapist) As an OT, I think that in OT, we look so much in detail to every occupation that… I would find that normal that it [addressing sexuality] comes from the OT. (P15 – Occupational therapist) It has to be addressed by more than one person [...] it has to be multidisciplinary because the problem is not always related to the same aspect. (P19 – Physical therapist)
4) Adding new sexuality-related tools	The availability of tools that could support the detection of the need to address sexuality in rehabilitation was mentioned. Ideally, these tools should detect not only the general need to address sexuality, but also the specific consequences of stroke that might influence sexuality and support targeted referral. A version of that screening tool could be created in a self-administered format allowing clients to be able to explore their need to address sexuality by themselves. Assessment tools that would help clinicians get a better understanding of the nature of the sexual difficulties faced by people who sustained a stroke were deemed necessary. These tools should be usable by all allied health and medical professionals, or their use by specific disciplines should be clarified. Participants shared a preference for assessment tools with open-ended	A screening would be important. Because if we know exactly what are the needs in that area [sexuality] : is it positions, is it information, is it communication? From there, we will be able to tell who would be the proper clinician to address them. (P3 – Nurse) I need a tool where the clients will answer simply and tell us if it's something that they want to address regarding sexuality. Then, can the client identify what are the issues to know to which clinician… who has to intervene about them? (P21 – Nurse) I'm not saying it absolutely takes a cold questionnaire about sexuality […] I see the balance between making sure that it is made systematically [addressing sexuality] […] but also how should the person be addressed, when, etc., and that is was done in a delicate way. (P6 – Neuropsychologist)

	questions that would foster discussions with their clients, rather than questionnaires with only close-ended questions. Intervention tools were the most requested by participants. Fact sheets, infographics and checklists pertaining to different subjects of sexuality (e.g., positioning, communication, medication) could support provision of sexual rehabilitation services. Moreover, decision algorithms guiding clinicians to choose specific interventions depending on the situation, or orienting them when specific limitations affecting sexuality were shared or presented by the clients, were requested by participants. The tools should be available in online and paper formats to be suitable to different contexts of practice.	
5) Post-stroke sexuality knowledge translation toolkit	Short tools such as pamphlets and informative posters, or more detailed resources such as booklets or synchronous or asynchronous informative capsules or the visual support for educational sessions were suggested by participants. Moreover, participants favored the variety of media to transfer the knowledge, either to 1) the client alone, 2) the client and the clinician or 3) in group setting, in order to adapt to clients' own preferences, comfort and limitations. Knowledge translation tools should be adapted for people with aphasia and/or cognitive impairment, be complementary and provide only the most important	Information sessions where the person [client] would not necessarily feel obliged to discuss his sexual problems from the first meeting and could on the other hand receive some information […] At least to have information meetings that are general, where you are going to be given information on sexuality or also by zoom… the person can very well receive the information by zoom. (P14 – Physical therapist) That we would have something to give to the patient… it would be very cool. (P1 – Occupational therapist)

	notions for people who sustained a stroke who wish to improve their knowledge regarding sexuality. Knowledge translation tools should be made available in both paper and online formats, and clients and relatives should be able to access them without intervention of a clinician and/or outside of the therapy setting.	Clearly, I think that a poster […] could raise a flag. Maybe, to have something visual, could have acted as a reminder and make me think: "Yeah, there will be that [sexuality] to address too". (P8 – Patient-Partner)
6) Access to a contact-person	A person that could answer to clinicians' questions and provide guidance on the methods they could use in their own practice regarding sexual rehabilitation was considered a relevant strategy by participants. The support of the contact person was considered relevant 1) in the process of changing practice (eg, following training) and 2) also in routine practice. That person could be a sex therapist or a clinician of the same discipline more experienced in sexual rehabilitation. Ideally, that person would work in their organization, but could also be a consulting clinician from another institution. Access to that contact-person should be easy for clinicians.	Yes, I would be super interested in a training. But that there would be a contact-person in the team, I would say yes. (P20 – Specialized educator) It's good to be able to talk with someone [a specialist] that can make us think. (P18 – Physical therapist) A specialist that knows more, that […] when we don't know what to do with what the patient told us and that it is not in our competencies, to have someone that we can contact, and maybe refer to. (P19 – Physical therapist)
Environmental restructuring		
7) Clarifying the nature of recommended sexual rehabilitation services	Clarifying the different services that could be delivered in relation to available guidelines, and transmitting them to clinicians in a user-friendly format such as a checklist, a memory aid or other, could support the provision of sexual rehabilitation services. Moreover, such clarification could include which services are mandatory in order to comply with guidelines, and which are optional. Better knowledge of the relative importance of each sexual rehabilitation service could foster	I think it's having this listening, the person who dares to talk about it, who dares to approach the subject, then to refer to the right people, if you don't have the knowledge, but I think everyone should be able to receive these comments and to offer any support, whether it is the own clinician or other professionals around. (P16 – Social worker)

	collaboration and distribute the burden between each phase of stroke rehabilitation.	
8) Access to environment ensuring privacy	All clinicians from any discipline should have access to a room with a closable door. That room would need to be easily and quickly accessible in the event that an unforeseen opportunity arises to address sexuality with the client. That environment dedicated to address sexuality may include comfortable chairs, soothing decorations and a window, to foster comfort and relaxation. No specific strategy to support the access of clients to an environment giving them the necessary privacy to experience their sexuality in the inpatient context was shared.	A room that is always available. The door is open [and closable], a welcoming room with flowers that would therefore also be bright with a window. So, when possible, it would be ideal to have a room available to be able to isolate ourselves with our clients. (P14 – Physical therapist)
9) Access to referral options	Access to referral options was deemed essential for participants. While most discussion on the subject outlined the relevance of including sex therapists to the stroke rehabilitation teams and being able to refer clients to them, the possibility of accessing clinicians from other disciplines such as social workers and psychologists was also considered necessary. Ideally, clinicians who are the target of the referral would be inside the stroke rehabilitation organization, would not have long waiting lists, referral procedures would be easy for clinicians and services would be free for clients. Participants also asked to have an easy access to the available healthcare and community resources pertaining to sexuality in their area. Having a list of resources outside their organization and related to sexuality was	Just for clinicians to be able to give reliable resources or websites that address sexuality, when the time is right for patients, that would be good for them. (P3 – Nurse) Perhaps, if we don't have them on site [sexuality specialists], that we know a little … where we can refer patients, whether for perineal physio, a sex therapist or any another professional who would be useful for the return to satisfying sexuality? Professionals who also know what a stroke is? (P13 – Occupational therapist) For me, it's the most important. It's really what is gonna secure me, to know that I can refer my patients to someone when needed. (P18 – Physical therapist)

	seen as an important tool since participants thought that certain needs of their clients may not be met in rehabilitation.	
10) Slowing down the pace of stroke rehabilitation	Participants asked for their organization to have more resources in order to lower their workload and give them more time to provide quality services to their clients. Expression of strategies was more abstract than the other strategies. Although it was less tangible than other strategies, a desire for change regarding workload was shared among participants.	"If I understand correctly, the money so that you have more time in your follow-ups. Is that what I heard? More time and interventions?" (Facilitator). "More time to make an assessment that looks good in our files and more time to just say "OK, we think about our room, where we could set up as needed" [to address sexuality]. You know it still requires, precisely, you know if a problem that emerged, well it requires us to intervene. It's going to take some money. (P18 – Physical therapist)

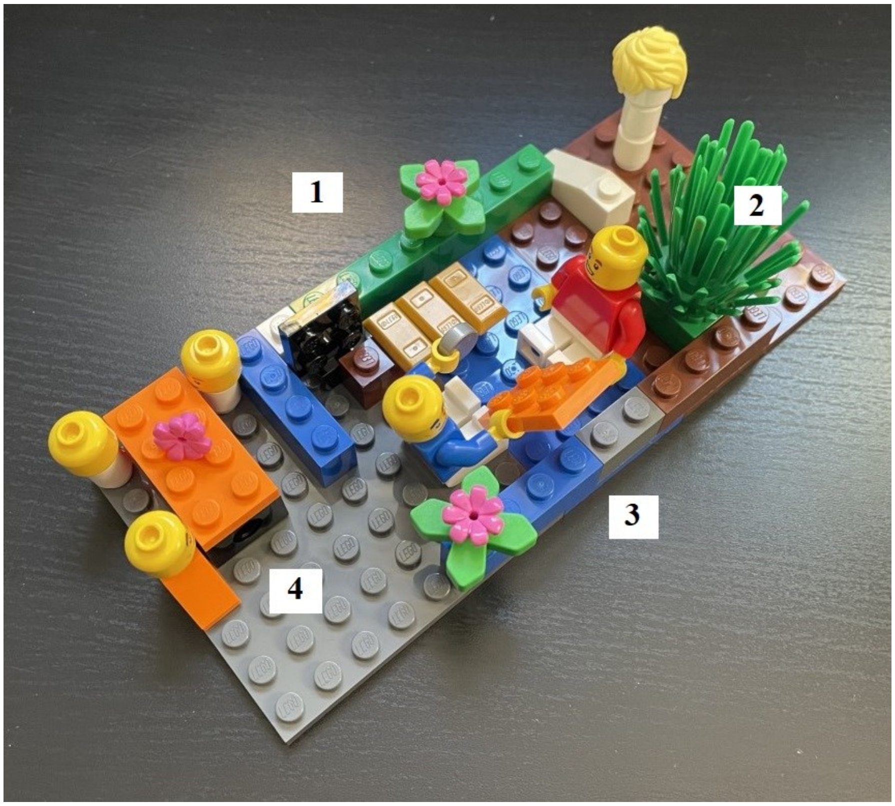

Figure 5. – Participant 15's LEGO® model representing a proper context to address sexuality.

Paraphrasing of participant 15's discourse: 1) The two personas in the center (post-stroke client in red, clinician in blue) are in a closed room with two doors to ensure privacy. The room contains plants, which represent comfort and relaxation. The two personas are seated facing each other, the desk to the side, in an open posture. 2) This beige rod with hair represents the partner of the client, which can be involved in the sexual rehabilitation process if the client wishes so. The door is opened by the clinician, representing the organization. 3) The clinician was designated by his team or his organization to address sexuality with the client. He holds in his right hand a disciplinary assessment used with every client, in which sexuality is included. In his left hand is a clock, which means that he can give the client the freedom to choose if the timing is right to address sexuality, or if it needs to be addressed later in the rehabilitation. To the clinician's left are three gold bars, which represent sexuality-specific assessment tools and knowledge transfer resources such as a pamphlet. A black cube representing a television shows the possibility of presenting an educational video on post-stroke sexuality. 4) The interdisciplinary team is open, complete and available to meet the needs of the client after it has been addressed by the clinician in blue.

Discussion

The aim of this study was to gain a deeper understanding of the factors influencing the provision of sexuality-related services by post-stroke rehabilitation clinicians, and to explore strategies to improve services.

Numerous factors (mainly considered to be barriers) were identified according to participants' experiences (n = 20), which prevented them from addressing sexuality with clients. According to the COM-B system which was used to sort the barriers, the factors were either at the level of capabilities (e.g., Knowledge), motivation (e.g., Emotion) or opportunities (e.g., Specialized resources) to address sexuality (i.e., the desired behaviour). This is in line with the results of a scoping review of 69 studies on barriers and strategies in guideline implementation showing that barriers can pertain to the personal, environmental or guideline's level (Fischer et al., 2016). Perceived lack of capabilities and motivation (especially comfort) in addressing sexuality by healthcare professionals regardless of the health condition is supported by two systematic reviews that included respectively 103 (McGrath et al., 2021) and eight (Dyer & das Nair, 2013) studies. However, it is Richards and collaborators' (2016) multi-site qualitative study with ten post-stroke rehabilitation clinicians that supports our results the most. Their exploration of professional approaches in relation to sexuality and influencing factors also showed that environmental barriers influenced clinicians' opportunities to address sexuality, and their analysis of the importance of clinicians' comfort level as a central aspect for clinicians to include sexuality in their clinical practice resonates with ours. Indeed, both studies found that clinicians had a heavy workload, lacked time, had poor access to an interdisciplinary team (in outpatient rehabilitation) and lacked privacy in their workspace to address sexuality. Among what our study adds to the body of knowledge regarding opportunities to address sexuality is the important need for environmental/organizational intervention to support clinicians' practice, including the availability of specialized support related to sexuality (e.g., sex therapists) and the lack of tools to support clinical practices such as screening, assessment and intervention. Richards and collaborators' (2016) study and ours both found that comfort is key in addressing sexuality. However, our participants suggested that comfort is not only a contributing factor to addressing sexuality, but a "hit or miss" factor that will lead people to bring up or avoid the subject of sexuality, regardless of their abilities and opportunities. In fact, our results suggest that improving, or reducing barriers related to, capabilities and opportunities could likely improve motivation and more specifically comfort, to address sexuality. This could then be the precursor to the actual "doing" in practice. However, this hypothesis will need to be tested in future studies. Our results show that the challenges related to addressing sexuality are many and complex, that they imply the characteristics of the individuals and of the environment in which they carry out their activities, and that some factors, such as comfort, may be more important than others.

The multiple influencing factors that were identified by the study participants highlight that a variety of strategies is needed to better address sexuality post-stroke. The strategy falling under the category of Training was mostly aimed at improving their capabilities and indirectly their motivation, and a training on sexual rehabilitation was the most important strategy among the ten according to participants. McGrath and collaborators (2021) also suggested that a professional training on sexual rehabilitation may lead to improvement in participants' perceived knowledge, skills and attitudes. However, they also concluded that multicomponent interventions that tackle the various barriers to addressing sexuality are more likely to lead to measurable and positive changes in sexual rehabilitation practices with persons who sustained a stroke. This mirrors our findings and conclusions of other studies (Grimshaw et al., 2012; Grimshaw & Russell, 1993; van der Wees et al., 2008).

An innovative aspect of our findings are the strategies that could regulate clinicians' practices. The five strategies under the category "Enablement" were aimed at influencing the capabilities, motivation and opportunities of participants to address sexuality in their practice by reducing barriers or emphasizing facilitators. Among these strategies, some were meant to facilitate the task of addressing sexuality by clinicians, such as the provision of a knowledge translation toolkit and access to new sexuality-related tools among the resources that could be used by clinicians in their practice. Strategies that aim to reduce the complexity of following guidelines (Harris et al., 2013), for example by offering user-friendly (Cabana et al., 2002), relevant and applicable tools (Katz, 1999), have been shown to enhance implementation of guidelines. These could contribute to improve sexual rehabilitation post-stroke.

Other strategies that targeted the opportunities (i.e., Environmental restructuring) that would aim to foster the provision of sexual rehabilitation by providing more resources such as sexuality specialists and reducing the workload to provide clinicians' more time to address sexuality (Bekkering et al., 2005; Powell, 2003) have been described elsewhere as relevant environmental strategies to foster guideline implementation (Fischer et al., 2016). Few studies have addressed the effects of strategies aiming to influence the opportunities to address sexuality in stroke rehabilitation. However, provision of an interview guide and systematization of procedures showed to facilitate the screening of needs regarding post-stroke sexual rehabilitation in two Canadian studies (Auger, Pituch, et al., 2021; Guo et al., 2015), which shows promise for future studies. Therefore, future studies aiming to improve sexual rehabilitation services for persons who sustained a stroke should choose multiple strategies between the numerous ones suggested in the present study and articulate them in a multifactorial program that will tackle personal and environmental barriers in order to lead to more promising results.

Finally, we found that an adapted version of the LEGO Serious Play method to explore influencing factors and strategies to guideline implementation, contextualized here to post-stroke sexual rehabilitation was feasible and relevant. Considering that this study was conducted during the Covid-19 pandemic, adaptations in the form of an online format were meant to respect social distancing measures. Our adapted version of the LEGO Serious Play method was not only feasible, but it was also appreciated by participants, who shared that it brought a sense of pleasure and creativity to the process. Moreover, the depth and breadth of our analyses and results were certainly related to the predominance of data collected by the adapted LEGO Serious Play method along with the focus group. This is reflected in the detail regarding each factor and strategy that is presented in that manuscript, and the interrelation that participants made between many factors and/or strategies, which led to innovative results that contribute uniquely to the scientific literature.

Strengths and limitations

The present study has many methodological strengths that favored the credibility of its conclusions, a key scientific features in qualitative research (Drapeau, 2004). First, using the TDF (Cane et al., 2012), the COM-B system and the BCW (Michie et al., 2011) to orient data collection and analysis, the co-coding of 20% of data by two independent reviewers, and regular validation of the analysis with the research team ensure reliability of the analysis between each corpus of data and an objective interpretation of the data. Moreover, the combination of focus groups (i.e., Advisory group) and work groups using an adapted version of the LEGO® Serious Play® method varied the data collection methods by using verbal and visual means of communication. The adapted LEGO® Serious Play® method was appreciated by participants for its relevance and ludic character, and they shared that they felt more involved than in past studies where they participated in focus groups. Therefore, the combined methods are likely to have brought a balance between breath (focus group) and depth (LEGO® groups) of the data collected and analyzed by capitalizing their respective strengths (Fontana, 2000; Krefting, 1991).

This study has also some limitations when sample composition and size, which mostly influence our results' transferability (Drapeau, 2004). Indeed, the study sample only included females living in the province of Quebec, Canada, mostly included clinicians and lacked the involvement of a partner of a post-stroke individual. This could affect the relevance of the results by men or people of other genders who may experience different challenges and/or have other preferences in their clinical practice in comparison to women. Moreover, the sample composition could limit the use of the outcomes of this study for non-clinician stakeholders and people outside of the province of Quebec. Nonetheless, the Advisory and LEGO® groups allowed for a diversity of perspectives, experiences and contexts considering the inclusion of a variety of professional disciplines a representative from each of the five partner organizations in the groups. Moreover, the results of the present study are in alignment with other studies (Dyer & das Nair, 2013; Low et al., 2022; Richards et al., 2016), mostly not from Canada, which suggests that they may be relevant for post-stroke rehabilitation stakeholders outside Canada.

Conclusion

This study will help guide the design and implementation of future interventions aimed at improving post-stroke sexual rehabilitation services. The factors influencing the provision of post-stroke sexual rehabilitation services appear to be multiple and interrelated. The complexity of sexuality makes it a subject that is challenging to integrate into the clinical practices of clinicians in post-stroke rehabilitation. Thus, the numerous strategies suggested and detailed in the present study would benefit from being developed and used in combination to lead to more durable service implementation results in post-stroke sexual rehabilitation.

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Chapitre 6 – Les méthodes d'évaluation liées à la sexualité pouvant être utilisées par les intervenants en réadaptation post-AVC

Dans ce chapitre est présenté le quatrième article inclus à cette thèse, publié dans la revue *Disability and Rehabilitation* (Auger, Aubertin, et al., 2021), avec des modifications minimes issues du processus de révision de la thèse. Cet article est associé à l'étape 3 (Choix des méthodes basées sur la théorie et des stratégies) de la cartographie des interventions (Bartholomew et al., 2016) et répond partiellement au deuxième et quatrième objectifs spécifiques de la thèse : Explorer des stratégies qui pourraient être mises en œuvre pour améliorer les services de réadaptation sexuelle post-AVC et Identifier des méthodes et stratégies, fondées sur la théorie et les données probantes, qui devraient être considérées dans la création des interventions du programme. Cette étude est également utilisée parmi les interventions du programme cocréé (c.-à-d., objectif spécifique #5), ce qui est décrit en détail dans le chapitre 7. Le fait que le chapitre 6 aborde l'étape 3 avant que ne soit abordée l'étape 2 de la cartographie des interventions est liée au caractère itératif de la démarche de cocréation du programme. En effet, la revue de la portée présentée dans ce chapitre a été réalisée et complétée durant le processus de cocréation du programme.

Assessment methods in sexual rehabilitation after stroke: a scoping review for rehabilitation professionals

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Abstract

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 ≥ 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

Introduction

Sexuality is among the domains that can be affected by a stroke (Grenier-Genest et al., 2017) and is related to quality of life (McCabe et al., 2000; Robinson & Molzahn, 2007) and depression (Kim, 2008; Korpelainen et al., 1999) 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 (Geyh et al., 2004). However, stroke survivors rarely have the opportunity to address sexuality during rehabilitation (Calabrò & Bramanti, 2014; McGrath et al., 2018; Stein et al., 2013) even though it is recommended that therapists address it with clients (Mountain et al., 2020). 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 (Dyer & das Nair, 2013). 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 (Haboubi & Lincoln, 2003). Furthermore, therapists were even less likely to initiate a discussion on the subject than nurses or doctors (Haboubi & Lincoln, 2003). Yet, rehabilitation professionals such as occupational and physical therapists are in a privileged position to address sexuality with their clients in stroke rehabilitation (Auger, 2019; Vajrala et al., 2019) and could significantly increase the proportion of people who have the opportunity to address sexuality concerns in that context (Guo et al., 2015). 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 (Lepage et al., 2020).

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 (Courtois et al., 2018) and one narrative review focusing on men recovering from a stroke (Calabro et al., 2011). Courtois et al. (2018) 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. (2011) 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 reported using the Preferred Reporting Items for Systematic Review and meta-analysis extension for scoping reviews (PRISMA-ScR) guidelines (Tricco et al., 2018).

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 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 (Mokkink et al., 2018). 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 (Geyh et al., 2004): 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 (Dunh & Medves, 2004), 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.

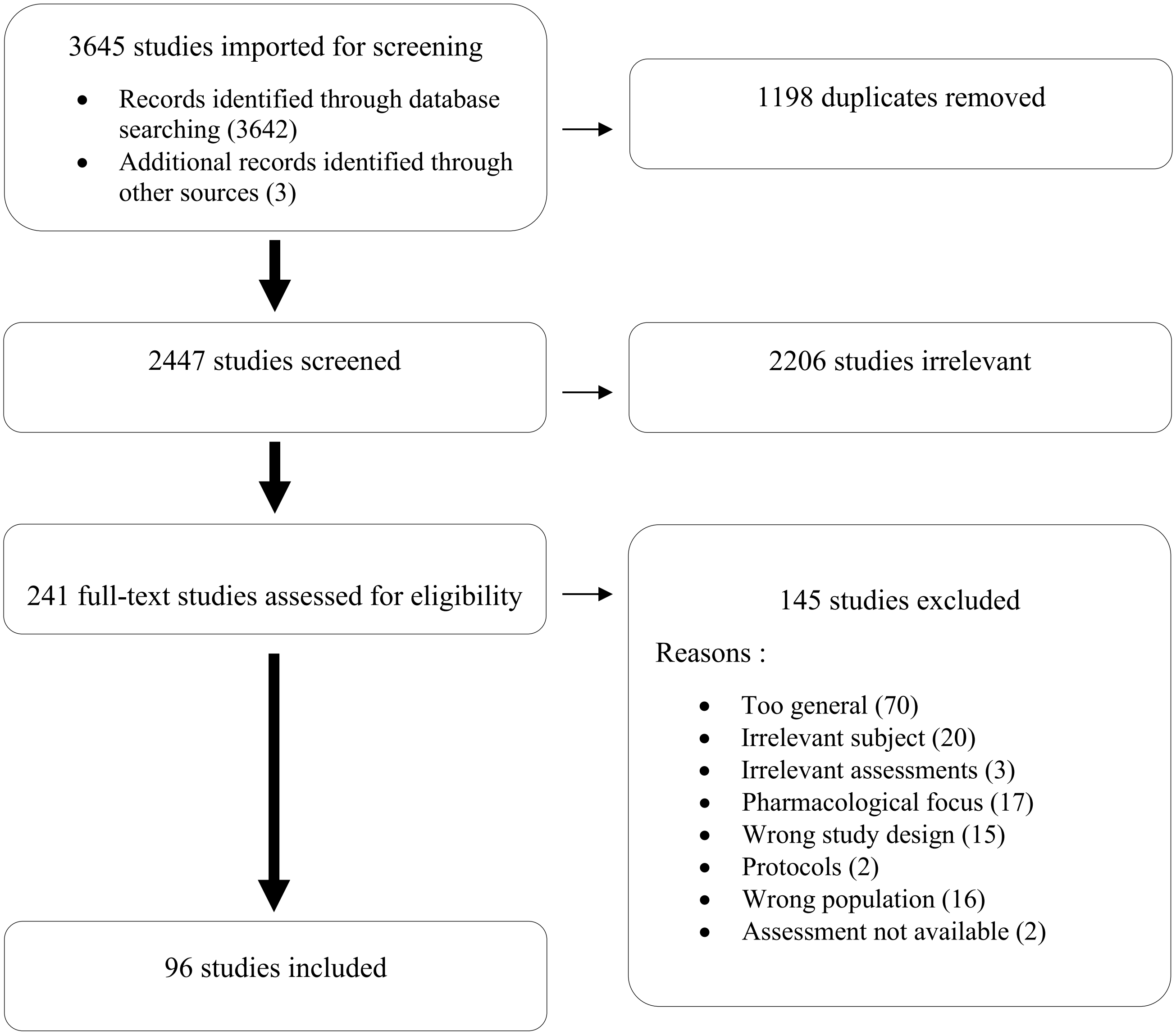
Results

Study selection

Data extracted

A total of 2447 articles remained after duplicates were removed from the initial database search and manual searches (see Figure 6). After irrelevant articles were excluded, 96 matched the inclusion criteria. Justifications for exclusion of full texts are presented in Figure 6.

Figure 6. – Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart of articles selection process



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 (see Annexe 2). Among the 96 studies included, two used mixed methods (Millenbruch, 2009a; Thomas, 2016) to assess sexuality post-stroke. The study by Thomas (2016) combined the Canadian Occupational Performance Measure, the Quality of Sexual Function Scale and the Stroke Impact Scale with a semi-structured interview, and Millenbruch (2009a) 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 11. 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) (Duncan et al., 1999), the Quality of Life Index – Stroke version (Ferrans & Powers, 1985) and the Canadian Occupational Performance Measure (COPM) (Law et al., 1990; Law et al., 1994) 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.

Tableau 11. – Description of standardised tools used to assess sexuality in stroke literature (n=27) according to their psychometric properties and clinical characteristics

Assessment tool	Description	Reliability	Validity	Clinical utility
VALIDATED FOR THE STROKE POPULATION				
Canadian Occupational Performance Measure (Law et al., 1990) Used in (Thomas, 2016)	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 cut-off between 0.90 and 1.90 as perceived by the client suggests significant improvement (Eyssen et al., 2011).	**Test-retest:** r= 0.89 for performance and 0.88 for satisfaction ($p<0.001$) for the stroke population (Cup et al., 2003); r = 0.88-0.89 for the stroke population (Yang et al., 2017); **Intra/inter-rater:** Not found **Internal consistency:** Not found	**Construct validity:** Good construct responsiveness (Eyssen et al., 2011); *Convergent and discriminant validity* significantly different from the KB-ADL scale and not strongly correlated with the SPSQ or the FIM (Yang et al., 2017) **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. (Eyssen et al., 2011)	**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., 1999)	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 living (ADL), mobility, communication, emotion, memory and social participation are the eight	**Test-retest:** ICCs: 0.7 – 0.92 for the 8 domains except for emotion (0.57) (Duncan et al., 1999)	**Construct validity:** Reasonable: item-domain correlations ≥ 0.4 (except 1 in the emotion domain) (Duncan et al., 1999)	**Time:** 15-20 min **Therapist training:** None

Used in (Seymour & Wolf, 2014)	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. **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.	**Intra/inter-rater:** Not found **Internal consistency:** Cronbach's alpha: 0.83-0.90 (Duncan et al., 1999)	*Discriminant validity:* Excellent (P. W. Duncan et al., 1999) **Criterion validity:** Good (Duncan et al., 1999) **Content validity:** "Potential for floor effect in hand in hand function domain and possibility for a ceiling effect in communication domain." (Duncan et al. (P. W. Duncan et al., 1999)) **Responsiveness:** Sensitivity to change regarding the severity and time since stroke (P. W. Duncan et al., 1999)	**Cost and ordering information:** Free, available online: https://www.strokengine.ca/pdf/sis.pdf or in the Appendix of Duncan et al. (1999), cost according to the value of the article.
Quality of Life Index - Stroke version (Ferrans & Powers, 1985) Used in (Millenbruch, 2009a)	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. **Scoring:** 6-points Likert-type scale for each item from 1 ("very unsatisfied" or "very unimportant") to 6 ("very satisfied" or "very important"). A higher score indicates a higher QOL.	**Test-retest:** 0.87 for two weeks and 0.81 for one month (Ferrans & Powers, 1985) **Intra/inter-rater:** Not found **Internal consistency:** Cronbach's alpha = 0.93 for the entire instrument, 0.87 for the health and	**Construct validity:** Good: r > 0.3 between factors (Ferrans & Powers, 1992) *Convergent validity*: Good: r = 0.77 with the single-item life satisfaction assessment (Ferrans & Powers, 1992) **Criterion validity:** Not found	**Time:** 5-10 min **Therapist training:** None **Cost and ordering information:** Free, available online https://qli.org.uic.edu/questionaires/pdf/strokeversionIII/stroke.PDF

		functioning subscale, 0.82 for the socioeconomic subscale, 0.90 for the psychological/spiritual subscale and 0.77 for the family subscale (Ferrans & Powers, 1992); Cronbach's alpha = 0.90-0.93 (Ferrans & Powers, 1985)	**Content validity:** The content was based on a literature review of issues related to QOL and on the reports of patients (Ferrans & Powers, 1985) **Responsiveness:** Not found	
SEXUALITY-SPECIFIC TOOLS				
International Index for Erectile Function – 5 (IIEF-5) (Rosen et al., 1999) Used in (Bener et al., 2008; Calabro et al., 2011; Dai et al., 2020; Jung et al., 2008; Koehn et al., 2015; Li et al., 2020; Ossou-Nguiet et al., 2012; Purwata et al., 2019; Radic et al., 2013; Sikiru et al., 2009; Tibaek et al., 2017; Tibaek et al., 2015; Winder et al., 2017)	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. **Scoring:** 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.	**Test-retest:** Sufficient*** (Neijenhuijs, Holtmaat, et al., 2019) **Inter/intra-rater:** Not found **Inernal consistency:** Indeterminate*** (Neijenhuijs, Holtmaat, et al., 2019)	**Construct validity:** Sufficient (Neijenhuijs, Holtmaat, et al., 2019) **Criterion validity:** Sufficient (Neijenhuijs, Holtmaat, et al., 2019) *Sensitivity:* 0.98 (Rosen et al., 1999) *Specificity:* 0.88 (Rosen et al., 1999) **Content validity:** Not found **Responsiveness:** Indeterminate (Neijenhuijs, Holtmaat, et al., 2019)	**Time:** < 5 min **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., 1997) Used in (Duits et al., 2009; Epprecht et al., 2018; Jeon et al., 2009; Rodrigues Pereira et al., 2017)	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. **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).	**Test-retest:** Relatively high (r = 0.82 for the total scale) (Rosen et al., 1997); Inconsistent (Neijenhuijs, Holtmaat, et al., 2019) **Intra/inter-rater:** Not found **Internal consistency:** Highly consistent (alpha values greater than 0.90 for the total scale) (Rosen et al., 1997); Inconsistent (Neijenhuijs, Holtmaat, et al., 2019)	**Construct validity:** Adequate (Rosen et al.,(Rosen et al., 1997)) *Discriminant validity:* Highly significant differences between patients with ED and control group (Rosen et al., 1997) *Convergent and divergent validity:* No statistical significance with the Marital adjustment test (Locke et al., 1987) and the Marlowe–Crowne Social Desirability Scale (Crowne & Marlowe, 1960) (Rosen et al., 1997) **Criterion validity:** Sufficient (Neijenhuijs, Holtmaat, et al., 2019) *Sensitivity:* High (Rosen et al., 1997) *Specificity:* High (Rosen et al., 1997) **Content validity:** Not found **Responsivness:**	**Time:** 5-10 min **Therapist training:** None **Cost and ordering information:** Free, available online: https://www.baus.org.uk/_userfiles/pages/files/Patients/Leaflets/iief.pdf

			Sufficient (Neijenhuijs, Holtmaat, et al., 2019)	
Female Sexual Function Index (FSFI) (Rosen et al., 2000) Used in (Chaturvedi & Bhola, 2017; Epprecht et al., 2018; Yilmaz et al., 2017)	Self-reported questionnaire of 19 items about sexual function for women. Desire, arousal, lubrification, 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 cut off score of 26 or less indicates female sexual dysfunction.	**Test-retest:** r = 0.88 for the total scale (Rosen et al., 2000) **Intra/inter-rater:** Not found **Internal consistency:** Cronbach's alpha ≥ 0.82 and higher (Rosen et al., 2000); Sufficient (Neijenhuijs, Hooghiemstra, et al., 2019)	**Construct validity:** Inconsistent (Neijenhuijs, Hooghiemstra, et al., 2019) *Discriminant validity*: Good (Rosen et al., 2000) *Divergent validity*: "Low" to "Very low" correlations with the Marital Adjustment Test (Locke et al., 1987) (Rosen et al., 2000) **Criterion validity:** Sufficient (Neijenhuijs, Hooghiemstra, et al., 2019) **Content validity:** Not found **Responsiveness:** Indeterminate (Neijenhuijs, Hooghiemstra, et al., 2019)	**Time:** 5-10 min **Therapist training:** None **Cost and ordering information:** Free, available online : https://eprovide.mapi-trust.org/instruments/female-sexual-function-index
Change in Sexual Functioning Questionnaire Short Form (CSFQ-14Q) (Keller et al., 2006) Used in (Ng et al., 2017; Oyewole et al., 2017; Sansom	Self-reported questionnaire of 14 questions about current sexual behaviors and problems. Male and female versions. Desire/frequency, arousal/excitement, orgasm/completion and pleasure are assessed. **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.	**Test-retest:** Not found **Intra/inter-rater:** Not found **Internal consistency:** Cronbach's alpha for the toral score = 0.90 for female and 0.89 for male	**Construct validity:** Good, >0.4 for each item (except 14) (Keller et al., 2006) **Criterion validity:** *Sensitivity:* 92.9% for male and 91.9% for female version (Garcia-Portilla et al., 2011) *Specificity:*	**Time:** Average time = 15-19min **Therapist training:** None **Cost and ordering information:** Free, available online: https://www.dbsalliance.org/wp-

et al., 2015; HoSook Song et al., 2011; Vajrala et al., 2019)	Total score ranges from 14 and 70. Cut off scores indicating sexual dysfunction: total score ≤ 41; desire phase ≤ 15; arousal phase ≤ 12; orgasm phase ≤ 11; desire/frequency phase ≤ 6; desire/interest phase ≤ 9; pleasure phase ≤ 4.	version (Keller et al., 2006)	59.5% for male and 62.5% for female version (Garcia-Portilla et al., 2011) **Content validity:** Not found **Responsiveness:** Not found	content/uploads/2019/02/Restoring_Intimacy_CSFQ_Handout.pdf
Hudson's Index of Sexual Satisfaction (ISS) ((Hudson et al., 1981a)) Used in (Chambon, 2011)	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. **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 (Hudson et al., 1981a)	**Test-retest:** 0.93 (Hudson et al., 1981a) **Intra/inter-rater:** Not found **Internal consistency:** Excellent: Cronback alpha between 0.906 – 0.925 (Hudson et al., 1981a)	**Construct validity:** Good; Excellent measurement error characteristics (Hudson et al., 1981a) *Discriminant validity* Good (Hudson et al., 1981a) **Criterion validity:** Not found **Content validity:** Not found **Responsiveness:** Not found	**Time:** 5-10min **Therapist training:** None **Cost and ordering information:** See Table 1 of Hudson et al. (Hudson et al., 1981a), cost according to the value of the article.
Arizona Sexual Experience Scale (ASEX) ((McGahuey et al., 2000)) Used in (Calabro et al., 2011)	5-item self-reported questionnaire assessing sexual functioning, including drive, arousal, penile erection/vaginal lubrification, ability to reach orgasm and satisfaction with orgasm. **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	**Test-retest:** Strong (r = 0.801 for patients and r = 0.892 for controls, p<0.01) (McGahuey et al., 2000) **Intra/inter-rater:** Not found	**Construct validity:** Positive predictive value (PPV) = 88% and negative predictive value (NPV)= 85%; items correlated with the Brief Index of Sexual Functioning for Women (Taylor et al., 1994) factors (McGahuey et al., 2000)	**Time:** Less than 5min **Therapist training:** None **Cost and ordering information:** Free, available online : https://www.mirecc.va.gov/visn22

	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.	**Internal consistency:** Excellent: Cronbach's alpha = 0.901 (McGahuey et al., 2000)	**Criterion validity:** *Sensitivity:* 82% (McGahuey et al., 2000) *Specificity:* 90% (McGahuey et al., 2000) **Content validity:** Not found **Responsiveness:** Area under the curve = 0.929 (McGahuey et al., 2000)	/Arizona_Sexual_Experiences_Scale.pdf or http://depts.washington.edu/psychres/wordpress/wp-content/uploads/2017/09/asex_scale.pdf
Kflner [Cologne] Evaluation of Erectile Dysfunction (KEED) (Braun et al., 1998) Used in (Bohm et al., 2007)	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. **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.	**Test-retest:** Not found **Intra/inter-rater:** Not found **Internal consistency:** Not found	**Construct validity:** Not found **Criterion validity:** Predictive value = 0.98 (Braun et al., 1998) *Sensitivity:* 0.97 (Braun et al., 1998) *Specificity:* 0.93 (Braun et al., 1998) **Content validity:** Not found **Responsiveness:** Not found	**Time:** 5-10min **Therapist training:** None **Cost and ordering information**: Appendix 1 of Braun et al. (Braun et al., 1998), cost according to the value of the article.
Quality of Sexual Function Scale ((Heinemann et al., 2005)) Used in (Seymour & Wolf, 2014; Thomas, 2016)	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. **Scoring:**	**Test-retest:** Not found **Intra/inter-rater:** Not found **Internal consistency:**	**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 (L. A. Heinemann et al., 2005).	**Time:** Less than 10 min **Therapist training:** None, **Cost and ordering information:**

	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.	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" (L. A. Heinemann et al., 2005)	**Criterion validity:** Not found **Content validity:** Promising (L. A. Heinemann et al., 2005) **Responsiveness:** Not found	Appendix of Heinemann et al. (L. A. Heinemann et al., 2005), cost according to the value of the article.
Sexual Beliefs and Information Questionnaire (SBIQ) (Adams et al., 1996) Used in (H. Song et al., 2011)	25 items self-reported questionnaire to evaluate sexual knowledge and belief. **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.	**Test-retest:** 0.82, p<0.001 (Adams et al., 1996) **Intra/inter-rater:** Not found **Internal consistency:** r = 0.82 (p<0.001) (Adams et al., 1996); r = 0.71 (HoSook Song et al., 2011)	**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:** Appendix of Adams et al. (Adams et al., 1996), cost according to the value of the article.
Derogatis Sexual Functioning Inventory (Derogatis & Melisaratos, 1979) Used in (H. Song et al., 2011)	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 **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	**Test-retest:** Good: *r* = 0.42 to 0.96 (Derogatis & Melisaratos, 1979) **Intra/inter-rater:** Not found **Internal consistency:** Very good, Cronbach’s alpha ranges from 0.56 to	**Construct validity:** Good (Derogatis & Melisaratos, 1979) **Criterion validity:** Not found **Content validity:** Not found **Responsiveness:** Not found	**Time:** 45-60 min **Therapist training:** None **Cost and ordering information:** Distributed exclusively by Clinical Psychometric Research, Inc. (www.derogatis-tests.com)

	Satisfaction Index, which reflects subjective perception of sexual behaviour.	0.97 (Derogatis & Melisaratos, 1979)		
Sexual Inhibition/Sexual Excitation Scale Version for men: (Janssen et al., 2022) Version for women: (Graham et al., 2006) Version for men and women: (Milhausen et al., 2010) Used in (Duits et al., 2009)	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. **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.	**Test-retest:** Version for men: r = 0.73 for SES, r = 0.74 for SIS1 and r = 0.62 for SIS2 (Janssen et al., 2002) Version for women: SE = 0.81 and SI = 0.82 at p<0.005 (Graham et al., 2006) Version for men and women: r ranges from 0.66 to 0.82 with a mean correlation of 0.76 at p<0.005 (Milhausen et al., 2010) **Intra/inter-rater:** Not found **Internal consistency:** Version for men: 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 (Janssen et al., 2002)) Version for women: 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 (Graham et al., 2006)	**Construct validity:** Version for men: r = 0.73 for SES, r = 0.74 for SIS1 and r = 0.62 for SIS2 (Janssen et al., 2002) Version for women: SE = 0.81 and SI = 0.82 (p<0.05) (Graham et al., 2006) Version for men and women: r ranges from 0.66 to 0.82 with a mean correlation of 0.76 (p<0.05) (Milhausen et al., 2010) **Criterion validity:** Not found **Content validity:** Not found **Responsiveness:** Not found	**Time:** 5-10min **Therapist training:** None **Cost and ordering information:** Version for men: Appendix of Janssen et al. (Janssen et al., 2002), cost according to the value of the article.

Eleven Questions about Sexual Functioning (ESF) (Vroege, 1998) Used in (Meesters et al., 2020)	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/lubrification, reduced duration of stiffness/lubrification, actually having an orgasm, having a postponed orgasm, having a premature orgasm, experiencing pain in genitals and general satisfaction are assessed in the questionnaire. **Scoring:** 7-point and 5-point Likert scales	**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:** Table 2 of Meesters et al. (J. Meesters et al., 2020), cost according to the value of the article.
Sexual Self Schema Scale Version for women: (Andersen & Cyranowski,, 1994) Version for men: (Andersen et al., 1999a) Used in (Millenbruch, 2009a)	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. **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. (Millenbruch, 2009b)	**Test-retest:** Version for women: r = 0.89 ($p<0.0001$) for 2 weeks and 0.88 ($p<0.0001$) for 9 weeks (Andersen & Cyranowski, 1994) Version for men: R = 0.81 ($p = 0.0001$) at 9 weeks (Andersen et al., 1999a) **Intra/inter-rater:** Not found **Internal consistency:** Version for women: 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 (Andersen et al., 1994)	**Construct validity:** Not found **Criterion validity:** Not found **Content validity:** Not found **Responsiveness:** Not found	**Time:** 5-10 min **Therapist training:** None **Cost and ordering information:** Version for women is available in the Appendix of Andersen and Cyranowski (1994) and the version for men is available in the Appendix B of Andersen et al. (Andersen et al., 1999a). Cost according to the value of the articles.

Version for men:
Cronbach's alpha = 0.86
for the total scale; 0.89 for
Factor 1; 0.78 for Factor 2;
0.65 for Factor 3
(Andersen et al., 1999a)

GENERIC TOOLS

Life Satisfaction Checklist (LiSat-9) (Fugl-Meyer et al., 1991)) Used in (Forsberg-Warleby et al., 2002; Forsberg-Warleby et al., 2004)	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. **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	**Test-retest:** Kappa = 0.82 for sexual life; p = 0.74 for the mean score (Boonstra et al., 2012) (chronic pain population) **Intra/inter-rater:** Not found **Internal consistency:** Chronbach's alpha = 0.75 (Post et al., 2012)(Spinal cord injury population)	**Construct validity:** *Divergent validity:* r = 0.52 with the Mental Health Scale (SF-36) (Van Leeuwen et al., 2012); , r = 0.66 with the Hospital Anxiety and depression scale (Woolrich et al., 2006); r = -0.45 with the Social Dimension of the Sickness Impact Profile 68 (Post et al., 1996). (Post et al., 2012) **Criterion validity:** r = 0.59 (Post et al., 2012) **Content validity:** No floor or ceiling effects (Post et al., 2012) **Responsiveness:** Not found	**Time:** 10-30 min **Therapist training:** None **Cost and ordering information:** Free, available online: https://www.sralab.org/rehabilitation-measures/life-satisfaction-questionnaire-9
Life Satisfaction Checklist (LiSat-11) (Fugl-Meyer et al., 2002) Used in (Ekstrand et al., 2018; Mibu et al., 2018)	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). **Scoring:** Six grade ordinal scales for each item: 1 = "Very dissatisfying", 2 = "Dissatisfying", 3 = "Rather	**Test-retest:** For all the items, the kappa coefficient ranged from 0.59 to 0.97 and the percent agreement (PA≤1) from 89% to 100% for the chronic stroke population. Kappa = 0.84 and PA≤1 = 91 for sexual life. (E. Ekstrand et al., 2018); ICC = 0.71 (Mibu et al., 2018)	**Construct validity:** Not found **Criterion validity:** Not found **Content validity:** Not found **Responsiveness:** Not found	**Time:** 5min **Therapist training:** None **Cost and ordering information:** Free, available online: https://www.fsfiquestionnaire.com/FSFI%20questionnaire2000.pdf;

	dissatisfying”, 4 = “Rather satisfying”, 5 = “Satisfying”, 6 = “Very satisfying”. Cut off : 1-4 = Dissatisfied; 5-6 = Satisfied	**Intra/inter-rater:** Not found **Internal consistency:** Good: Cronbach's alpha = 0.89 (Mibu et al., 2018)		
World Health Organization Quality of Life scale abbreviated (WHOQOL-BREF) (WHOQOL group ("The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties," 1998)) Used in (Piravej et al., 2014; Rodrigues Pereira et al., 2017)	Self-reported questionnaire of 26 items measuring a health condition’s impact on quality of life in 4 domains: physical health, psychological well being, 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 ?” **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.	**Test-retest:** Not found **Intra/inter-rater:** Not found **Internal consistency:** Cronbach's alpha = 0.7 for the total sample; = 0.68 for relationship domain (Skevington et al., 2004); Cronbach's alpha = 0.65-0.93 ("The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties," 1998)	**Construct validity:** Significant correlations with the Overall Quality of Life score ranging from r = 0.244 to 0.676 for all domains ("The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties," 1998) **Criterion validity:** Not found **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 (Skevington et al., 2004). **Responsiveness:** Not found	**Time:** Less than 5 min **Therapist training:** None **Cost and ordering information:** Free, available online https://www.who.int/mental_health/media/en/76.pdf
Grid for Measurements of Activity and	ICF-derived (World Health Organization, 2001) assessment tool evaluating activity limitation and participation restriction. It consists of a 26 items Grid for Measurements of Activity and Participation which	**Test-retest:** Not found **Intra/inter-rater:**	**Construct validity:** Not found **Criterion validity:**	**Time:** 15-30min **Therapist training:**

Participation (G-MAP) (Belio et al., 2014) Used in (Babin et al., 2017)	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. **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).	Not found **Internal consistency:** Cronbach's alpha = 0.89 (2014)	Not found **Content validity:** According to Belio et al. (2014), data obtained were in agreement with clinicians and patients representatives' opinions. **Responsiveness:** Not found	None **Cost and ordering information:** Appendixes 1 and 2 of Belio et al. (2014), cost according to the value of the article.
Beck Depression Inventory (Beck et al., 1961)) Used in (Stein et al., 2013)	Self-reported questionnaire of 21-question assessing depressive symptoms. The last item is about loss of libido. **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.	**Test-retest:** 0,60-0,83 for nonpsychiatric patients and 0,48-0,86 for psychiatric patients for the BDI (Beck et al., 1988)Instability of the scores over short time intervals (Richter et al., 1998) **Intra/inter-rater:** Agreement in the rating of depression = 97% of the cases; Interrater : high degree of consistency among interviewers for the mean score (A. T. Beck et al., 1961) **Internal consistency:** All categories have a significant relationship to the total score (p<0.001 except for one category); Pearson coefficient = 0.86	**Construct validity:** *Convergent validity* r = 060-0,72 with clinical ratings and 0,73-0,74 with Hamilton Psychiatric Rating Scale for Depression (Beck et al., 1988); r = 0.93 (p<0.01) between the BDI and the BDI-II (Dozois et al., 1998); *Discriminant validity* Against anxiety, validity in differentiating between depressed and nondepressed subjects (Richter et al., 1998) **Criterion validity:** Not found **Content validity:** High, reflects well 6 of the 9 DSM-III criteria (Richter et al., 1998) **Responsiveness:**	**Time:** 5-10min **Therapist training:** None **Cost and ordering information:** Free, available online : https://www.ismanet.org/doctoryourspirit/pdfs/Beck-Depression-Inventory-BDI.pdf

		and rose to 0.93 with a Spearman-Brown correction (A. T. Beck et al., 1961)	In 85% of the cases the BDI adequately predicted a change in the score in 85% of the cases (A. T. Beck et al., 1961)	
Hamilton Depression Rating Scale (Hamilton, 1960)) Used in (Li et al., 2015; Purwata et al., 2019)	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. **Scoring:** 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. 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.	**Test-retest:** Poor (Bagby et al., 2004) **Intra/inter-rater:** *Interrater*: $r = 0.84$ (M. Hamilton, 1960); Poor (Bagby et al., 2004); **Internal consistency:** Adequate, range from 0.46 to 0.97, with ≥ 0.70 in 10 studies (Bagby et al., 2004).	**Construct validity:** Not found(Bagby et al., 2004) **Criterion validity:** Not found **Content validity:** Not found **Responsiveness:** Not found	**Time:** 15-20 min **Therapist training:** Yes **Cost and ordering information:** Free, available online: https://dcf.psychiatry.ufl.edu/files/2011/05/HAMILTON-DEPRESSION.pdf
Social Functioning Examination (SFE) (Starr et al., 1982)) Used in (Kimura et al., 2001)	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. **Scoring:** 3-point scale about sexual satisfaction. 0 = “Normal”, 1 = “Moderately dissatisfied”, 2 = “Severely dissatisfied”.	**Test-retest:** High, for the total score $r = 0.90$ ($p<0.01$) (Starr et al., 1983) **Intra/inter-rater:** High, interrater: $r = 0.92$ ($p<0.01$) (Starr et al., 1983) **Internal consistency:** Not found	**Construct validity:** Correlation coefficient with the Social Ties Checklist is $r = 0.65$ ($p<0.01$) and with the Hollingshead social class is $r = 0.41$ ($p<0.05$) (Starr et al., 1983); No significant correlation with the Hamilton depression scale (Max Hamilton, 1960) and the Mini-Mental State Examination (Folstein et al., 1983) (Starr et al., 1982) **Criterion validity:**	**Time:** 10-30 min **Therapist training:** None **Cost and ordering information:** Tables 2 and 3 of Starr et al. (Starr et al., 1983) and Table 3 of Starr et al. (Starr et al., 1982). Cost according to the value of the articles.

			Not found **Content validity:** Not found **Responsiveness:** Not found	
Psychological Adjustment to Illness Scale (PAIS) (Morrow et al., 1978)) Used in (Garlinghous, 1987)	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. 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.	**Test-retest:** Not found **Intra/inter-rater:** *Inter-rater*: r = 0.83 for the total score and 0.81 for the sexual relationship domain (Morrow et al. (G. R. Morrow et al., 1978)); **Internal consistency:** "the reliability coefficient ranged from r = 0.82 to r = 0.33 on subtests." (Weissman et al.(Weissman et al., 1981)); High, Cronbach's alpha ranges in mean from 0.60 to 0.90 for the 7 domains with 3 different populations (Derogatis, 1986)	**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 (G. R. Morrow et al., 1978); Partially established (Weissman et al., 1981) **Criterion validity:** Strong (G. R. Morrow et al., 1978); Partially established (Weissman et al., 1981) **Content validity:** Not found **Responsiveness:** Not found	**Time:** 20-30min **Therapist training:** Yes **Cost and ordering information:** Distributed exclusively by Clinical Psychometric Research, Inc. (www.derogatis-tests.com)
Post-Stroke Checklist (Philp et al., 2013))	15 item checklist to identify long-term problems following a stroke. One item assesses intimate relationships in the latest version of Turner et al.(G. M. Turner et al., 2019).	**Test-retest:** Not found **Intra/inter-rater:**	**Construct validity:** Not found **Criterion validity:**	**Time:** 5-10min **Therapist training:**

Used in (Grace M. Turner et al., 2019)	**Scoring:** Yes or No choices	Not found **Internal consistency:** Not found	Not found **Content validity:** Not found **Responsiveness:** Not found	None **Cost and ordering information:** Philp et al. (2013). The 15 items are listed in Table 4 of Turner et al. (2019).
Maudsley Marital Questionnaire (MMQ-rs) (Arrindell et al., 1983)) Used in (J. J. L. Meesters et al., 2020)	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. **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.	**Test-retest:** Appropriate: r = 0.60-0.90 (Arrindell et al., 1983) **Intra/inter-rater:** Not found **Internal consistency:** Cronbach's alpha = 0.90 for the M scale, 0.80 for the S scale and 0.66 for GL scale (Joseph et al., 2007); 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 (Arrindell et al., 1983)	**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.(Joseph et al., 2007)) Correlation with global desirability scale = 0.27 (p=0.001) for M, 0.09 (p<0.05) for S and 0.25 (p<0.05) for GL (Arrindell et al., 1983); **Criterion validity:** Not found **Content validity:** Not found **Responsiveness:** Not found	**Time:** 5-10min **Therapist training:** None **Cost and ordering information:** Appendix of Arrindell, Boelens and Lambert (1983), cost according to the value of the article.

Assessment of Life Habits (LIFE-H) (Fougeyrollas et al., 1998) Used in (Rozon & Rochette, 2015)	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. **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 satisfaction on a 5 grades scale from "Very satisfied" to "Very dissatisfied".	**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 (Fougeyrollas et al., 1998) **Intra/inter-rater:** Inter-rater reliability: " highly reliable (ICC ≤ 0.89) (Noreau et al., 2004) **Internal consistency:** Not found	**Construct validity:** *Discriminant validity* Good (Desrosiers et al., 2004) *Convergent validity* Moderately correlated (r = 0.70) with the SMAF, no significant association for the "Interpersonal relationships" domain (Desrosiers et al., 2004) **Criterion validity:** Not found **Content validity:** 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. (Fougeyrollas et al., 1998) **Responsiveness:** Not found	**Time:** 20-40 min for the short form. 20-120min for the long form **Therapist training:** None **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.

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 (Mokkink et al., 2018)

Domains of sexuality assessed

The complete list of sexual domains considered by the studies covered by this review is provided in Table 12. 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 (Heinemann et al., 2005) (8/8) and Mitchel-Pedersen et al.'s (1994) semi-structured interview (7/8). The CSFQ-14 (Keller et al., 2006), the Eleven Questions about Sexual Functioning (ESF) (Vroege, 1998), Giaquinto et al.'s questionnaire (2003) and Lemieux et al.'s (2001) semi-structured interview each covered six sexual domains. Specific proportions of measured categories are presented in Table 12. 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%).

Tableau 12. – Sexual domains covered in each assessment method according to the International Classification of Function and Disability Core Set for Stroke (Geyh et al., 2004)

		Sexual functions				Intimate relationships			Environment		
Sexuality assessments		Arousal	Preparatory	Orgasmic	Satisfaction	Individual sex	Romantic	Sexual	Immediate family	Sub-total (/8)	Other aspects
Standardized tests	Canadian Occupational Performance Measure (COPM) (Law et al., 1990; Law et al., 1994)				X			X		2	Importance of sexuality
	Stroke Impact Scale (Pamela W Duncan et al., 1999)									0	Relationships in general (family/friends) or social activities
	Quality of Life Index - Stroke version (Ferrans & Powers, 1985)				X		X			2	Importance of sex life and partner
	International Index of Erectile Function – 5 (IIEF-5) (Rosen et al., 1999)		X		X					2	
	International Index of Erectile Function – 15 (IIEF-15) (Rosen et al., 1997)	X	X	X	X					4	
	Female Sexual Function Index (FSFI) (Rosen et al., 2000)	X	X	X	X					4	Pain
	Change in Sexual Functioning Questionnaire Short Form (CSFQ-14) (Keller et al., 2006)	X	X	X	X	X		X		6	
	Hudson's Index of Sexual Satisfaction (ISS) (Hudson et al., 1981b)				X		X	X		3	

	Arizona Sexual Experience Scale (ASEX) (McGahuey et al., 2000)	X	X	X	X					4	
	Kflner [Cologne] Evaluation of Erectile Dysfunction (KEED) (Braun et al., 2000)	X	X	X	X			X		5	
	Quality of Sexual Function Scale (L. A. J. Heinemann et al., 2005)	X	X	X	X	X	X	X	X	8	Urogen/sexual complaints
	Sexual Beliefs and Information Questionnaire (SBIQ) (Adams et al., 1996)									0	Beliefs and knowledge
	Derogatis Sexual Functioning Inventory (Derogatis & Melisaratos, 1979)	X			X					2	Knowledge, attitudes, psychological symptoms, affects, gender role definition, fantasy, body image
	Sexual Inhibition/Sexual Excitation Scale (Milhausen et al., 2010)	X								1	Sexual inhibition
	Eleven Questions about Sexual Functioning (ESF) (Vroege, 1998)	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 (Andersen & Cyranowski, 1994; Andersen et al., 1999b)	X								1	Perceptions of self as sexual
	Life Satisfaction Checklist (LiSat-9) (Fugl-Meyer et al., 1991)				X		X			2	
	Life Satisfaction Checklist (LiSat-11) (Axel R Fugl-Meyer et al., 2002)				X		X			2	
	World Health Organization Quality of				X					1	

	Life scale (WHOQOL-BREF) (Whoqol Group, 1998)										
	Grid for measurements of activity and participation (G-MAP) (Belio et al., 2014)				X		X	X		3	Attitudes
	Beck Depression Inventory (Aaron T Beck et al., 1961)	X								1	
	Hamilton Depression Rating Scale (Max Hamilton, 1960)	X								1	
	Social Functioning Examination (SFE) (Starr et al., 1982)						X	X		2	
	Psychological Adjustment to Illness Scale (PAIS) (Gary R Morrow et al., 1978)	X			X		X	X	X	5	Sexual dysfunction
	Post-Stroke Checklist (Ian Philp et al., 2013)							X		1	
	Maudsley Marital Questionnaire (MMQ-rs) (Arrindell et al., 1983)			X	X		X	X		4	Related psychophysical effects
	Assessment of Life Habits (LIFE-H) (Fougeyrollas et al., 1998)						X	X		2	
	Sub-total	**13**	**8**	**8**	**18**	**3**	**10**	**12**	**2**		
Questionnaires	(Monga et al., 1986)	X	X	X	X			X		5	Enjoyment/pleasure
	(McCall-Hosenfeld et al., 2008)				X	X		X		3	
	(Korpelainen et al., 1999)	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., 1998)	X	X	X	X			X		5	

	(Jung et al., 2008)	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
	(Sjögren & Fugl-Meyer, 1982)							X		1	
	(Humphrey, 1985)						X			1	
	(Giaquinto et al., 2003)	X	X	X	X		X	X		6	Positioning, drug use
	(Edmans, 1998)							X		1	Needs and preferences for sexuality related services
	(de Freitas Lucena et al., 2017)	X	X	X	X					4	
	(Choi-Kwon & Kim, 2002)	X	X					X		3	
	(Cheung, 2002)	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., 2017)						X			1	
	(Akinpelu et al., 2013)	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 & Jain, 1989)	X						X		2	
	(Song et al., 2011)							X		1	
	(Kim, 2008)					X		X		2	
	(Dusenbury et al., 2020)							X		1	
	(Na et al., 2020)						X			1	Fear of rejection by the partner, premorbid sexual dysfunction
	(Habot et al., 1989)				X			X		2	
	(Epprecht et al., 2018)							X		1	Past sexual experiences
	(Stead & White, 2019)						X		X	2	
	(Howes et al., 2005)	X								1	Appearance of sexual organs
	(Bugnicourt et al., 2014)	X	X	X	X					4	
	Sub-total	**12**	**9**	**8**	**11**	**2**	**5**	**17**	**1**		
Struc	(Boldrini et al., 1991)		X	X	X			X	X	5	Overall feelings about sexual life after stroke
	(Aloni et al., 1993)	X	X	X	X			X		5	
	(Aloni et al., 1994)	X	X	X						3	Menstrual cycle

	(Tamam et al., 2008)	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., 1992)	X	X	X						3	
	(Sjogren & Fugl-Meyer, 1981)		X	X				X		3	Frequency of sexual difficulties
	(Sjogren et al., 1983)		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
	(Sjögren, 1983)	X	X	X				X		4	Shown interest in partner, thought of mutual sexuality
	(Fugl-Meyer & Jaasko, 1980)							X		1	Couple's communication
	(Coslett & Heilman, 1986)	X						X		2	
	(Buzzelli et al., 1997)	X			X			X		3	Importance of sexuality, frustrations, medications taken
	(Bray et al., 1981)	X	X	X						3	Menstruation, importance of sexual functioning
	(Allsup-Jackson, 1981)		X	X				X		3	
	Sub-total	**8**	**10**	**10**	**4**	**0**	**1**	**10**	**2**		
Semi-structured interview	(Yilmaz et al., 2015)									0	General changes in sex life since stroke, support received by clinicians regarding sexuality
	(Thomas, 2016)								X	1	Perceptions regarding sexual difficulties
	(Schmitz & Finkelstein, 2010)						X			1	Questions other post-stroke individuals may ask themselves regarding sexuality, support and services offered regarding sexuality and related appreciation
	(Nilsson et al., 2017)									0	Description of changes regarding sexuality, professional support received regarding sexuality and related preferences
	(Mitchell-Pedersen, 1994)	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, 2009a)				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 & Bauer, 2015)						1		1	2	Stroke's impact on the person, on the partner and on the couple's life
	(Lever & Pryor, 2017b)						1			1	Identity as a woman
	(Lemieux et al., 2001)	1	1	1	1			1	1	6	Emotional lability, importance of sexuality, fears, clinician addressing sexuality
	(Carod et al., 1999)	1	1		1					3	
	(Kattari, 2014)				1					1	Couple's communication about sexuality, confidence
	(Hawton, 1984)	1	1	1				1		4	Couple's communication about sexuality
	(Goddess et al., 1979)	1						1		2	
	(Beal & Millenbruch, 2015)							1		1	
	(McCormick et al., 1986)							1		1	Performance anxiety, acceptance of changes, sexual conditioning
	(McCarthy et al., 2020)						1		1	2	Factors challenging the relationship
	(Pryor & Lever, 2020)						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**	

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 (Adams et al., 1996; Andersen et al., 1994; Braun et al., 1998; Derogatis & Melisaratos, 1979; Heinemann et al., 2005; Hudson et al., 1981b; Keller et al., 2006; McGahuey et al., 2000; Milhausen et al., 2010; Rosen et al., 2000; Rosen et al., 1999; Rosen et al., 1997; Vroege, 1998), two were non-specific to sexuality (Pamela W Duncan et al., 1999; Law et al., 1990) and 12 had some questions regarding sexuality, ranging from a single item (n=6) (A. T. Beck et al., 1961; Fugl-Meyer et al., 1991; Axel R Fugl-Meyer et al., 2002; Max Hamilton, 1960; Ian Philp et al., 2013; Whoqol Group, 1998) to multiple items (n=6) (Arrindell et al., 1983; C. Belio et al., 2014; Ferrans & Powers, 1985; Fougeyrollas et al., 1998; Gary R Morrow et al., 1978; Starr et al., 1982). Among the 13 tools that focused on sexuality, seven had cut-off scores indicating the presence of a sexual dysfunction (Braun et al., 1998; Hudson et al., 1981b; Keller et al., 2006; McGahuey et al., 2000; Rosen et al., 2000; Rosen et al., 1999; Rosen et al., 1997). 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) (Law et al., 1990; Law et al., 1994) 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 (Eyssen et al., 2011). The COPM was used by Thomas (2016) 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 (Lever & Pryor, 2017a) 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 (Tsang et al., 2017). For example, five studies included in our review based their questionnaires or structured interviews on Monga et al.'s (1986) 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 (Pamela W Duncan et al., 1999), the Canadian Occupational Performance Measure (COPM) (Law et al., 1990; Law et al., 1994) and the Quality of Life Index – Stroke Version (Ferrans & Powers, 1985). 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 (Onwuegbuzie & Leech, 2005). 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 (Pluye & Hong, 2014) are thus promising for assessing sexuality after a stroke, but few studies have used such approaches to date (Millenbruch, 2009a; Thomas, 2016).

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 (Axel R Fugl-Meyer et al., 2002), 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 (Mountain et al., 2020) and promote appropriate use of resources, considering that around 50% of post-stroke individuals will not experience sexual issues (Korpelainen et al., 1999), 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 (Dyer & das Nair, 2013).

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 (Keller et al., 2006) 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 (Auger et al., 2020). 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 (Fougeyrollas, 2010; Fougeyrollas et al., 1998). 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 (L. A. J. Heinemann et al., 2005) 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 (L. A. J. Heinemann et al., 2005), followed by the CSFQ-14 (Keller et al., 2006) and the "11 questions on sexual function" tool (Vroege, 1998). 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 (Tricco et al., 2018). 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 (Mokkink et al., 2018) and the ICF core set for stroke (Geyh et al., 2004), 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, which raises a significant risk of bias. 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 behavio* 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

Chapitre 7 – Cocréation du programme multifactoriel d’amélioration des services de réadaptation sexuelle post-AVC

Dans ce chapitre est présenté le cinquième article inclus à cette thèse, soumis et en cours d’évaluation par la revue *Disability and Rehabilitation* (Auger, Filiatrault, Allegue, Thomas, et al., 2023). Cet article est associé au étapes 2 à 4 de la cartographie des interventions (Bartholomew et al., 2016) et répond partiellement au deuxième objectif spécifique de la thèse : Explorer des stratégies qui pourraient être mises en œuvre pour améliorer les services de réadaptation sexuelle post-AVC. Cette étude sera également utilisée parmi les interventions du programme cocréé (c.-à-d., objectif spécifique #5), ce qui est décrit en détail dans le chapitre 8.

Sexuality after a stroke: Using Intervention Mapping to co-design an evidence-based program to improve rehabilitation services

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Abstract

Purpose: To co-design with various stakeholders involved in stroke rehabilitation a theory-driven program to improve clinicians' delivery of post-stroke sexual rehabilitation services.

Methods: This qualitative co-design study was conducted using the first four steps of the Intervention Mapping and an integrated knowledge translation approach. An advisory group composed of one individual with stroke, five clinicians, two managers and three researchers participated in four online co-design sessions to create the program prototype. The prototype was validated with five individuals with stroke and four partners in an online session, then improved. Data collection and analysis was based on the Theoretical Domains Framework and the Behaviour Change Wheel.

Results: A multifaceted program aiming to influence nine determinants of behaviours with 11 complementary components aiming to restructure the environment, to enable or to train stroke rehabilitation clinicians was co-designed. A logic model, a matrix of change objectives and procedures for implementation were designed.

Conclusions: The evidence-based multifaceted program for improving post-stroke sexual rehabilitation services is likely to be acceptable, useful for stroke rehabilitation and to be implemented since it was co-designed with stakeholders. Future implementation of the program will contribute to supporting stroke rehabilitation organizations and clinicians in providing sexual rehabilitation that answers guidelines.

Keywords

Sexuality, stroke, rehabilitation, Behaviour change, Implementation

Introduction

Stroke can have important consequences on participation for all activities of daily living by impacting a persons' physical, cognitive, emotional, communicative, and social functions and how they interact with their physical and social environment (Engel-Yeger et al., 2018; Ribeiro de Souza et al., 2022; Rochette et al., 2007). Rehabilitation is a dynamic and goal-oriented process that aims to foster the recovery of functions and the adaptation to residual limitations in individuals who sustained a stroke (hereafter referred to as "individuals with stroke") so that they may reach their optimal functional level (Canadian Stroke Best Practices, 2022). Numerous activities of daily living are addressed in rehabilitation, but those related to sexuality are often neglected (Low et al., 2022), although more than 50% of individuals can experience these difficulties after stroke (Grenier-Genest et al., 2017). Nevertheless, international evidence-based guidelines in stroke rehabilitation recommend that sexuality be addressed with all individuals with stroke (Mountain et al., 2020; Stroke Foundation, 2022). Two cross-sectional studies conducted respectively with 67 and 100 participants who sustained a stroke showed that sexual dysfunction was associated with poorer scores on depression and quality of life assessments, which support the hypothesis that failing to integrate sexuality in rehabilitation may put clients at higher risk of depression and poor quality of life (Kim & Kim, 2008; Kimura et al., 2001; Korpelainen et al., 1999). Therefore, there is a crucial need for interventions to narrow this gap between guidelines recommendations and actual practices in post-stroke sexual rehabilitation.

Based on Teasell and collaborators' (2020) definition of rehabilitation and the World Health Organization's definition of sexuality (2006), we define sexual rehabilitation as *a set of interventions designed to optimize functioning and reduce the experience of disability for individuals who are experiencing difficulties in their sexuality (comprising biological sex, gender identity and roles, sexual orientation and activities, eroticism, pleasure, intimacy and reproduction).* Multiple factors have been shown to impact the integration of sexuality in stroke rehabilitation, including factors related to the clients, the clinicians and the organizations (Richards et al., 2016). However, given current practices, specific attention must be devoted to the factors influencing clinicians' behaviours, which can help to better understand why sexual rehabilitation is either included or left out. A systematic review including 103 studies addressing clinicians' personal factors and practices related to sexuality with individuals presenting a chronic health condition showed that clinicians generally feel uncomfortable to address sexuality with their clients and report a lack of confidence and/or competence in that domain (McGrath et al., 2021). The scarcity of clinical tools and lack of human and/or material resources have also been outlined as factors influencing the provision of sexual rehabilitation services (Dyer & das Nair, 2013). Considering McGrath and collaborators' (2021) conclusions and that numerous factors may influence sexual rehabilitation practices, there is an important need for the development of multiple strategies with complementary purposes. Doing so is likely to improve the provision of sexual rehabilitation services for individuals with stroke.

A recent systematic review including eight studies showed that sexual rehabilitation interventions such as personalized education (Ng et al., 2017; Sansom et al., 2015) and pelvic floor muscle training (Tibaek et al., 2015) can improve knowledge, functioning and/or satisfaction related to sexuality in individuals with stroke (Auger, Grondin, et al., 2021). However, past studies have focused on the effects of single interventions pertaining to sexual rehabilitation (Auger, Grondin, et al., 2021) and few of them have assessed interventions' effects on sexual rehabilitation services improvement (Auger, Pituch, et al., 2021; Guo et al., 2015). Furthermore, to our knowledge, no comprehensive sexual rehabilitation program has been developed for individuals with stroke until now. Moreover, considering the results of an Australian Delphi study conducted with 30 individuals with stroke, 18 partners of individuals with stroke and 45 clinicians and researchers involved in stroke rehabilitation, the rehabilitation setting would be optimal to provide sexual rehabilitation considering that there was a consensus that sexuality should be addressed in priority in the subacute and chronic phases of stroke (McGrath et al., 2019). Therefore, the creation of a program to improve the provision of sexual rehabilitation services in stroke rehabilitation is needed.

Intervention Mapping is a rigorous and systematic method for the development of single or multiple interventions (i.e., multifaceted program) aiming to change behaviours, or practices (Bartholomew et al., 2016). Numerous studies have successfully used *Intervention Mapping* in the development of programs to change health-related behaviours (e.g., condom use, self-management of diabetes) (Acuña Mora et al., 2020;

Hadjiconstantinou et al., 2020; Miranda & Côté, 2017; Peskin et al., 2017; Wolfers et al., 2007), but none have used it for sexual rehabilitation.

The overarching aim of this study was to co-design, with various stakeholders involved in stroke rehabilitation (individuals with stroke and their partners, clinicians, managers and researchers), a theory-driven program to improve clinicians' delivery of post-stroke sexual rehabilitation services. The specific objectives of this study were to:

1) Identify the main outcomes, behavioural or environmental changes that would be required (i.e., performance objectives), determinants and the related change objectives of the program.
2) Identify the evidence-based methods and strategies that should be considered in the development of the programs' components.
3) Co-design a preliminary version of the components of the program.

Materials and methods

Theoretical frameworks and approach

This study was conducted using an integrated knowledge translation approach, which consists in involving stakeholders (e.g., individuals with stroke, clinicians) throughout the conduction of the study to produce knowledge that is more likely to be useful and acceptable by them (Gagliardi et al., 2015; Kothari & Wathen, 2017). The co-design of the program was oriented by the first four steps of the *Intervention Mapping,* namely: 1) Conducting a needs assessment; 2) Preparing matrices of change objectives; 3) Selecting theory-informed methods and strategies; and 4) Producing the program (Bartholomew et al., 2016). The specific objectives were directly related to the *Intervention Mapping* steps: objective 1 (steps 1-2); objective 2 (step 3); and objective 3 (step 4). In addition to the *Intervention Mapping* that structured the project as a whole, Morales and collaborators' (2012) co-design model was used to conceptualize and plan each co-design sessions conducted to develop the program. Data collection and analysis was oriented with the *Theoretical Domains Framework* (TDF) (Cane et al., 2012) for steps 2 and 3 of the *Intervention Mapping* (Bartholomew et al., 2016), and the *Behaviour Change Wheel* (BCW) (Michie et al., 2011) guided step 4. The TDF is an empirically founded framework that can be used to describe 14 different domains, or determinants, that can influence a person's behaviour: Knowledge, Skills, Social/Professional Role and Identity, Beliefs about Capabilities, Optimism, Beliefs about Consequences, Reinforcement, Intentions, Goals, Memory, Attention and Decision Processes, Environmental Context and Resources, Social Influences, Emotions, and Behavioural Regulation (Cane et al., 2012). The BCW is a useful framework for classifying behaviour change interventions between two categories: interventions and policies. In the present study, we used only the interventions' category, including: Education, Persuasion, Incentivisation, Coercion, Training, Restriction, Environmental restructuring, Modelling and Enablement (Michie et al., 2011).

Design

This qualitative study was part of a larger research project, whose methods have been described in detail elsewhere (Auger, Allegue, et al., 2022). The development of this qualitative study was reported based on the *Consolidated criteria for reporting qualitative research* - *COREQ* (Tong et al., 2007). The process of the study, including each of the co-design sessions, respective stakeholders involved, complementary contribution of the research team and outcomes associated with each step of the *Intervention Mapping* is presented in Table 13.

Tableau 13. – Process of the study related to the steps of the *Intervention Mapping* (Bartholomew et al., 2016)

Intervention Mapping* steps	**Step 1: Conducting a needs assessment**		**Step 2: Preparing matrices of change objectives** **Step 3: Selecting theory-informed methods and strategies**	**Step 4: Producing the program**		
Co-design sessions with stakeholders	Advisory group 1 (Oct. 2021)	LEGO® groups (n = 4 groups, Nov-Dec 2021)**	Advisory group 2 (Feb. 2022)	Advisory group 3 (April 2022)	Advisory group 4 (June 2022)	Validation group (Dec. 2022)
Outcomes	Initiation of the reflection on the general objectives of the program	Influencing factors and strategies for sexual rehabilitation	Establishing: • Behavioural and environmental outcomes • Performance objectives related to each outcome • Priority strategies for each performance objective	Revision and improvement of the preliminary version of the strategies of the program		Evaluation of the program prototype, suggestions for improvements and highlighting of missing elements
Complementary contribution of the research team***	Analysis of participants' discourse and translation in potential behavioural and environmental outcomes (i.e., general objectives)	Analysis and categorization of the influencing factors and strategies using the TDF, the COM-B system and the BCW	Associate determinants and objectives of change with each performance objective; Preparation of a logic model and a matrix of change for clients/partners, clinicians and managers; use of the theory and technique tool (Johnston et al., 2020) and Kok and collaborators' (2016) taxonomy to select theory-informed methods; Combine the strategies identified by the advisory group with those of the	Residual improvements that could not be made during the session		Residual improvements that could not be made during the session

		LEGO groups

TDF: Theoretical Domains Framework (Cane et al., 2012); COM-B system: Capability, Opportunity, Motivation and Behaviour system (Michie et al., 2011); BCW: Behaviour Change Wheel (Michie et al., 2011).

* The steps 5 and 6 of the *Intervention Mapping* (Bartholomew et al., 2016) will be addressed in future studies.

**Influencing factors and strategies for sexual rehabilitation (in grey) have been described in another study (Auger, Filiatrault, Allegue, Vachon, et al., 2023).

***The complementary contribution of the research team was generally realized after the conduction of each co-design session, in preparation of the next one.

Population

The study population consisted of stakeholders from stroke rehabilitation, namely individuals with stroke, their partners, clinicians, managers and researchers. The program to be developed aimed to improve the provision of sexual rehabilitation services in five partner organizations. Located in the three largest cities of Quebec, Canada, these five rehabilitation centers provide most of the post-stroke rehabilitation services in the province.

Sample and recruitment

Two distinct groups of participants were created to address the study objectives. First, an interdisciplinary advisory group was formed to guide the co-design of the program and create a preliminary version of the program. This group included one clinician working in stroke rehabilitation from each of the five partner organizations, one manager, one individual with stroke and three researchers with an expertise in stroke rehabilitation, sexuality or knowledge translation. Clinicians were recruited by convenience via an email sent by managers of the five stroke rehabilitation program teams. The individual with stroke, manager and researchers were recruited using the research team's professional network. Second, a group (i.e., validation group) of individuals with stroke, including their partners when possible, was formed to validate the preliminary version of the program, suggest improvements and provide insights on the program prototype to further future implementation. To be included in the validation group, individuals with stroke had to be at least six months post-stroke and have completed their rehabilitation follow-up (either inpatient rehabilitation, early supported discharge or outpatient rehabilitation). If participants had a partner at that time, he/she was also invited to participate in the study. Potential participants were recruited using a list of clients from two of the five partner organizations. A minimum of five individuals with stroke and one partner was targeted to gather a variety of perspectives.

Course of the study

The course of the study is described below. Although it is presented step by step, it should be noted that the co-design of the program was conducted using an iterative approach.

Step 1: Conducting a needs assessment

This step was addressed in a previous study, in which the advisory group participated, added to ten other stroke rehabilitation clinicians (i.e., two from each of the five partner organizations) from various disciplines (Auger, Filiatrault, Allegue, Vachon, et al., 2023). The only part of the first step of the *Intervention Mapping* that was realized in the present study was the definition of the program's general objectives, which constitutes the stakeholders' (i.e., clinicians and individuals with stroke) behavioural outcomes or their environmental outcomes.

Step 2: Preparing matrices of change objectives

According to the *Intervention Mapping*, once the general objectives of the program are established (i.e., behavioural and environmental outcomes), these must be divided in performance objectives, which are observable and measurable actions or changes at the level of stakeholders' behaviours or environment (Bartholomew et al., 2016). Each performance objective (e.g., a certain clinical practice) is associated to a set of relevant determinants based on the TDF (e.g., skills) (Cane et al., 2012). The hierarchy for the concepts mentioned above is presented in Figure 7. Finally, to determine the actions that will be taken to address these determinants to reach the performance objective, more specific change objectives are formulated. The program's matrix of change is thus created when combining each performance objectives with their associated determinants and their change objectives.

Step 3: Selecting theory-informed methods and strategies

Depending on the priority determinants targeted in the matrix of change, one or more theoretical models can be chosen to guide the selection of the determinants and the strategies to influence them. The selection of the determinants to be targeted in the program was based on the theoretical model of influencing factors for post-stroke sexual rehabilitation by Auger and collaborators (2022). According to that model, the following determinants of the TDF (Cane et al., 2012) influenced clinicians' sexual rehabilitation practices: knowledge, skills, attention, memory and decision processes, behavioural regulation, beliefs about capabilities, professional role and identity, emotions, goals, social influences and environmental context and resources. The selection of strategies to influence the determinants (i.e., desired mechanism of action) was guided using a combination of Auger and collaborators' results (2022), participants' suggestions in the advisory and validation groups, the Theory & Techniques Tool (TTT) (Johnston et al., 2020) and Kok and collaborators' (2016) taxonomy of behaviour change methods.

Step 4: Producing the program

Based on the results of the last three stages, the research team produced a preliminary version of the different behavior change strategies, or components. For specific strategies, participants in the advisory committee were contacted via email between the sessions to collect their recommendations regarding specific subjects (e.g., validation of disciplinary roles in relation to sexual rehabilitation). The preliminary program with draft versions of the strategies were presented to the advisory committee in two separate meetings. Participants' feedback and related improvements by the research team led to the creation of the prototype of the program, which was presented to the validation group for final review and optimization.

Data collection and iterative analysis

The age and gender of each participant were recorded to allow a description of the study sample. Individuals with stroke shared information regarding their stroke (i.e., localisation, date) and the type of rehabilitation they received (i.e., inpatient, early supported discharge, and/or outpatient). Clinicians and managers provided information on their professional discipline and years of experience in stroke rehabilitation. Co-design activities were conducted online via Zoom to obtain the perspectives of individuals from a diversity of contexts (i.e., three cities) and to comply with the Covid-19 sanitary measures. Co-design activities were co-moderated by the first and last authors and discussions were recorded audiovisually. Each co-design session lasted approximately two hours and consisted of presenting results from previous steps of the larger study or past co-design sessions. During these sessions, participants shared their perceptions and suggestions regarding the preliminary version of the program created by the research team. The preliminary components of the program were improved or corrected during and between co-design sessions. Specifically for the validation group, participants who were not available at the time set for the group were met individually by the first author.

Besides the iterative analysis of data that was realized during the co-design sessions and the modifications that were executed *in situ*, the first author listened to the recordings repeatedly to incorporate participants' suggestions to improve the program in preparation of the upcoming co-design session. The results of the analysis have been articulated in concordance with the expected deliverables for steps 1 to 4 of the *Intervention Mapping*.

Ethical considerations

This study was approved by the research ethics board of the research center to which the first author is affiliated (#MP-2022-1277). To take part in the study, each participant had to provide an informed consent by signing an information and consent form.

Results

Participants' sociodemographic, professional and health data

The advisory group included one individual with stroke, five clinicians, two managers and three researchers. All members of the advisory group were female. They were aged between 29 and 65 years (see Table 14). The validation group was composed of five individuals with stroke and four partners, all couples were heterosexual (see Table 15). Individuals with stroke were mostly male (n = 4/5) and aged between 28 and 62 years. The majority (n = 4/5) reported having sustained a left stroke and were between 7 months and 14 years post-stroke. Partners were aged between 45 and 65 years and were mostly female (n = 3/4).

Tableau 14. – Sociodemographic and professional characteristics of clinicians (n = 5), managers (n = 2) and researchers (n = 3)

Participant ID	Age	Gender	Professional discipline	Stroke program	Years of experience in stroke rehabilitation	Affiliation*
Advisory Group						
1	29	Female	Occupational therapist	Outpatient	4	1
2	65	Female	Psychologist specialized in sexuality	Outpatient, Inpatient, Research	8	1, A
3	29	Female	Nurse	Early supported discharge	4	2
4	38	Female	Physical therapist	Inpatient	14	3
5	53	Female	Nurse	Inpatient	18	5
6	36	Female	Neuropsychologist	Inpatient, Early supported discharge, Outpatient	7	4
7	60	Female	Manager	Inpatient, Early supported discharge, Outpatient	30	1
8	55	Female	Research manager	NA	NA	1
9	50	Female	Occupational therapist	Research	<1	B
10	52	Female	Occupational therapist	Research	30	C

*For confidentiality purpose, the identification of the partner organization and universities to which each study participant was affiliated has been associated to a number and a letter, respectively. [a]NA: Not applicable.

Tableau 15. – Individuals with stroke (n = 6) and partners' (n = 4) sociodemographic and health characteristics

Participant ID	Age	Gender	Individual with stroke or partner	Localisation of stroke	Duration post-stroke	Rehabilitation received
Advisory Group						
11	37	Female	Individual with stroke	Left stroke	8 years 9 months	Inpatient, outpatient
Validation Group						
12	48	Male	Individual with stroke	Left stroke	2 years 9 months	Early supported discharge, outpatient
13	39	Male	Individual with stroke	Left stroke	2 years 7 months	Inpatient, outpatient
14	28	Male	Individual with stroke	Unspecified (did not remember)	2 years 1 month	Early supported discharge, outpatient
15	54	Female	Individual with stroke	Left stroke	1 year 0 month	
16	62	Male	Individual with stroke	Left cerebellar stroke	0 year 7 months	Outpatient
17	45	Female	Partner	-	-	-
18	50	Female	Partner	-	-	-
19	55	Male	Partner	-	-	-
20	65	Female	Partner	-	-	-

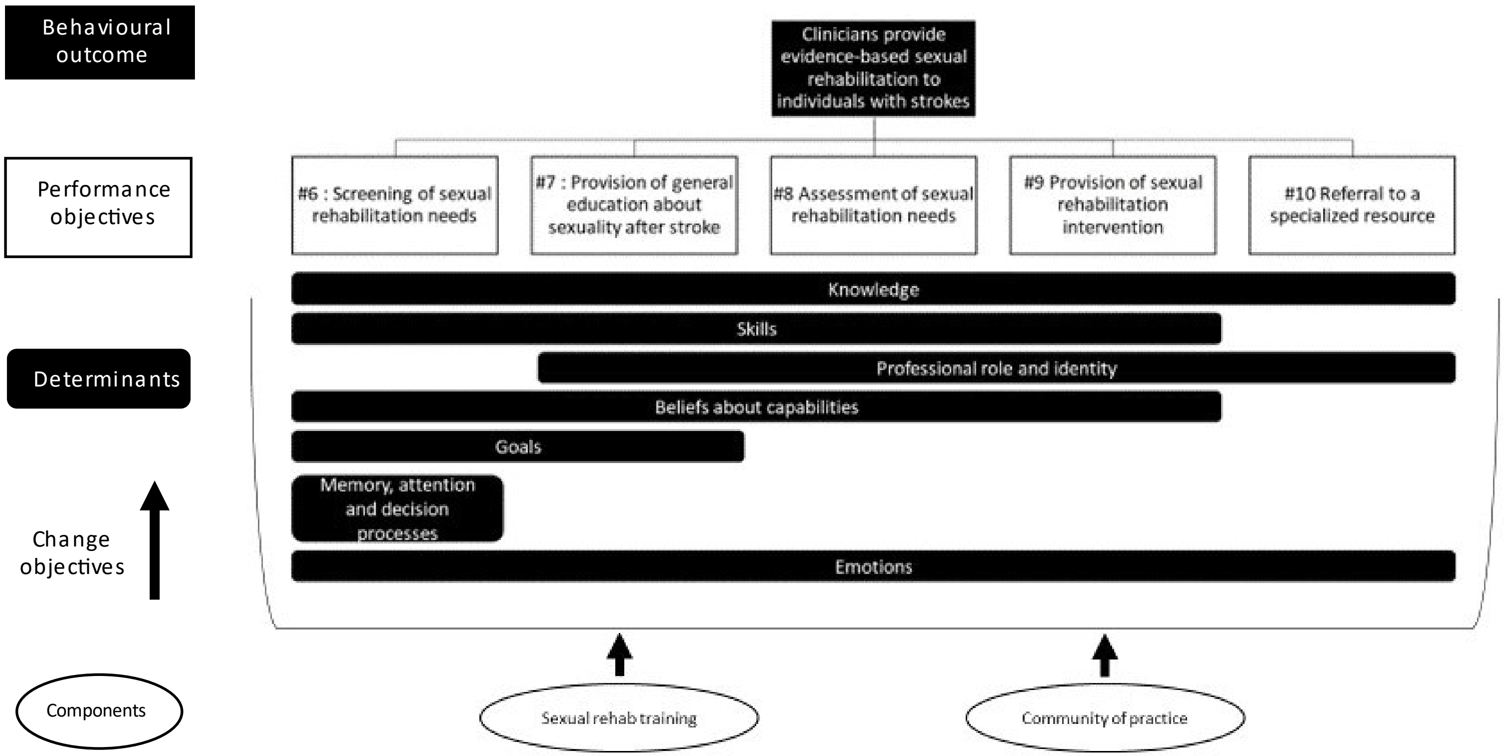
Objective 1: Identify the main outcomes and the general and specific objectives of the program

Step 1: Conducting a needs assessment

A stakeholder needs assessment was conducted with stakeholders (mostly clinicians) and is presented in detail in another study (Auger, Filiatrault, Allegue, Vachon, et al., 2023). Discussions and negotiations between the advisory group members led to two general objectives for the program that are interdependent, and to target the main stakeholders for the program. During the study process, it was decided that the program should target clinicians in priority. In fact, they were deemed as central stakeholders for the improvement of sexual rehabilitation services, considering that reaching the behavioural outcomes of the program (i.e., clinical practices) would mean influencing the provision of services to clients and their partners, and that reaching the environmental outcomes would imply that managers were influenced as well. Therefore, the first general objective was mostly focused on clinicians' practice and was stated as: **to ensure that all individuals with stroke get the opportunity to receive sexual rehabilitation services based on the recommendations of the Canadian stroke rehabilitation guidelines**. This first objective was related to the second one, which focused on individuals with stroke and their partners and was stated as: **To achieve optimal sexual satisfaction for individuals with stroke and their partners**. Therefore, the behavioural outcome that was aimed by the program was that "Clinicians will provide evidence-based sexual rehabilitation to individuals with stroke". Moreover, the environmental outcome of the program was that "Clinicians will practice in an environment that fosters the provision of sexual rehabilitation to individuals with stroke". Further analysis by the research team resulted in prioritizing fulfillment of the environmental outcome before the behavioural outcome, as fulfilling the former was likely to positively influence the latter.

Step 2: Preparing matrices of change objectives

The matrices of change objectives for the environmental and behavioural outcomes, each including performance objectives associated to their respective determinants and change objectives (CO) are presented in detail in supplementary material. In total, five performance objectives were targeted for the environmental outcome of the program, which were related to two following determinants: “Environmental context and resources” (n = 10 CO) and “Social influences” (n = 3 CO). The behavioural outcome of the program was associated to seven determinants, namely: “Knowledge” (n = 10 CO), “Skills” (n = 5 CO), “Professional role and identity” (n = 6 CO), “Beliefs in capabilities” (n = 4 CO), “Goals” (n = 2 CO), “Memory, attention, and decision processes” (n = 1 CO), and “Emotion” (n = 5 CO). A logic model showing the interdependent behavioural and environmental outcomes (n = 2), performance objectives (n = 10) and determinants (n = 9) is showed in Figure 7.



Page 1/2, see instructions below for interpretation.

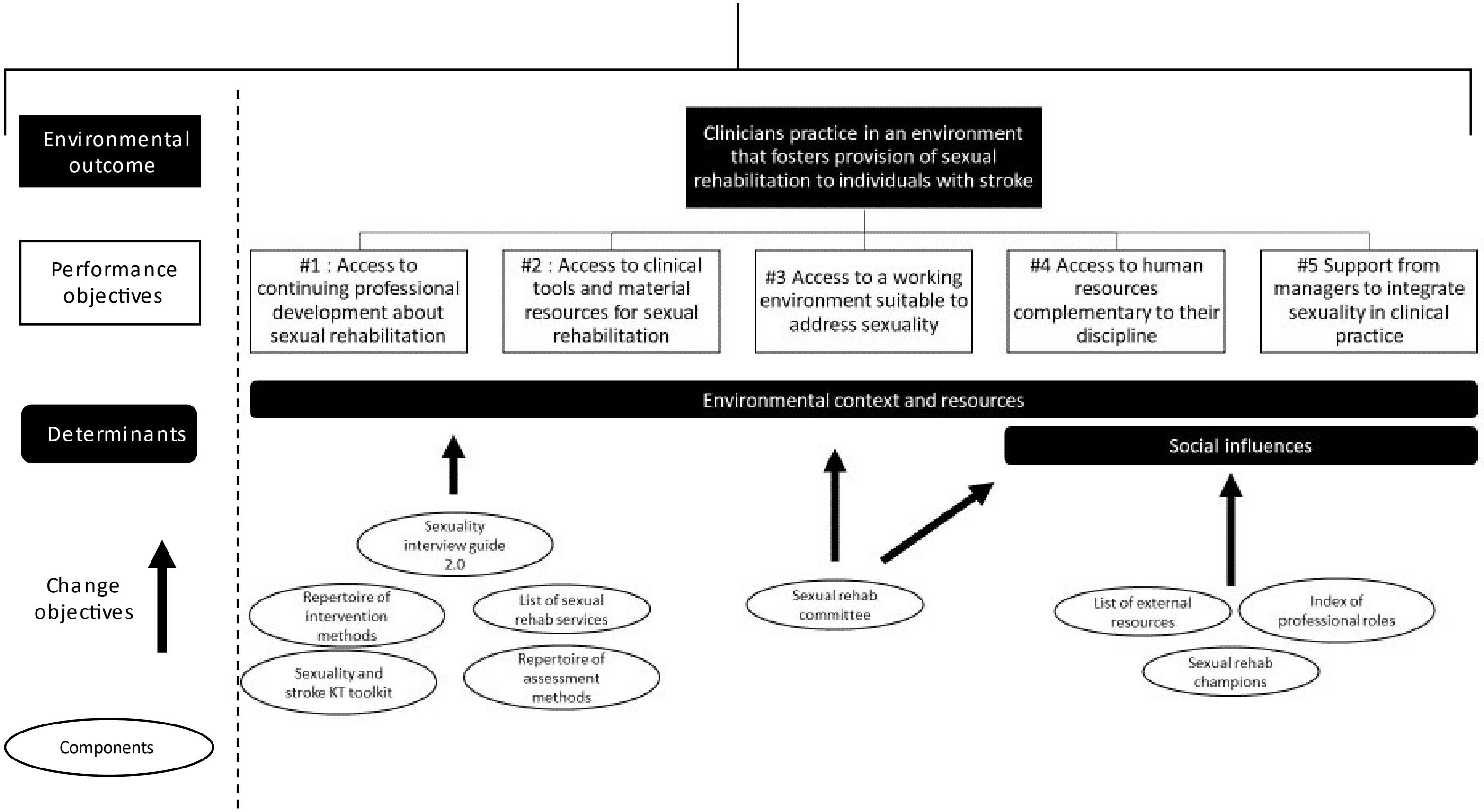


Figure 7. – Logic model of the program for improvement of sexual rehabilitation services (page 2/2)

On the left are presented the headings to interpret the logic model. The logic model should be analyzed from the bottom to the top. Components (circles) were associated to specific determinants (black rectangles) with a change objective (arrows). The width and arrangement of the determinants show their association with a performance objective (e.g., "Social influences" is related to performance objectives #4 and #5). Each performance objective is related to an outcome.; KT: Knowledge translation.

Objective 2: Determine the evidence-based methods and strategies that should be considered in the programs' components development.

Step 3: Selecting theory-informed methods and strategies

To ensure that the program meets the established change objectives, the nine determinants targeted (presented above) were associated to evidence-based (Johnston et al., 2020) and theory-informed (Kok et al., 2016) methods and strategies, which are presented in detail in tables available in supplementary material (See Annexes 3 and 4). The most frequently reported strategies among the nine determinants paired with to evidence-based (Johnston et al., 2020) and theory-informed (Kok et al., 2016) methods and strategies were: 1) problem-solving of case histories that were representative of practice, 2) role plays, 3) guided assessment about the role play or the actual clinical practice. Clinicians in the advisory group shared their past experiences and preferences regarding the format of specific strategies to guide their development. For example, there was a consensus in the advisory group that it would be preferable for the training to be provided face-to-face rather than online:

> "*I think that face-to-face is completely necessary. I would not do this* [the sexual rehabilitation training] *online. I feel like people who are uncomfortable* [with sexuality] *will just zone out, when in fact it's exactly the opposite that need to happen. I think that everyone has to be able to talk about it together and face-to-face.*" (P4 – Physical therapist)

Objective 3: Develop the components of the program with stakeholders

Step 4: Producing the program

Based on the needs assessment, the matrix of change objectives and the iterative work between the co-design sessions with the advisory and validation groups, a multifaceted program comprising 11 components was created. These components aimed to restructure the environment, to enable or to train clinicians, based on the methods and strategies that influence determinants in concordance with change objectives (Michie et al., 2011). The components aiming environmental restructuring were: 1) Committee for improvement of sexual rehabilitation; 2) Professional champions on sexual rehabilitation services; 3) List of sexual rehabilitation services offered in the organization, 4) List of local and provincial relevant health and community resources outside the organization. The components aiming clinicians' enablement were: 5) Knowledge translation (KT) toolkit pertaining to sexuality after a stroke; 6) Sexuality Interview Guide (SIG) version 2.0; 7) Index of professional roles in sexual rehabilitation; 8) Repertoire of quantitative and qualitative assessment methods in sexual rehabilitation; 9) Repertoire of sexual rehabilitation intervention methods; 10) Community of practice. The eleventh (#11) component of the program, in the training category of the BCW (Michie et al., 2011), was a sexual rehabilitation training. The multifaceted program was made to be flexible and tailored to the needs and context of each organization (cf., choice and chronology of components to be implemented). In all cases, it is suggested that a sexual rehabilitation committee be created (Component #1) to allow to reflect about potential components and select those considered to be most suitable for the organization for future implementation. For example, the sexual rehabilitation committee could use the repertoire of assessment methods to choose one or several assessment tools to integrate into their program. Moreover, the committee could reflect on which educative resource to implement with the guidance of the KT toolkit (e.g., organizations may choose to use only the flyer, while others may select the flyer, the poster, the booklet and the powerpoint presentation to offer an educational group). Then, organizations could implement the sexual rehabilitation training (Component #11), then implement a community of practice (Component #10) to support clinicians during the implementation of the program. The advisory group shared their preferences for the components and tools and recommended that these should be as user-friendly as possible, easy to integrate in clinical practice, and guide their clinical reasoning in relation to sexual difficulties after a stroke.

> “*I think that for each step* [of the sexual rehabilitation follow-up], *I think we should leave as little room as possible for* blurring [uncertainty]. *The more structured it will be, like in telling us when to use which tool, which topic to assess for which clinician, then: here is the tool that you could use …*” (P4 – Physical therapist)

However, they mentioned preferring tools that provide suggestions rather than prescriptions for future interventions. For example, a discussion occurred about the section of the interview guide on sexuality 2.0 used to guide the appointment of one or some clinicians in relation to the difficulties reported by clients (which was presented as a column). P8 and P10 suggested the section be removed, whereas P1-P3-P4-P5 preferred to keep it:

> “*I like that column, and the reason I like it is because I think that it ensures a follow-up regarding that* [sexuality]. *But it’s sure that it could be more vague and leave more space to the team to choose the appropriate clinician depending on who is on the team. But for me, as a clinician, if we don’t put it* [the column], *I think it’s easy to just check the problems, to put the form in the medical file and to never talk about it again*. (P3 – nurse)

Participants in the validation group agreed with the proposed components and reinforced the relevance of offering multiple choices to each individual with stroke and their partner since experiences and preferences in relation to sexuality are likely to vary from one person to another. However, a preference that many (but not all) of the participants shared was that education be provided individually (rather than in group), either in-person or online.

> “*I'm a bit mixed between the two, for a general presentation I wouldn't mind following it as a group, but since each couple will probably have different problems* [….], *I think everyone is different and I think only a general capsule, which presents what is happening, what are our options, it's interesting, but after that, I think that the therapy and the follow-up afterwards, I would prefer an individualized approach, really adapted to my*

situation and my couple. Even if other couples are in the same situation as me, I think I would be more comfortable doing it [receiving education or therapy] *just with my couple.*" (P17 – Partner)

All components of the program are presented in detail in Table 16 and a chronological approach for their implementation is suggested in Table 17.

Tableau 16. – Description of the 11 program's components categorized using the Behaviour Change Wheel (Michie et al., 2011)

Components	Description
Environmental restructuring	
1) Committee for improvement of sexual rehabilitation	Who: This committee should be made up of clinicians representing the different disciplines available in the organization, managers, as well as patients and their partners, if possible. In the event that researchers are involved in the organization, they could also be involved. When: This committee should be set up at the moment the organization wishes to implement the program, and it should pilot each stage of preparation, execution and evaluation of the implementation of the program. What: The committee should evaluate practices of the organization before the implementation to detect their specific needs in order to choose and adapt the components of the program so that they meet their needs in an optimal way. They should also choose how sexual rehabilitation services will be implemented in the organization.
2) Professional champions on sexual rehabilitation services	Who: For each professional discipline offering stroke rehabilitation services in the organization, a champion could be designated to support the rest of their team during day to day clinical activities. These professionals could be designated according to their level of comfort, perceived competence, or the level or training they received in relation to sexuality, or for their position in the team.
3) List of sexual rehabilitation services offered in the organization	What: Founded on the Canadian stroke rehabilitation guidelines, the list of sexual rehabilitation services and interventions to be provided is: A) Screening for the need of sexual rehabilitation services, B) Assessing clients' and partners (if applicable) specific needs and objectives for sexual rehabilitation, C) Providing education in relation to sexuality after a stroke, D) Provide disciplinary and interdisciplinary sexual rehabilitation interventions, E) Refer clients to specialized resources for persisting difficulties.
4) List of local and provincial relevant health and community resources outside the organization	What: A list of specialized sexuality-related resources either in the health system or in the community. These can include specialized sex therapy and medical services, organizations defending the rights of people who have suffered trauma or abuse, representation resources for people who are part of the 2SLGBTQIA+ community, etc.

Enablement	
5) Knowledge translation (KT) toolkit pertaining to sexuality after a stroke	Whom / who: Can be used by any person needing to improve knowledge regarding the subject, but the content was primarily dedicated for individuals who sustained a stroke and partners. What: KT tools include A flyer, an informative poster, a more detailed booklet founded on a literature review and expert consensus (McDermott & Rochette, 2021), and educational capsules. These KT tools have for objective to 1) raise awareness in clients, partners, relatives and clinicians that sexuality can be addressed in stroke rehabilitation, 2) provide general information regarding sexuality after a stroke and 3) support clinicians' educational interventions. How: The flyer, the booklet and the poster can be made available physically and online by the organizations (this hybrid format for each tool was requested by members of the advisory group), in the environments they feel relevant (e.g., on certain units, in waiting rooms, in therapy rooms). The educational capsules could be provided in-person or online by a clinician, either in group or individual format, and could also be adapted in an asynchronous narrated capsule. When: KT tools should be adapted to the organization's context before the implementation of the program, and their provision should be supported (e.g., print new copies of the flyer) throughout the implementation period.
6) Sexuality interview guide (SIG) version 2.0	What: The original version of the Sexuality interview guide (Auger, Pituch, et al., 2021), which included four questions to orient the interview for the need of sexual rehabilitation services, was improved to include more questions regarding clients' preferences and expectations regarding sexual rehabilitation, such as the desire to include the partner in the process (if applicable). Moreover, an inventory of the main potential consequences of stroke on sexuality (eg, sensorimotor influences, incontinence), associated with suggestions from professionals qualified to respond to these specific consequences, has been added to the MIS. This inventory was based on the Sexual Rehabilitation Framework (Elliott et al., 2017) and was intended to facilitate exploration of client needs and facilitate interdisciplinary work and referrals if needed.

	How: A two-pager tool including verbatim for semi-structured interview and checklists to orient the discussion and clinical reasoning. Can be used in 5 to 15 minutes depending of the clients' discourse. When: Should be used during the implementation of the program.
7) Index of professional roles in sexual rehabilitation	What: An index including every profession that can be included in stroke rehabilitation and sexual health. The index presents 1) many disciplines including occupational therapy, physical therapy, speech language pathology, sexology, etc., with 2) the description of their field of practice according to their professional order or association, and 3) a description of potential applications of the field of practice of the professional in relation to sexuality. The index can be adapted to the local context and to resources available outside the organization. How: Clinicians can consult the index before and during sexual rehabilitation intervention to guide their disciplinary intervention and to orient the interdisciplinary work and referrals.
8) Repertoire of quantitative and qualitative assessment methods in sexual rehabilitation	What: An open-access scoping review of assessment methods related to sexuality after a stroke that can be used by allied health (and medical) professionals (Auger et al., 2021). It includes validated tools, questionnaires and semi-structured interviews (see Appendix 2), a description of psychometric and pragmatic (e.g., duration of use, cost) of methods (when applicable) and suggestions from the authors for the assessment in sexual rehabilitation after stroke.
9) Repertoire of sexual rehabilitation intervention methods	What: An open-access systematic review of sexual rehabilitation intervention methods that can be used by most, or certain, allied health professionals (e.g., pelvic floor muscle training in physical therapy) (Auger et al., 2020). Moreover, a repertoire of intervention methods will be compiled and improved iteratively to accumulate more and more tools. Two practice guides related to sexuality for occupational therapists and physiotherapists are included in this directory, which will gradually grow.
10) Community of practice	What: Group meetings with clinicians to make the follow-up of their experience of the implementation of sexual rehabilitation services in their practice. This community of practice would be the occasion for clinicians to share their emotions, thoughts and experiences regarding sexual rehabilitation practices, and to exchange together and with a trained facilitator regarding

	clinical situations that they experienced and to problem-solving. How: In-person or online meetings, it is suggested that one hour per month may be feasible. When: From the beginning of the implementation of the program until clinicians feel it is not necessary anymore.
Training	
11) Sexual rehabilitation training	What: An interdisciplinary training where every clinician from the stroke rehabilitation team can attend. The training aims to improve knowledge regarding subjects such as the potential impacts of stroke on sexuality, guidelines on sexual rehabilitation after stroke and certain methods for screening, assessing and intervening for sexuality after a stroke. Moreover, exercises are designed for participants to acquire experience and feedback regarding provision of sexual rehabilitation services. How: In-person training, ideally with the clinicians from the same organization, and that the training be divided in 1-3 hours periods, was requested by the advisory group. When: It is suggested that the training occur before, or right at the beginning, of the implementation of the program.

Tableau 17. – Procedural of tasks to guide the Committee for improvement of sexual rehabilitation for improvement in the implementation of the program

Pre-implementation	
1. Set up the committee	As far as possible, a representative from each clinicians' discipline, a clinical-administrative staff member and a stroke rehabilitation manager should be included
2. Assess the organization's specific needs for improvement	Methods such as auditing medical files and surveys among clinicians and/or clients may be considered.
3. Establish improvement objectives	The committee could use the performance objectives available in the matrix of change objectives (See Appendix 4) to orient their discussion and adapt the "List of sexual rehabilitation services to be provided" (Component #3). A timeline with specific milestones could be established to plan the beginning and the assessment of the implementation of the program.
4. Identify professional champions for sexual rehabilitation (Component #2)	Among each discipline the committee deems relevant, a champion could be designated. That information should be communicated to the champions' disciplinary colleagues.
5. Clarify clinicians' respective roles in relation to sexual rehabilitation	Using the Index of professional roles in sexual rehabilitation (Component #7, see the French version in Appendix 5), representative from each discipline could adapt its content to their own context, resulting in a chart that could be followed by the interdisciplinary team. This chart should be made available to every member of the organization.
6. Choose the method to detect the need of sexual rehabilitation services in clients	The committee could evaluate if the Sexuality Interview guide 2.0 (Component #6, see the French version in Appendix 6), or other methods in the repertoire of assessment methods (Components #8-9), could be suitable.
7. Choose the knowledge translation tools to be implemented in the organization	Using the Knowledge translation toolkit regarding sexuality after a stroke (Component #5), the committee could choose and adapt the knowledge translation tools they consider relevant and applicable in their organization. See the French versions of: • A flyer in Appendix 7 • A bookmark in Appendix 8 • A poster in Appendix 9 • A detailed informative document on sexuality after a stroke (French and English versions) at: French: https://strokengine.ca/wp-content/uploads/2020/07/PFinfo_sexualite_fr.pdf

	English: https://strokengine.ca/wp-content/uploads/2020/07/Sexuality_PatientFamily-Info_Final-Feb2021.pdf • A Powerpoint presentation for a 60-minute educational session on sexuality after a stroke in Appendix 10
8. Choose the assessment and intervention methods to be implemented in the organization	Using the repertoires of assessment (Components #8-9) and intervention (Component #10) methods, the committee can identify and plan the implementation of specific methods in the organization. If applicable, methods may be provided specifically to specific disciplines.
9. Create a list of external resources	Using a list of local and provincial health and community resources outside the organization (Component #4), the committee could adapt the resources to their own context.
Implementation	
10. Begin the implementation of the program	-----
11. Provide professional development opportunities to the interdisciplinary team regarding sexual rehabilitation	Organizations should choose a professional development activity that would be provided to each clinician of the stroke rehabilitation program. The sexual rehabilitation training (Component #12, see the French version of the training plan in Appendix 11) and/or the community of practice (Component #11) could be strategies chosen.

Discussion

This study was part of a larger project aimed at designing an evidence-based program to improve stroke sexual rehabilitation services. In this paper, we report on the development of a multifaceted program anchored in the needs expressed by the stakeholders involved in stroke rehabilitation and based on available evidence on behavior change. It was also guided by the *Intervention Mapping* steps described by Bartholomew and collaborators (2016). The multifaceted program offers multiple and interrelated components to improve stroke sexual rehabilitation services, which is innovative considering that the vast majority of studies in this domain have focused on outcomes of a single intervention strategy (Auger, Grondin, et al., 2021).

The multifaceted program was built on a thorough assessment of needs and priorities of a sample of the population targeted by the program, and its general and specific objectives were designed in close collaboration with an advisory group composed of all relevant stakeholders. According to Garst and McCawley (2015), involving stakeholders in a needs assessment is necessary when planning and developing such a program. Moreover, it fosters a democratic approach, which is important since the program aims to influence stakeholders and their behaviours, therefore decisions aiming to affect them should be made with them (Garst & McCawley, 2015). Involving stakeholders in the assessment of their needs and priorities ensure that the program addresses the actual problems encountered by clinicians and managers and contribute to the implementation of acceptable strategies to address the identified needs, which is in alignment with an integrated knowledge translation approach (Kothari & Wathen, 2017).

A thorough analysis of performance objectives based on targeted determinants, and the extent to which they could be influenced (i.e., change objectives), required the use of rigorous theoretical models and a solid knowledge of evidence in behaviour change. Consequently, the elaboration of change matrices and the selection of empirically supported methods to influence each of the nine determinants targeted by the program was mainly conducted by the research team. The members of the advisory group were particularly involved in generating suggestions for the strategies that should constitute the components and in optimizing the prototype iteratively. These discussions, combined with the balance in the participation of different stakeholders in the co-design of innovations is coherent with the *Intervention Mapping* and often used in participatory research; it is therefore a good practice as members bring their own expertise at the most opportune time (Bartholomew et al., 2016). However, to ensure that these choices were well supported, the TDF (Cane et al., 2012) was used to identify the determinants, and combined the Theory and Technique tools (Johnston et al., 2020) with the Taxonomy of behavior change interventions (Kok et al., 2016) to select evidence-based methods and strategies to influence the determinants. This approach is more likely to contribute to the efficacy of the program since it uses a robust framework, which fosters exhaustivity of the concepts taken into account, and it favors the use of strategies and methods whose efficacy has already been showed.

A positive aspect that helped in the creation of the program was the fact that most components were founded on methods that have already proved to be feasible or effective in past studies; examples include the Sexuality Interview Guide (Auger, Pituch, et al., 2021), provision of client-centered sexual education and counseling (Ng et al., 2017; Sansom et al., 2015) and an interdisciplinary sexual rehabilitation training (Fronek et al., 2005; Fronek et al., 2011). Moreover, the level and description of stakeholder involvement make the present study stand out from others that used Intervention Mapping which is consistent with the findings of Majid and collaborators (2018) in their scoping review that included 61 studies. The authors found that 28% of studies did not include stakeholders in the development of their program using the Intervention mapping, and among those who did, more than 50% did not describe how they were involved (Majid et al., 2018). Finally, the fact that all the program components and strategies can be adapted to the local context may also contribute positively to their implementation and their usefulness (Baker et al., 2010; de Beurs et al., 2013).

Like more than 90% of research available in the literature that used the *Intervention Mapping* to develop an intervention or program (Majid et al., 2018), the present study did not focus on the implementation of the program. As such, it does not include a measurement of its impact, as these are related to steps 5 and 6 of the *Intervention Mapping* (Bartholomew et al., 2016). A feasibility study aimed at implementing and assess the impact of the program in a stroke rehabilitation center is currently underway and will guide future larger-scale research work aimed at meeting the program's objectives, namely to promote the provision of evidence-based sexual rehabilitation services to individuals with stroke. Moreover, future studies on the subject should also consider the interventions that will have to be carried out with managers as well as at the organizations' policy levels to implement the program (Michie et al., 2011). Indeed, the preparatory work for this co-design study, which required education, sensitization and persuasion of managers to include their organization as partners in the study, was carried out upstream of the study by the first author. These steps taken informally to plan the study could certainly have facilitated its success and could inspire future steps to implement the program (Berta et al., 2015). Finally, future studies could also explore the program's impact in other rehabilitation contexts and populations, such as individuals who sustained a traumatic brain injury (Anto-Ocrah et al., 2020) or a spinal cord injury (Fritz et al., 2015) and individuals with multiple sclerosis (Esteve-Ríos et al., 2022).

Strengths and limitations

This study has many strengths which promote the credibility and transferability of the analysis and work underpinning the program's development (Drapeau, 2004). First, the use of the *Intervention Mapping* (Bartholomew et al., 2016) and the TDF (Cane et al., 2012) cultivated coherence and relevance of the collaborative work realized throughout the development of the program. Second, the diversity of participants in the advisory and validation groups ensured the consideration of a variety of point of views during the collaborative development of the program (Todres & Galvin, 2005). Moreover, the numerous co-design sessions conducted in the present and previous (Auger, Filiatrault, Allegue, Vachon, et al., 2023) studies fostered greater depth of the analysis, ensuring that the program would be representative of participants' needs, perspectives and priorities (Todres & Galvin, 2005).

However, this study also has some limitations that mainly affect transferability (Drapeau, 2004). First, all data collection was conducted with a relatively small sample (i.e., 11 participants in the advisory group and nine participants in the validation group, including 15 females out of a total of 20 participants). This higher representation of women, particularly in the roles of partners, clinicians and researchers, may have led the program components to respond more to the needs of female clinicians, at the expense of the needs that may be different for clinicians that self-identify as male or another gender. However, the mixed representation of men and women in the validation group suggests that the program is likely to answer clients' and partners' sexual rehabilitation needs, especially for heterosexual couples. Future studies will need to explore if the program answers the needs of single persons and people that consider themselves part of Lesbian, Gay, Bisexual, Trans, Queer, Intersex, Asexual + (LGBTQIA+) community. Second, participants were living in the province of Quebec, Canada, which has a specific health care system and political context that may render certain components of the program less relevant in other countries or cultures. However, we did mitigate this limitation by describing the program's development in detail and designing multiple complementary components, so that future knowledge users may choose what is most relevant for them and their context. A third limit is that, although the advisory group was multidisciplinary, it did not include all professional discipline involved in stroke rehabilitation, such as physicians, social workers and speech language pathologists. However, the point of view of speech language pathologists and social workers was considered, since participants from these professions were integrated into a previous study (Auger, Filiatrault, Allegue, Vachon, et al., 2023), which was used for step 1 of the *Intervention Mapping*.

In conclusion, this paper reports on the co-design process of the first evidence-based multifaceted program for improvement of sexual rehabilitation services for stroke rehabilitation that is ready for implementation. Based on behaviour change theories and designed using an integrated knowledge translation approach *with* and *for* stroke rehabilitation stakeholders, this program is likely to address clinicians' needs to be supported for providing evidence-based sexual rehabilitation services to individuals with stroke. Future research should focus on assessing the feasibility of implementing this program in different settings. Documenting how the program is delivered, who is involved in the program, the factors that influence its implementation, the perspective of each stakeholder about the program and, ultimately, its impact on individuals with stroke and their partners would be an essential contribution for continued improvement of the program and advance knowledge and practice in sexual stroke rehabilitation. Nonetheless, this program has the potential to lead to important improvement in sexual rehabilitation services provided to individuals with stroke and could be adapted to improve services related to sexuality for other individuals with disabilities.

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Declaration of interest statement

The authors report there are no competing interests to declare.

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Chapitre 8 – Discussion

Cette thèse porte sur l'amélioration des services de réadaptation sexuelle pour les personnes ayant subi un AVC. Plus de 50% des personnes ayant subi un AVC présentent des difficultés sexuelles (Grenier-Genest et al., 2017) en lien avec la nature, la localisation et /ou l'étendue de leur AVC (ex., lésion affectant une zone telle que l'hypothalamus qui est impliqué dans la réponse sexuelle (Argiolas & Melis, 2005)), ou liées à d'autres conséquences potentielles de l'AVC comme l'hémiparésie (Yilmaz et al., 2015) ou l'aphasie (Stead & White, 2019) qui peuvent influencer la réalisation des activités sexuelles. Toutefois, rares sont les personnes ayant subi un AVC qui reçoivent des services de réadaptation sexuelle (McGrath et al., 2019) et ce, en lien avec de multiples facteurs (Dyer & das Nair, 2013), dont plusieurs influencent les cliniciens dans leurs pratiques cliniques (Richards et al., 2016). Ce manque de services va à l'encontre des lignes directrices canadiennes en réadaptation de l'AVC en ce qui a trait à la sexualité (Mountain et al., 2020) et met les individus ayant subi un AVC à risque plus élevé de dépression et peut réduire leur qualité de vie (Kim & Kim, 2008; Korpelainen et al., 1999). Afin de résoudre cette problématique, cette thèse se centre sur la synthèse et la cocréation des connaissances liées à la réadaptation sexuelle via l'intégration de cinq articles scientifiques complémentaires. Son objectif général était de cocréer avec des parties prenantes de la réadaptation post-AVC un programme multifactoriel pour améliorer les services de réadaptation sexuelle offerts en réadaptation post-AVC. Cette discussion reprend de manière intégrative les principaux résultats et les messages clés rapportés dans les articles composant cette thèse. Par la suite, la discussion enchaîne en approfondissant l'analyse des fondements théoriques du programme cocréé dans le cadre de la thèse en le comparant avec des modèles de référence dans les domaines de la réadaptation post-AVC et de la sexualité. Cette comparaison vise à faire ressortir la pertinence de la thèse pour : 1) favoriser une meilleure réponse aux lignes directrices canadiennes en réadaptation sexuelle post-AVC et 2) guider les intervenants dans l'offre de services qui peuvent répondre aux besoins variables de chaque personne (via le modèle PLISSIT (Annon, 1976)). S'enchaînera ensuite une explicitation des démarches politiques futures qui pourront être réalisées en vue de la diffusion et de l'implantation du programme, qui sont des démarches importantes à considérer bien qu'elles ne fassent pas l'objet des travaux entourant cette thèse. Finalement, les perspectives de recherche futures sont présentées pour conclure ce chapitre.

Rappel des études composant cette thèse

Le premier article inclus à cette thèse présente une revue systématique des écrits dont l'objectif était de documenter et décrire les données probantes pouvant appuyer les interventions de réadaptation sexuelle post-AVC (Auger, Grondin, et al., 2021). En suivant les critères du PRISMA (Moher et al., 2015) et en effectuant des recherches par mots-clés dans sept bases de données bibliographiques (jusqu'en mai 2020), 2 446 articles ont été examinés et huit ont été inclus. Deux ECR (Ng et al., 2017; Sansom et al., 2015) et une étude quasi-expérimentale avec groupe contrôle (Song et al., 2011) ont montré une amélioration du fonctionnement sexuel et de la satisfaction sexuelle après un programme d'enseignement et counseling structuré de 30 à 45 minutes. Deux autres ECR ont montré une amélioration significative du fonctionnement sexuel avec un programme de physiothérapie orienté vers : 1) le counseling et l'enseignement en lien avec la sexualité (Vajrala et al., 2021) ou 2) l'entraînement des muscles du plancher pelvien (Tibaek et al., 2015). De plus, trois études ont montré respectivement que : la réadaptation sexuelle interdisciplinaire améliorait la satisfaction et le fonctionnement sexuel chez la personne participante (Thomas, 2016) ; la mise en place d'un guide d'entrevue semi-structuré pour les cliniciens a amélioré la proportion de clients ayant abordé la sexualité de 0 à 80 % en 10 mois (Guo et al., 2015) ; et des retraites de couple de deux jours coanimées par des orthophonistes et des ergothérapeutes ont amélioré l'intimité perçue entre les couples participants (Stead & White, 2019). En résumé, cette revue systématique a démontré que des interventions de réadaptation sexuelle pouvaient mener à une amélioration du fonctionnement sexuel, de la satisfaction sexuelle et/ou de l'intimité dans les couples (lorsque applicable) pour les personnes ayant subi un AVC et que des initiatives pouvaient être implantées pour améliorer la proportion de personnes pouvant aborder la sexualité au cours de leur réadaptation post-AVC. Ces conclusions sur l'aspect prometteur de la réadaptation sexuelle ont soutenu la mise en place des autres études composant cette thèse.

Le deuxième article de cette thèse (Auger, Allegue, et al., 2022) présente les méthodes qui ont été utilisées pour réaliser les études #3 (Auger, Filiatrault, Allegue, Vachon, et al., 2023) et #5 (Auger, Filiatrault, Allegue, Thomas, et al., 2023) incluses à cette thèse. La combinaison d'une approche de transfert de connaissances intégrée (Jull et al., 2017) et de méthodes de co-design (Morales et al., 2012), jumelée à la structure de la cartographie des interventions (Bartholomew et al., 2016), y a été présentée et justifiée en détail. Les méthodes présentées visaient la construction collaborative du programme en impliquant au moment opportun différentes parties prenantes selon leurs expertises expérientielles ou professionnelles respectives, parmi : des personnes ayant subi un AVC, des partenaires/conjoints, des cliniciens, des gestionnaires et des chercheurs, dans les groupes aviseurs, LEGO® ou de validation. L'implication des participants était répartie en trois grandes catégories d'activités complémentaires qui se sont déroulées en ligne. Premièrement, des rencontres du groupe aviseur étaient réalisées sous forme de groupes de discussion/travail. Deuxièmement, des groupes LEGO® consistant en une version ajustée (c.-à-d., raccourcie et en ligne) de la méthode d'idéation et de co-design LEGO® Serious Play® (Frick et al., 2013) ont été organisés. Troisièmement, un groupe de validation a été mis sur pied pour contre-vérifier les produits de la recherche de cocréation. Les modèles théoriques guidant l'analyse des données pour les deux études ont aussi été présentés, soit la CIF (Geyh et al., 2004; World Health Organization, 2001); les six étapes de la cartographie des interventions de Bartholomew et collaborateurs (2016), dont les quatre premières ont été utilisées dans cette thèse (Bartholomew et al., 2016); le TDF (Cane et al., 2012); et finalement le système COM-B et la roue du changement de comportement (ou *Behaviour Change Wheel* (BCW)) décrits initialement dans la même étude de Michie et collaborateurs (2011).

Le troisième article porte sur l'évaluation des besoins et des priorités pour l'amélioration des services de réadaptation sexuelle post-AVC (c.-à-d., étape 1 de la cartographie des interventions (Bartholomew et al., 2016)) réalisée avec les membres du groupe aviseur et des deux groupes LEGO® (Auger, Filiatrault, Allegue, Vachon, et al., 2023). Au total, 21 participantes (n = 11 au comité aviseur, n = 10 aux groupes LEGO®; 100% étaient des femmes; n = 15 cliniciennes) ont pris part à au moins une des cinq séances de travail collaboratif en groupe d'une durée de deux heures chacune, ce qui a permis de faire ressortir les principaux facteurs influençant positivement ou négativement l'offre de services de réadaptation sexuelle par les intervenants en réadaptation post-AVC. Un total de vingt facteurs appartenant soit aux catégories « Capacité » (n = 8 ; p. ex. Connaissance des procédures de réadaptation sexuelle), « Motivation » (n = 4 ; p. ex. Limites professionnelles) ou « Opportunité » (n = 8 ; p. ex. Charge de travail) du système COM-B (Michie et al., 2011) ont été ressortis. Un modèle théorique a été conceptualisé avec ces facteurs pour en montrer leur diversité et leurs interrelations. Les stratégies (n = 10) ont été classées en concordance avec le BCW, soit les catégories Formation (n = 1), Habilitation (n = 5) ou Restructuration environnementale (n = 4). Cette étude a aidé à guider la conception du programme d'amélioration des services de réadaptation sexuelle post-AVC.

Le quatrième article de cette thèse décrit une recension des écrits qui a mené à l'identification et la description des méthodes d'évaluation utilisées par les professionnels de la réadaptation pour évaluer la sexualité des personnes ayant subi un AVC, ainsi que les domaines de la sexualité abordés (Auger, Aubertin, et al., 2021). En utilisant une méthode de revue de la portée fondée sur les critères de PRISMA pour les revues de portée (PRISMA-Scr) (Tricco et al., 2018), sept bases de données ont été interrogées à l'aide de mots clés (jusqu'en mai 2020). Sur les 2 447 articles examinés, 96 répondaient aux critères de sélection et ont permis d'identifier un total de 116 méthodes d'évaluation classées comme suit : 1) des outils d'évaluation standardisés (n = 62), 2) des questionnaires originaux sans étude de qualités psychométriques (n = 28), 3) des entretiens semi-structurés (n = 16) ou 4) des entretiens structurés (n = 10). L'exploration des domaines de la sexualité fondés sur la CIF a montré que les fonctions sexuelles sont principalement évaluées à l'aide d'outils standardisés, tandis que les relations intimes et la perspective du partenaire sont généralement abordées par des questionnaires originaux et des méthodes qualitatives. Une approche par étapes combinant plusieurs des méthodes d'évaluation a été présentée. En conclusion, cette étude a montré que chaque méthode d'évaluation répertoriée abordait un nombre limité de domaines liés à la sexualité et que les recherches futures devraient combiner des méthodes quantitatives et qualitatives pour que l'évaluation englobe la plupart des domaines de la sexualité pour les personnes ayant subi un AVC. Cette étude a également permis de constituer un répertoire de méthodes d'évaluation en ce qui a trait à la sexualité qui pourraient être utilisées par les intervenants en réadaptation post-AVC (incluant l'Annexe 2).

La cinquième et dernière étude incluse à cette thèse décrit le processus de cocréation du programme d'amélioration des services de réadaptation sexuelle post-AVC (Auger, Filiatrault, Allegue, Thomas, et al., 2023). En combinant le travail collaboratif avec le groupe aviseur, les groupes LEGO® et le groupe de validation, un programme multifactoriel comprenant 11 composantes a été élaboré en vue d'être implanté en réadaptation post-AVC. Les 11 composantes du programme ont été conçues afin d'avoir un effet sur les principaux facteurs d'influence des intervenants qui ont été identifiés dans l'étude de leurs besoins et priorités (Auger, Filiatrault, Allegue, Vachon, et al., 2023), en ayant soit un impact sur leur environnement, en visant leur habilitation (c.-à-d., renforcer les facilitateurs et limiter l'effet des barrières) ou en leur offrant une formation. En complément du programme, une matrice décrivant les objectifs de changement pour chaque déterminant ciblé par les composantes du programme (ex., connaissances, habiletés), un modèle logique et un procédurier pour l'implantation du programme a été conçu par l'équipe de recherche. Le programme tel qu'il est conçu correspond aux deux couches proximales du BCW, soit le système COM-B permettant de mieux comprendre les déterminants du comportement et les interventions visant le changement de comportement (correspondant aux composantes du programme) (Michie et al., 2011). Cette étude a résulté en la cocréation avec les parties prenantes pertinentes du premier programme fondé sur la théorie visant à soutenir les intervenants et les milieux de réadaptation post-AVC à offrir des services de réadaptation sexuelle répondant aux lignes directrices canadiennes en réadaptation de l'AVC (Mountain et al., 2020).

La combinaison de ces cinq études permet maintenant d'avoir un état des connaissances exhaustif et à jour des écrits scientifiques sur l'évaluation et l'intervention en réadaptation sexuelle post-AVC et d'offrir aux intervenants et aux milieux de réadaptation un programme qui est prêt à être implanté et testé dans la réalité de la réadaptation post-AVC. Afin de mieux justifier la pertinence des travaux futurs portant sur le programme, il apparaît important de le comparer aux lignes directrices canadiennes en réadaptation de l'AVC en ce qui a trait à la sexualité. De plus, afin de favoriser la crédibilité et l'utilité du programme pour la communauté scientifique, il importe de le comparer aux modèles d'intervention liés à la sexualité qui sont internationalement reconnus, bien que non spécifiques à l'AVC.

Comparaison du programme avec les modèles

Les lignes directrices canadiennes en réadaptation de l'AVC en lien avec la sexualité et l'intimité (Mountain et al., 2020) et le PLISSIT (Annon, 1976) ont servi de modèles pour les travaux de la présente thèse. Les lignes directrices canadiennes en réadaptation de l'AVC ont été choisies, car les études composant cette thèse ont été réalisées dans le contexte de la pratique canadienne en réadaptation post-AVC. Elles offrent aussi un plus grand niveau de précision comparativement aux lignes directrices américaines (Winstein et al., 2016), britanniques (National Institute for

Health Care Excellence, 2013) et australiennes (Stroke Foundation, 2022). Quant à lui, le modèle d'intervention lié à la sexualité PLISSIT (Annon, 1976) a été privilégié car il est abondamment utilisé dans les écrits scientifiques (Tuncer & Oskay Ü, 2022), il est simple d'utilisation, et parce qu'il contient les composantes essentielles du modèle EX-PLISSIT (Davis & Taylor, 2006) et qu'il contient davantage d'éléments essentiels à la réadaptation sexuelle que le modèle BETTER (Quinn & Happell, 2012), décrits en détail dans le chapitre 2. Le modèle EX-PLISSIT (Davis & Taylor, 2006) diffère principalement du PLISSIT (Annon, 1976) par la phase de *Permission* qui se répète tout au long de la prise en charge des difficultés sexuelles (ex., *Permission – Limited Information*; *Permission – Specific Suggestions*). Quant au modèle BETTER (*Bring up, Explain, Tell, Timing, Educate, and Record*) (Quinn & Happell, 2012), il contribue de manière plus limitée à la réflexion sur les composantes d'une intervention multifactorielle puisqu'il ne conçoit pas l'intervention au-delà de l'éducation et qu'il porte une attention particulière à des éléments qui sont implicites dans la prise en charge par un professionnel de la santé au Canada (ex., réaliser la tenue de dossiers avec *Record*).

Les interventions de restructuration de l'environnement, d'habilitation et de formation du programme créé dans le cadre de cette thèse favorisent une meilleure adéquation avec les lignes directrices canadiennes en réadaptation de l'AVC en lien avec la sexualité et l'intimité et la réalisation des différentes étapes du PLISSIT (Annon, 1976), selon les besoins de la personne. Cette comparaison des cadres avec les interventions du programme est résumée dans le tableau 18.

Tableau 18. – Comparaison des composantes du programme avec les lignes directrices canadiennes en réadaptation de l'AVC (Mountain et al., 2020) et le modèle PLISSIT (Annon, 1976)

Lignes directrices canadiennes*	**Étapes du PLISSIT****	**Composantes du programme**
Après avoir subi un AVC, les gens devraient avoir l'occasion de discuter de leur intimité, de leur sexualité et de leurs fonctions sexuelles avec leur professionnel de la santé.	Permission	• Comité d'amélioration des services de réadaptation sexuelle (Composante #1) • Guide d'entrevue sur la sexualité 2.0 (Composante #6, recto)
Les personnes ayant subi un AVC, leur famille et leurs aidants devraient être informés et conseillés concernant l'impact potentiel de l'AVC sur les relations.	Limited Information Specific Suggestion	• Trousse d'outils de transfert de connaissances sur la sexualité post-AVC (Composante #5) • Guide d'entrevue sur la sexualité 2.0 (Composante #6, verso) • Répertoire des rôles professionnels liés à la sexualité (Composante #7) • Formation interdisciplinaire sur la réadaptation sexuelle (Composante #11) • Champion disciplinaire (Composante #2) • Communauté de pratique (Composante #10) • Répertoires de méthodes d'évaluation en réadaptation sexuelle (Composante #8) • Répertoire de méthodes d'intervention en réadaptation sexuelle (Composante #9)
Les séances d'éducation à l'intention des personnes ayant subi un AVC ou de leurs partenaires peuvent porter sur les changements prévus relatifs à l'intimité et à la sexualité et sur les stratégies pour maximiser la fonction sexuelle et pour fournir une foire aux questions sur les relations après un AVC.		
Les médecins peuvent discuter de l'utilisation de médicaments pour traiter la dysfonction sexuelle ainsi que de leurs contre-indications.	Specific Suggestion	
L'aiguillage vers un spécialiste de la santé sexuelle est envisageable pour les personnes aux prises avec une atteinte d'une dysfonction sexuelle persistante,	Intensive Therapy	• Liste des ressources en santé sexuelle externes à l'organisation (Composante #4)

* Recommandations canadiennes pour les pratiques optimales de soins de l'AVC; Réadaptation, rétablissement et participation

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communautaire après un AVC; Deuxième partie : Les transitions et la participation communautaire après un AVC; Section 4.6 – Participation aux responsabilités sociales et quotidiennes après un AVC : les relations et la sexualité (ordre modifié) https://heartstrokeprod.azureedge.net/-/media/1-stroke-best-practices/transition-of-care-nov2019/french/2019-csbpr6-transitions-module-final-fr-dec2019.ashx (Ordre des recommandations modifié pour la cohérence de la présentation des informations).

**Modèle PLISSIT : *Permission, Limited Information, Specific Suggestions, Intensive Therapy* (Annon, 1976).

Premièrement, l’intégration du guide d’entrevue sur la sexualité 2.0 (Composante #6, recto) aux outils disponibles pour les intervenants et aux procédures établies de manière normative pour chaque client par le comité d’amélioration des services de réadaptation sexuelle (Composante #1) favorisera que chaque personne ayant subi un AVC recevra l’opportunité d’intégrer la sexualité aux thèmes abordés dans sa réadaptation, ce qui correspond à la première ligne directrice canadienne présentée dans le tableau 18. L’utilisation de la trousse d’outils de transfert de connaissances sur la sexualité post-AVC (Composante #5) permettra quant à elle d’offrir de l’information générale aux personnes ayant subi un AVC et aux partenaires, qui idéalement sera adaptée aux capacités des personnes (deuxième ligne directrice en réadaptation sexuelle post-AVC; étape *Limited Information* du PLISSIT) et correspond aux lignes directrices 2 et 3 du tableau 18. Pour les personnes qui en auront besoin, le verso du guide d’entrevue sur la sexualité 2.0 (Composante #6) favorisera la meilleure compréhension des besoins de réadaptation sexuelle de la personne post-AVC et le répertoire des rôles professionnels liés à la sexualité (Composante #7) favorisera que l’individu post-AVC soit référé vers un intervenant habilité à résoudre, du moins partiellement, les problèmes spécifiques de la personne. Les intervenants vers qui les clients post-AVC seront dirigés devraient être habilités à réaliser une évaluation disciplinaire des difficultés relatives à la sexualité et à offrir de l’éducation personnalisée ainsi que des stratégies d’intervention spécifiques à leur discipline. Ceci sera permis grâce à la formation interdisciplinaire sur la réadaptation sexuelle qu’ils auront reçue (Composante #11) ainsi qu’à l’accès au soutien de leur champion disciplinaire (Composante #2), à la communauté de pratique (Composante #10), ainsi qu’aux répertoires de méthodes d’évaluation (Intervention #8) et d’intervention (Composante #9) en réadaptation sexuelle. Les intervenants pourraient ainsi avoir une pratique clinique congruente avec la troisième ligne directrice en réadaptation sexuelle post-AVC qui consiste à offrir de l’éducation et des conseils spécifiquement liés aux enjeux vécus par la personne en lien avec la sexualité post-AVC, ce qui correspond également à l’étape *Specific Suggestions* du PLISSIT (Annon, 1976). Dans une certaine mesure, ceci correspond également à la ligne directrice #4 qui consiste à considérer les options pharmacologiques pour résoudre les difficultés sexuelles, ce qui représente une stratégie d’intervention spécifique aux médecins. Finalement, en cas de problèmes complexes, persistants et/ou ne pouvant être traités par les intervenants disponibles dans le milieu de réadaptation post-AVC, la liste des ressources en santé sexuelle externes à l’organisation (Composante #4) pourra faciliter la référence des personnes ayant subi un AVC vers des intervenants habilités à leur offrir les traitements dont elles ont besoin. Cette procédure de référence correspond à la cinquième et dernière ligne directrice en réadaptation sexuelle post-AVC et permet de favoriser que l'individu reçoive l'étape *Intensive Therapy* du PLISSIT (Annon, 1976) par autrui. Il faut toutefois rappeler que les intervenants en réadaptation post-AVC ont rapporté, dans l'étude de leurs besoins et priorités (Auger, Filiatrault, Allegue, Vachon, et al., 2023), une préférence pour les références à une ressource de l'organisation et avoir un certain malaise à l'égard d'une référence vers un service externe qui est difficilement accessible pour leurs patients (ex., service privé ou longues listes d'attente). Cet inconfort pourrait être une barrière à l'implantation du programme pour les intervenants, ce qui doit être pris en compte lors d'une implantation du programme dans un milieu n'ayant pas accès à certaines ressources professionnelles, telles que les sexologues, les psychologues ou les médecins spécialistes. Ainsi, dans la mesure où les différentes composantes sont intégrées dans les milieux de réadaptation et utilisées par les intervenants, le programme a le potentiel de soutenir les centres de réadaptation et les intervenants dans l'offre de services de réadaptation sexuelle qui répondent aux lignes directrices en réadaptation de l'AVC (Mountain et al., 2020) et qui prennent en considération toutes les étapes du PLISSIT (Annon, 1976).

En plus d'être en cohérence avec les modèles présentés ci-dessus, le programme contient plusieurs composantes dont les impacts positifs ont déjà été démontrés dans des études empiriques (voir le détail dans l'article 1 composant cette thèse (Auger, Grondin, et al., 2021)) et qui permettent de prévoir des retombées favorables de sa future implantation sur la qualité des services offerts ainsi que la participation et la satisfaction liée à la sexualité pour les personnes ayant subi un AVC et leurs partenaires. Premièrement, l'impact d'une séance d'éducation personnalisée sur la sexualité post-AVC et fondée sur le PLISSIT, de 30 à 45 minutes à la fin de la réadaptation fonctionnelle intensive (c.-à-d., avant le congé de réadaptation et le retour à domicile), a montré des effets mitigés mais positifs. En effet, l'étude quasi-expérimentale de Song et collaborateurs (2011) a montré que les participants du groupe expérimental ont présenté une amélioration significative de leur fonctionnement et de leur satisfaction sexuelle en comparaison aux participants du groupe contrôle qui n'avaient reçu aucune intervention en lien avec la sexualité. Toutefois, dans deux ECR portant sur une intervention semblable, le groupe expérimental recevant la séance d'éducation personnalisée fondée sur le PLISSIT a montré une plus grande amélioration du fonctionnement sexuel que le groupe contrôle, mais sans que cette différence soit statistiquement significative (Ng et al., 2017; Sansom et al., 2015). Dans ces deux études, les groupes contrôles recevaient uniquement de la documentation informative sur la sexualité après un AVC. Ces résultats appuient la pertinence que le programme encourage les intervenants et milieux de réadaptation post-AVC à offrir les deux types d'intervention éducatives (information générale vs éducation spécifique orientée par le PLISSIT), surtout considérant qu'une tendance favorable, bien que non statistiquement significative, pourrait tout de même mener à des retombées importantes pour la participation et la satisfaction des individus ayant subi un AVC et leurs partenaires dans leurs activités sexuelles (Hayat, 2010). De plus, dans les trois essais cliniques rapportés ci-dessus, la personne offrant l'intervention expérimentale était soit une personne spécialisée externe au centre de réadaptation, ou un physiatre expérimenté en réadaptation sexuelle (Ng et al., 2017; Sansom et al., 2015; Song et al., 2011). Le programme développé dans le cadre de cette thèse vise, quant à lui, à favoriser l'autodétermination des différents intervenants de la réadaptation post-AVC à contribuer à la réadaptation sexuelle des individus ayant subi un AVC dans le respect de leur champ d'exercice respectif et ce, dans un contexte réel. Ainsi, le suivi offert aux clients post-AVC recevant des services dans un centre de réadaptation où le programme aurait été implanté serait plus susceptible de ressembler à l'offre de services de physiothérapie liés à la sexualité et fondés sur le PLISSIT de l'essai clinique de Vajrala et collaborateurs (2021). En effet, le suivi offert au groupe expérimental de cette étude combinait une variété de méthodes d'intervention dont le counseling fondé sur le PLISSIT, la rééducation périnéale et pelvienne et des exercices de Kegel, en plus de la physiothérapie conventionnelle qui était également offerte au groupe contrôle. Ce suivi a résulté en des améliorations significatives dans le groupe expérimental sur les dimensions physiques (mesurées par le CSFQ-14 (Keller et al., 2006)) et psychologiques (sous-score de dépression, anxiété et stress du DASS-21 (Antony et al., 1998)) de la santé sexuelle (Vajrala et al., 2021). Ainsi, le programme développé dans le cadre de cette thèse apparaît comme pertinent à implanter en réadaptation post-AVC considérant qu'il devrait favoriser la conformité aux lignes directrices canadiennes en réadaptation sexuelle post-AVC (Mountain et al., 2020) et aux étapes du PLISSIT (Annon, 1976). De plus, le programme apparaît comme ayant un potentiel prometteur d'influencer positivement la sexualité des clients post-AVC et des partenaires puisqu'il reprend des composantes d'interventions qui ont mené à des améliorations du fonctionnement sexuel et de la satisfaction sexuelle généralement significatives dans les études recensées dans ce domaine (Auger, Grondin, et al., 2021).

Les politiques entourant le programme

Dans le cadre de cette thèse, le travail de cocréation du programme d'amélioration des services de réadaptation sexuelle s'est centré sur l'élaboration d'une série d'interventions (c.-à-d., présentées sous forme de « composantes » du programme) pour modifier les pratiques cliniques des intervenants en influençant des déterminants spécifiques du comportement. Lorsque située dans la roue du changement de comportement (Michie et al., 2011), le programme tel qu'il est conçu prend donc en compte les couches proximales et intermédiaires de la roue, respectivement associées au système COM-B permettant de mieux comprendre le comportement et aux interventions de changement de comportement. Toutefois, la dernière couche de la roue portant sur les politiques se doit d'être considérée afin de favoriser l'application des interventions (Michie et al., 2011). En effet, bien que nous ayons développé les 11 composantes du programme avec et pour les parties prenantes de la réadaptation post-AVC, celles-ci ne mèneront pas à des bénéfices si elles ne sont pas entérinées par les gestionnaires d'équipes de réadaptation et les décideurs de plus hauts niveaux et/ou si elles ne sont pas transmises aux personnes faisant partie du public cible, ou utilisées par celui-ci. Considérant que le manque de services liés à la sexualité met les personnes ayant subi un AVC à plus haut risque de dépression et d'une plus pauvre qualité de vie, la sous-utilisation du programme et de ses composantes pourrait contribuer à maintenir cette situation problématique où les besoins de réadaptation sexuelle sont peu considérés et potentiellement mener à des effets néfastes sur la santé des personnes ayant subi un AVC (Jones et al., 2017; Kim & Kim, 2008). Michie et collaborateurs (2011), dans leur étude menant au développement du système COM-B et de la roue du changement de comportement, ont associé les neuf catégories d'intervention de changement de comportement avec les sept catégories de politiques composant respectivement les couches intermédiaire et externe de la roue (voir la description détaillée dans le chapitre 4). Selon cette étude, les politiques associées aux trois catégories d'interventions composant le programme (c.-à-d., restructuration de l'environnement, habilitation et formation) sont : les « lignes directrices », les « mesures fiscales », la « réglementation » et la « législation ». De plus, les politiques de « planification de l'environnement social et/ou physique » (excluant l'intervention de formation), ainsi que la

« prestation de services » (excluant l'intervention de restructuration de l'environnement) sont chacune liées à deux des trois catégories d'intervention (Michie et al., 2011). Parmi ces six catégories de politiques, certaines apparaissent plus simples à appliquer que d'autres (c.-à-d., en termes de preuves à fournir, de démarches à réaliser, d'acteurs clés à impliquer). Celles qui apparaissent les moins applicables, à ce stade-ci de l'avancement du projet, sont la législation, la réglementation et les mesures fiscales, qui nécessiteraient une expertise dans certains domaines tels que le droit et des recherches visant à comprendre si des lois, des règlements ou des mesures fiscales devraient être mieux utilisés (ex., si déjà existants) ou élaborés (c.-à-d., si non existants) pour encadrer l'offre de services de réadaptation sexuelle pour les individus ayant subi un AVC. Ces trois catégories de politiques ne seront pas discutées davantage car elles s'écartent significativement des objectifs de cette thèse.

Du côté de la stratégie politique des « lignes directrices », celles-ci existent par rapport au domaine de la réadaptation post-AVC au Canada. Toutefois, ces lignes directrices pourraient être difficiles à appliquer par les milieux de réadaptation post-AVC en raison de leur caractère général ou en raison de leur formulation pouvant utiliser un langage non représentatif de la réalité de la réadaptation. En fait, une gradation existe au niveau du détail des lignes directrices, certaines pouvant être générales et d'autres pouvant être plus structurées et guider pas à pas les intervenants à réaliser certaines pratiques cliniques (Davies, 2002; Miller & Kearney, 2004). Le fait que les lignes directrices en réadaptation sexuelle post-AVC aient été formulées de façon plutôt générale pourrait, entre autres, être lié au niveau limité de preuve scientifique (Auger, Grondin, et al., 2021) et au soucis qu'elles puissent être applicables à travers le Canada. Ainsi, considérant le potentiel encadrant des lignes directrices pour les soins de l'AVC, il pourrait être pertinent qu'une version plus opérationnalisée soit disponible pour les milieux composant le continuum de soins post-AVC, incluant la réadaptation. Pour arriver à cette opérationnalisation, des balises pourraient être utilisées, telles que les cinq recommandations pour favoriser la reconnaissance et l'utilisation appropriée des lignes directrices élaborées par le groupe de travail GRADE (Guyatt et al., 2016). En résumé, ces recommandations liées à la formulation des lignes directrices par un panel d'experts portent sur : 1) la clarté et l'applicabilité, 2) l'utilité / la nécessité, 3) l'étendue et la nature positive des retombées prévues, 4) la limitation du temps consacré à la recherche et la synthèse des données probantes par le panel, ainsi que 5) l'élaboration d'un raisonnement bien documenté, clair et explicite pour justifier les lignes directrices (Dewidar et al., 2022; Guyatt et al., 2016). Plus précisément au Québec, le continuum de soins de l'AVC pourrait bénéficier d'une opérationnalisation des lignes directrices sur l'offre de services de réadaptation sexuelle, par exemple, en adoptant une approche par CIUSSS/CISSS. Considérant que l'application des lignes directrices est liée de façon importante au changement des comportements individuels (Grol et al., 2007), allier les lignes directrices au programme comprenant 11 composantes pour le changement de comportement serait susceptible d'influencer d'autant plus les services de réadaptation sexuelle post-AVC .

La planification de l'environnement social et/ou physique, ainsi que la prestation de services, apparaissent comme des solutions qui pourraient répondre aux demandes exprimées par les parties prenantes de la réadaptation post-AVC (ex., accès à plus d'intimité ou à des spécialistes en santé sexuelle) et soutenir l'application des interventions (Auger, Filiatrault, Allegue, Vachon, et al., 2023; Auger et al., 2020; Richards et al., 2016).

Premièrement, la planification de l'environnement social et/ou physique pourrait débuter au moment de la constitution du comité pour l'amélioration des services de réadaptation sexuelle (Intervention #1). Par rapport à l'environnement social, parmi les besoins évoqués par les participants des groupes LEGO® et aviseur figuraient l'accès à d'autres disciplines professionnelles lorsqu'une intervention interdisciplinaire est nécessaire. Bien que l'intégration de sexologues aux équipes de réadaptation post-AVC ait été une requête récurrente dans l'évaluation des besoins, l'accès à d'autres professionnels était également important pour les participants. En effet, la possibilité d'intégrer des professionnels aux expertises complémentaires dans un suivi de réadaptation sexuelle, tels que les psychologues, les travailleurs sociaux et les orthophonistes pour la réadaptation sexuelle était un besoin particulièrement rapporté par les intervenants travaillant en réadaptation externe. Majoritairement composés d'ergothérapeutes et de physiothérapeutes, ces intervenants œuvrant en réadaptation externe rapportaient avoir moins d'opportunités de réaliser des suivis interdisciplinaires, en comparaison avec ceux travaillant en réadaptation fonctionnelle intensive, par manque de ressources humaines (Auger, Filiatrault, Allegue, Vachon, et al., 2023). La planification de l'environnement physique pourrait consister à réfléchir à l'emplacement physique où les nouveaux outils (ex., évaluation, intervention) seront disposés dans les milieux de travail des intervenants au moment de l'implantation du programme, ou à désigner quels seront les endroits et les moments où des interventions de réadaptation sexuelle pourraient être offertes (ex., désigner des locaux, des horaires, etc.).

Deuxièmement, la prestation de services pourrait permettre de compenser une impossibilité de restructurer certains aspects de l'environnement social ou physique par la collaboration et/ou l'établissement d'une entente de services avec des ressources externes telles que des cliniques privées. L'accès à un spécialiste a justement été rapporté comme un facilitateur à l'intégration des services de réadaptation sexuelle par une participante physiothérapeute de l'un des groupes LEGO® (Auger, Filiatrault, Allegue, Vachon, et al., 2023) qui avait également pris part à une étude antérieure sur l'implantation de la version originale du guide d'entrevue sur la sexualité (Auger, Pituch, et al., 2021). Dans le cadre de cette étude, une psychologue spécialisée en réadaptation sexuelle du système public de soins de santé pouvait recevoir les références des intervenants participant à l'étude si les besoins étaient trop complexes pour ces derniers, ou hors de leur champ d'exercice (Auger, Pituch, et al., 2021). Pour soutenir l'application des interventions du programme, une personne externe à l'organisation et spécialisée en sexualité pourrait être sollicitée pour animer la communauté de pratique, pour encadrer les intervenants dans l'implantation du programme et/ou pour offrir des services spécialisés en sexualité. Par exemple, une clinique interdisciplinaire spécialisée en réadaptation sexuelle pourrait éventuellement être mise en place à l'Institut universitaire sur la réadaptation en déficience physique de Montréal et offrir des services de troisième ligne sous forme de pratique de pointe à l'ensemble des milieux de réadaptation post-AVC au Québec, autant pour encadrer les cliniciens que pour desservir la clientèle avec besoins plus complexes ou persistants.

Afin de favoriser que le programme soit connu et implanté par les milieux de réadaptation post-AVC, il importe de considérer également les stratégies de communication et de marketing, bien que ce ne soit pas directement associé aux trois catégories d'intervention composant le programme selon Michie et collaborateurs (2011). Ici, sera discutée particulièrement la dissémination de l'information, qui est un processus actif de transmission d'une information spécifique via l'utilisation de canaux de communication et de stratégies choisis en fonction du public cible (Brownson et al., 2017; Rabin et al., 2008). La dissémination se dissocie de la diffusion qui est plutôt un processus passif et moins structuré (Tabak et al., 2012). Trois grandes fonctions peuvent être utilisées pour départager l'utilité des différentes stratégies de dissémination : 1) augmenter la portée à une diversité de personnes (*reach*); 2) augmenter la motivation à appliquer l'information; et 3) augmenter les capacités à appliquer l'information (Bowen et al., 2009). Selon une revue systématique rassemblant 61 études comparant les effets de stratégies de communication et de dissémination des évidences en santé, sept essais cliniques randomisés ont démontré que l'utilisation combinée d'une variété des stratégies de dissémination, comprenant l'augmentation de la portée, des capacités ou de la motivation, serait plus efficace que l'utilisation de stratégies n'ayant qu'une des trois fonctions, pour influencer les comportements des intervenants et ce, tout particulièrement pour l'adoption de lignes directrices (McCormack et al., 2013). En plus de se baser sur la littérature scientifique pour éclairer de futures initiatives de communication et marketing pour favoriser la dissémination du programme, il importe de considérer que des démarches de communication et marketing ont été réalisées avant d'entamer cette étude. En effet, les gestionnaires des programmes AVC des cinq grands centres de réadaptation québécois ont été rencontrés par l'étudiant-chercheur (Louis-Pierre Auger), qui a réalisé lors de ces rencontres de l'éducation et de la persuasion. De plus, des conférences ont été réalisées sur le sujet de la sexualité post-AVC, dont la conférence présentée au 10ème sommet de l'AVC qui a eu lieu le 30 octobre 2020 (en ligne à cause de la pandémie) et auquel plus de 450 intervenants du Québec (c.-à-d., portée provinciale) provenant de différentes disciplines en réadaptation de l'AVC ont assisté. Ces stratégies pourraient avoir surtout servi à augmenter la portée de l'information (c.-à-d., l'AVC peut influencer la sexualité et la réadaptation peut jouer un rôle), ainsi que la motivation (c.-à-d., importance d'améliorer les services de réadaptation sexuelle) à l'utiliser (Bowen et al., 2009), par les intervenants et gestionnaires en réadaptation post-AVC au Québec. Ces stratégies ont certainement favorisé le recrutement des organisations comme partenaires à l'étude et pourraient être intégrées à un plan de dissémination de l'information structuré pour favoriser l'implantation future du programme en réadaptation post-AVC. Finalement, afin de favoriser le succès de la dissémination et en s'appuyant sur la littérature sur le sujet, des stratégies de dissémination visant l'augmentation des capacités à utiliser le programme devraient être élaborées (Bowen et al., 2009; McCormack et al., 2013). Ces interventions qui ont été réalisées en amont de la collecte de données et des activités de co-design composant cette étude, pourraient également être intégrées au programme comme une phase préliminaire à l'implantation.

Cette réflexion portant sur les politiques met la table pour discuter des démarches qui devront être réalisées dans le futur pour favoriser la diffusion, l'implantation et la pérennisation du programme en réadaptation post-AVC afin d'améliorer la qualité des services de réadaptation sexuelle offerts aux individus ayant subi un AVC.

Critiques méthodologiques transversales et perspectives futures

Les choix méthodologiques utilisés pour réaliser les études composant cette thèse ont déjà été décrits et critiqués en détail dans chacun des cinq manuscrits présentés ci-dessus. Toutefois, des enjeux transversaux aux différentes études composant cette thèse peuvent affecter l'utilisation de ses différents produits, qui doivent être explicités et mis en commun avec des orientations futures pour répondre à ces limitations et favoriser la pertinence et l'utilisabilité future du programme d'amélioration des services de réadaptation sexuelle post-AVC dans une démarche d'amélioration continue. Ainsi, en plus de mettre en évidence des critiques méthodologiques transversales, cette section de la discussion se centre également sur ce qui n'a pas été fait dans le cadre de cette thèse et ce qui devra être réalisé dans le futur pour que le programme puisse être diffusé, implanté, pérennisé, amélioré et adapté pour d'autres contextes de soins et services ou d'autres clientèles.

Pauvre considération du sexe et du genre

Une limite importante qui a été peu abordée dans les différentes études composant cette thèse est la pauvre considération du sexe et du genre (qui ont été définis dans le chapitre 2 de cette thèse) dans la collecte et l'analyse des données recueillies.

Considérant que le vécu dans les activités liées à la sexualité peut être influencé par le sexe et le genre (par exemple, en termes de violences sexuelles (Cotter & Savage, 2019)), que l'AVC peut affecter différemment les personnes de sexe masculin et féminin, et que le vécu en lien avec la survenue et la récupération de l'AVC peut varier en fonction du genre, il aurait été important de considérer davantage ces notions tout au long de la thèse.

Premièrement, les études recensées dans les deux revues de littérature ont été colligées avec une perspective centrée sur les retombées pour l'ensemble des échantillons, sans égard au sexe ou au genre. Il doit être noté que généralement les études recensées assumaient la concordance entre le sexe et le genre des participants et ne rapportaient que leur sexe. Cette absence de distinction est une limite importante des études sources puisque le sexe et l'identité de genre, bien qu'ils soient des concepts intimement reliés, vont influencer différemment le vécu d'un AVC et de la sexualité. Notamment, les rôles sociaux et sexuels (imposés, attendus ou souhaités) vont grandement varier selon l'identité de genre (Eagly & Wood, 2012). Au niveau de l'extraction des données dans la revue systématique portant sur les interventions en réadaptation sexuelle (Auger, Grondin et al., 2021), bien que la composition des échantillons en termes de nombre de femmes et d'hommes inclus était mise en évidence lorsque disponible dans l'étude source, une attention particulière aurait pu être portée lors de l'interprétation des résultats afin de souligner de potentielles différences ou similarités entre les hommes et les femmes, ce qui aurait permis d'améliorer le niveau de connaissances à ce niveau. À moyen terme, ces efforts de différenciation pourraient faciliter la mise en place d'interventions différenciées selon le sexe et le genre.

De plus, dans ces études d'intervention, le genre des intervenants qui offraient l'intervention n'était pas systématiquement décrit, et n'a aucunement été extrait dans les données d'intérêt de la revue systématique et ce, malgré que le genre des intervenants peut avoir eu un impact sur l'acceptabilité et les retombées des interventions de réadaptation sexuelle auprès des différents participants. Une conséquence potentielle de cette lacune méthodologique est la généralité des conclusions qui sont portées dans la revue systématique, comme quoi les interventions de réadaptation sexuelle pourraient être bénéfiques pour la clientèle post-AVC. Par exemple, une analyse plus approfondie en fonction du sexe et du genre aurait pu mettre en évidence certains paramètres d'intervention plus favorables pour les femmes ou les hommes ou souligner des retombées d'intervention influencées par les différences ou concordances de genre entre les intervenants et les personnes recevant l'intervention.

Au niveau de la revue de portée portant sur les méthodes d'évaluation en réadaptation sexuelle post-AVC (Auger, Aubertin, et al., 2021), bien que les outils comportant des versions pour chaque sexe aient été mis en évidence, il aurait été pertinent d'indiquer lorsque les outils étaient destinés uniquement aux personnes d'un certain sexe, considérant que ces outils spécifiques à la sexualité abordaient des notions liées à la réponse sexuelle qui porte particulièrement sur les notions de sexe biologique et de la réponse anatomophysiologique du corps à une stimulation sexuelle interne (ex., pensée) ou externe (ex., image, caresse). De plus, parmi les études intégrées à la revue de la portée, il n'a pas été compilé la proportion de personnes de sexe féminin ou masculin qui ont été intégrées aux études et évaluées en ce qui a trait à la sexualité, ce qui ne permet pas de rendre compte de la mesure à laquelle les femmes (tout particulièrement, considérant leur historique de moindre inclusion en recherche en santé (Bierer et al., 2022)) et les hommes ont contribué au corpus de connaissances portant sur les impacts de l'AVC sur la sexualité. Ainsi, les revues de littérature intégrées à cette thèse ne permettent pas de rendre compte avec exactitude des éléments propres aux femmes et aux hommes et leurs résultats devraient être interprétés avec prudence par les personnes qui visent à mieux comprendre l'impact de l'AVC sur la sexualité selon le sexe et le genre et/ou les retombées d'interventions de réadaptation sexuelle.

Deuxièmement, les études #2 (Auger et al., 2022), #3 (Auger, Filiatrault, Allegue, Vachon et al., 2023) et #5 (Auger, Filiatrault, Allegue, Thomas et al., 2023) décrivant le processus de cocréation du programme de réadaptation sexuelle comportent des limites qui sont majoritairement issues du processus de recrutement des participants 1) dans les groupes aviseur et de LEGO® et 2) dans le groupe de validation. En effet, une lacune méthodologique a été de privilégier un échantillonnage par convenance, où il a été convenu d'intégrer des personnes volontaires comme participant à l'étude. En effet, les offres de recrutement ont été envoyées à l'ensemble des intervenantes et intervenants des programmes de réadaptation post-AVC, parmi les cinq différents milieux partenaires, par leurs gestionnaires respectifs. Après avoir rassemblé les différentes candidatures de personnes volontaires à participer, qui pour certains milieux n'étaient suffisantes que pour composer les groupes aviseur et de LEGO® (n = 3 personnes), il a été constaté que seules des personnes s'identifiant comme femmes ont répondu à l'appel. Il doit également être mis en évidence que le recrutement a été lancé au cours des mois d'août à octobre 2021, en pleine pandémie de la COVID-19. Les défis de la réalisation d'un projet à multiples sites au niveau des démarches d'évaluation par un comité d'éthique de la recherche et cinq évaluations de convenance institutionnelle, ajoutés à ceux du fardeau de la COVID-19 sur les milieux cliniques et les difficultés de recrutement en termes de nombre de participants nous ont amené à privilégier la diversité des milieux, des professions et des phases de réadaptation desservies au détriment de la diversité des genres des participants. Ces choix liés à des contraintes de faisabilité pour réaliser ces projets de recherche dans le temps imparti pour une thèse peuvent toutefois avoir mené à des conséquences importantes sur la transférabilité et l'utilité des résultats obtenus dans le cadre des études la composant.

En effet, la perspective des femmes cliniciennes, gestionnaires et chercheuses a été sur-représentée par rapport à celle des hommes et des personnes ayant une autre identité de genre, ce qui pourrait entraîner comme conséquence que le programme d'amélioration des services de réadaptation sexuelle pourrait tout particulièrement répondre aux besoins des femmes intervenants dans l'amélioration de leurs pratiques. Toutefois, cette hypothèse devra être explorée dans de futures études où il serait important d'interroger le vécu des intervenants s'identifiant à un genre différent que celui de femme. Un autre biais de sélection est lié au recrutement des personnes post-AVC et des partenaires, qui étaient tous hétérosexuels et majoritairement en couple. Cela représente bien le biais déjà avéré dans la littérature comme quoi les intervenants abordent généralement uniquement la sexualité avec leurs patients jeunes, en couple et/ou hétérosexuels. Cette pauvre représentation des personnes célibataires ou faisant partie des communautés LGBTQIA+ limite l'interprétation de l'acceptabilité du programme aux personnes hétérosexuelles et en couple, majoritairement. Ceci constitue une limite et devra être considéré dans de futures études qui exploreront l'acceptabilité et les retombées du programme pour les personnes faisant partie de ces groupes. En résumé, ces limites liées à l'échantillonnage des différents groupes de participants composant les études #3 et #5 auraient dû être mises davantage en évidence dans les articles.

Représentativité de l'échantillon et transférabilité des résultats

Les méthodes qualitatives utilisées dans le cadre de cette thèse pour l'évaluation des besoins et des priorités des parties prenantes, ainsi que pour la cocréation du programme, nous a mené à recruter un échantillon total de 29 personnes provenant de différents centres de réadaptation, universités et régions administratives de la province de Québec, soit six personnes ayant subi un AVC, quatre partenaires, 15 intervenants, une gestionnaire et trois chercheures en réadaptation. Malgré cette diversité de participants et la profondeur des analyses qui ont été réalisées, les résultats produits dans le cadre des études #3 (évaluation des besoins et priorités) et #5 (cocréation du programme) de cette thèse sont sujettes à un biais de sélection. Ainsi, les résultats colligés pourraient ne pas être représentatifs de l'ensemble de la population représentée par l'échantillon et ici, nous référons particulièrement aux intervenants. En effet, les intervenants qui se sont volontairement impliqués dans l'étude sont susceptibles de présenter un biais positif pour l'amélioration des services de réadaptation sexuelle et pourraient avoir des besoins et priorités différents des intervenants qui seraient moins intéressés par ce sujet. De plus, le programme pourrait être moins bien accepté et/ou répondre moins bien aux besoins des intervenants non représentés par les participants aux études composant cette thèse. Sans dénigrer les informations colligées dans le cadre des études présentées ci-dessus, il serait pertinent de colliger un complément d'informations auprès d'un échantillon de plus grande envergure. Par exemple, le recours à une étude transversale quantitative où des questionnaires portant sur les besoins et priorités liés à la réadaptation sexuelle post-AVC seraient envoyés aux intervenants en réadaptation post-AVC au Québec pourrait répondre à cet objectif. Notre équipe de recherche, de façon parallèle aux travaux composant cette thèse, a justement travaillé à adapter deux questionnaires validés dans d'autres contextes : le *Knowledge, Comfort, Approach and Attitude towards Sexuality Scale* (KCAASS) (Kendall et al., 2003) et le *Determinants for Implementation Behaviour Questionnaire* (DIBQ) (Huijg et al., 2014). Le KCAASS (Kendall et al., 2003) a été conçu pour évaluer les besoins de formation liés à la sexualité auprès d'intervenants travaillant avec une clientèle présentant une lésion médullaire et le DIBQ a été conçu pour mesurer les déterminants (fondés sur le TDF (Cane et al., 2012)) qui influencent l'implantation d'une nouvelle pratique. Dans le cadre de nos études, notre équipe de recherche a adapté à l'AVC et la réadaptation sexuelle, traduit en français et diffusé vers sept milieux de réadaptation post-AVC ces deux questionnaires adaptés pour explorer les besoins de formation liés à la sexualité et les facteurs influençant les pratiques de réadaptation sexuelle chez les intervenants. Cette étude a débuté en 2021 et la collecte de données a été complétée à l'été 2022 avec plus de 190 participants (dont 50 ont complété les questionnaires une seconde fois, à environ deux semaines d'intervalle entre chaque complétion afin de documenter certaines qualités psychométriques, telles que la cohérence interne, la fidélité test-retest, l'erreur standard de mesure et le changement minimum détectable. Une fois les analyses terminées, cette étude ajoutera au corpus de connaissances sur les besoins et les facteurs d'influence en réadaptation sexuelle déjà entamé par Low et collaborateurs (2022), qui ont sondé plus de 900 intervenants en réadaptation post-AVC à travers le monde sur leurs besoins de formation et leurs pratiques cliniques en lien avec la sexualité. Si les résultats de l'étude appuient les qualités psychométriques de ces deux questionnaires, ceux-ci pourront être utilisés dans de future études à visées évaluatives pour le programme.

Connaissances à développer dans le futur

Cette thèse se conclut avec un programme dont l'acceptabilité a été explorée auprès de parties prenantes de la réadaptation post-AVC et qui est prêt à être implanté et évalué. Ceci mène à réfléchir sur ce qui devrait être évalué dans les études futures. Par exemple, pour les effets du programme sur les différentes parties prenantes, l'efficacité en contexte réel avec des conditions contrôlées (*efficacy*) et naturelles (*effectiveness*) pourraient être considérées (Greenwald & Cullen, 1984; Nichol, 2008). Toutefois, ces deux types d'efficacité devraient être évalués par des devis de recherche, tels que les essais cliniques randomisés (qu'ils soient plus ou moins pragmatiques), qui nécessitent des ressources matérielles (ex., financement de recherche) et humaines considérables (Bowen et al., 2009). Afin d'assurer une utilisation responsable des ressources, il importe d'obtenir des données sur la possibilité d'implanter le programme et sur ses retombées. Le devis des études de faisabilité permet d'obtenir des données qui éclairent sur la possibilité d'utiliser une innovation et sur la pertinence d'évaluer son efficacité en réalisant des études de plus grande envergure sur son efficacité (Bowen et al., 2009). Contextualisé au programme conçu dans le cadre de cette thèse, une étude de faisabilité permettrait :
1) l'exploration de la possibilité d'implanter le programme; ainsi que 2) l'évaluation des retombées de l'implantation du programme sur les usagers, les partenaires, les intervenants et les gestionnaires. Dans leurs recommandations sur la réalisation d'une étude de faisabilité, Bowen et collaborateurs (2009) suggèrent d'orienter la collecte des données liées aux dimensions suivantes : l'acceptabilité, la demande (ou l'utilisation), l'implantation, l'utilisabilité, l'adaptation, l'intégration, l'expansion (ex., généralisation à d'autres clientèles ou contextes) et une exploration des effets du programme. La réalisation d'une étude de faisabilité rigoureuse portant sur le programme d'amélioration des services de réadaptation sexuelle post-AVC favoriserait l'ajustement des méthodes de collecte et d'analyse de données relatives à l'implantation et aux effets du programme en vue d'études de plus grande envergure, ce qui optimisera le succès de son implantation.

Lorsque l'étude de faisabilité sera complétée et si les résultats sont concluants, des études pourront être planifiées pour répondre à des questions telles que: Quelle est l'efficacité du programme d'amélioration des services en réadaptation sexuelle post-AVC sur : 1) l'offre de services de réadaptation sexuelle?; 2) les facteurs influençant les pratiques de réadaptation sexuelle chez les intervenants en réadaptation post-AVC?; et 3) la participation et la satisfaction des individus ayant subi un AVC et des partenaires dans les activités liées à la sexualité? Pour répondre à ces questions, l'essai clinique randomisé pourrait être un devis approprié pour procéder à cette évaluation dans des conditions contrôlées. Toutefois, ce devis correspond davantage aux études incluses dans la revue systématique présentée dans la recension des écrits de cette thèse (Auger, Grondin, et al., 2021) qui ont été critiquées pour ne pas être représentatives de la pratique clinique et dont les résultats devraient être généralisés avec prudence (Chalkidou et al., 2012). Considérant que le programme a été développé en vue d'être implanté et utilisé par les intervenants et gestionnaires en réadaptation post-AVC (c.-à-d., conditions réelles d'implantation), l'ECR de type pragmatique serait une alternative pertinente. En effet, l'ECR pragmatique permettrait d'évaluer l'efficacité du programme d'une manière plus cohérente avec les objectifs de son utilisation car ce devis permet de mettre en commun la randomisation (c.-à-d., qui limite le biais de sélection) avec les conditions de vie réelles où l'intervention est implantée (Gamerman et al., 2019; Schwartz & Lellouch, 1967). En ce qui a trait à la randomisation, celle-ci pourrait, entre autres, être faite au niveau des clients suivis, ou par la désignation de certaines grappes (*clusters*; ex., professions, unités de soins, milieux de réadaptation) (Gamerman et al., 2019). En effet, pour des raisons éthiques et pratiques, il ne serait pas faisable ou souhaitable d'implanter le programme auprès de la moitié des intervenants d'un même milieu pour comparer les suivis offerts aux clients desservis par chaque groupe d'intervenants. Ainsi, la randomisation par milieux de soins apparaît comme une option à privilégier pour tendre vers une randomisation adéquate, tout en pouvant implanter le programme en totalité dans chaque milieu au moment de leur entrée dans l'étude (Christie et al., 2009). Les cinq milieux partenaires de cette étude, qui ont déjà manifesté leur intérêt à utiliser le programme lorsqu'il sera conçu, pourront certainement être considérés comme des participants en vue de cette future étude, ce qui facilitera le recrutement pour chaque grappe. Bien que ce devis soit pertinent, la réalisation d'une ECR pragmatique en grappes peut susciter des défis au niveau des choix de devis, de collecte et d'analyse des données (Puffer et al., 2005), ce qui renforce d'autant plus l'importance de réaliser une bonne étude de faisabilité. De plus, ceci nécessitera qu'une équipe chevronnée composée d'experts en méthodologie des études de faisabilité et des ECR soit mise sur pied pour favoriser le succès de l'étude.

Chapitre 9 – Conclusion

La sexualité est un domaine important du fonctionnement et de la vie des personnes (World Health Organization, 2001, 2006), incluant celles qui ont subi un AVC, mais qui est trop peu abordé au cours de leur réadaptation (McGrath et al., 2019). Cette thèse avait pour objectif d'offrir des solutions concrètes à cette situation problématique en faisant la synthèse des études sur le sujet et en cocréant des connaissances qui pourraient être appliquées par les intervenants en réadaptation post-AVC. Réparties entre cinq articles scientifiques, les connaissances composant cette thèse ont mené à l'élaboration d'un programme multifactoriel composé de 11 interventions, fondé sur les plus récentes études empiriques dans le domaine de la sexualité post-AVC, orienté par des théories du changement de comportement et cocréé en incluant plus de 25 personnes qui vivent la réalité de la réadaptation post-AVC soit dans les rôles de personne post-AVC, de partenaire, d'intervenant, de gestionnaire ou de chercheur. Ce programme représente, à notre connaissance, la première innovation dans le domaine qui vise à cibler plusieurs déterminants du comportement des intervenants, incluant les facteurs propres à leur environnement social et physique. Le programme a donc un potentiel important d'influencer positivement les pratiques des intervenants en réadaptation post-AVC au Québec, dans la mesure où il sera connu et implanté dans la province. Pour actualiser ce potentiel, de multiples études et travaux devront être entrepris dans le futur pour diffuser le programme, l'implanter, évaluer ses effets et en favoriser sa pérennité dans les milieux de réadaptation post-AVC. Ultimement, il est envisagé que ce seront les personnes ayant subi un AVC et leurs partenaires (le cas échéant) qui profiteront des retombées du programme en recevant de meilleurs services de réadaptation sexuelle et donc en ayant de meilleures chances d'avoir une participation satisfaisante en lien avec leur sexualité. Au-delà des personnes ayant subi un AVC, ce programme a un potentiel d'être généralisé à d'autres clientèles présentant des difficultés sexuelles et qui pourraient bénéficier d'une réadaptation sexuelle. Ainsi, la cocréation de ce programme d'amélioration des services de réadaptation sexuelle post-AVC représente certainement la « pose de la première pierre » de multiples initiatives dans le futur qui mèneront, espérons-le, à une révolution de la qualité des services de santé sexuelle offerts aux personnes Québécoises et Canadiennes et donc à une meilleure participation dans leurs activités liées à la sexualité.

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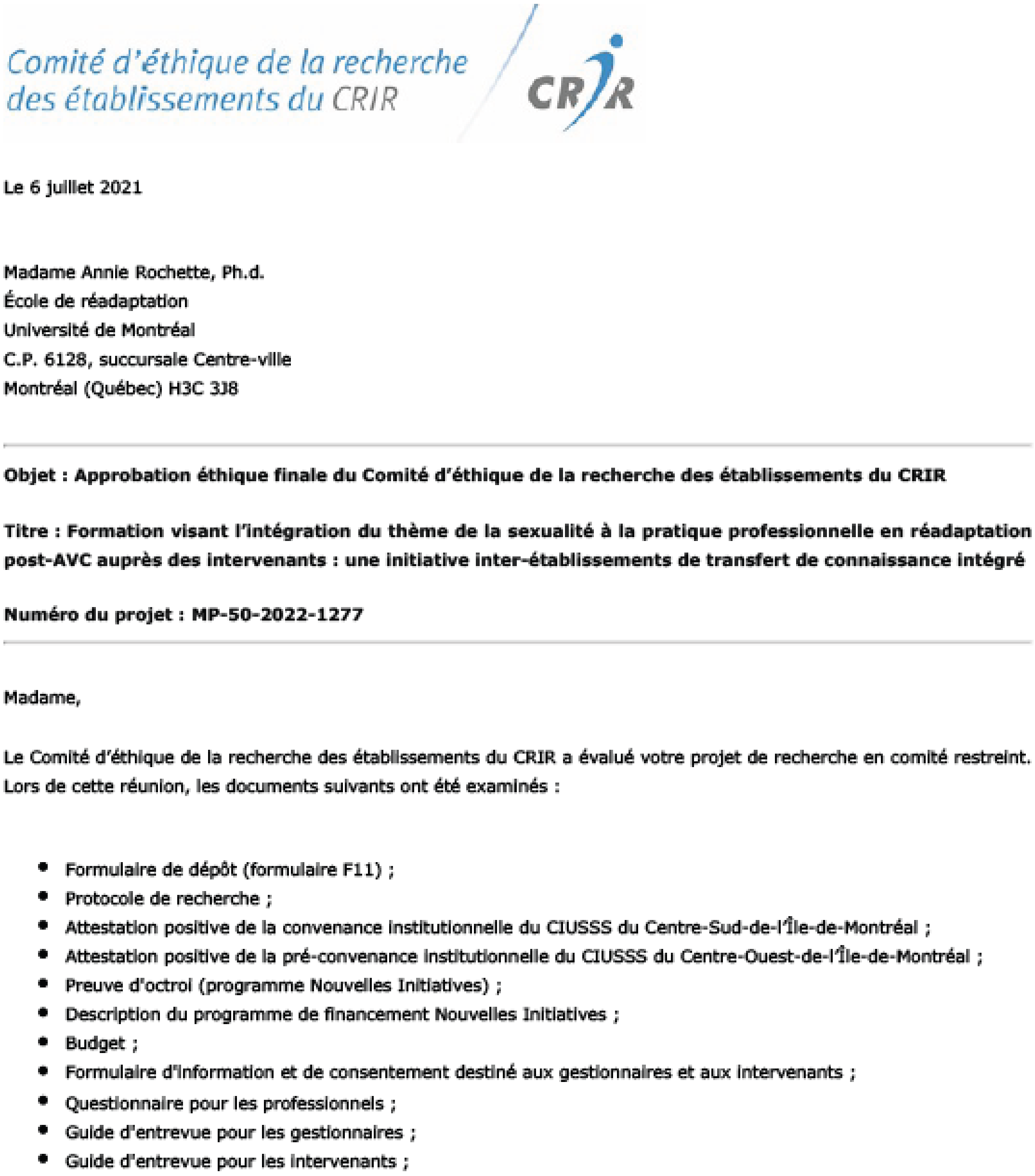
Annexe 1 – Certificat d'approbation du

Comité d'éthique de la recherche
des établissements du CRIR



Comité d'éthique de la recherche
des établissements du CRIR

Le 6 juillet 2021

Madame Annie Rochette, Ph.d.
École de réadaptation
Université de Montréal
C.P. 6128, succursale Centre-ville
Montréal (Québec) H3C 3J8

Objet : Approbation éthique finale du Comité d'éthique de la recherche des établissements du CRIR

Titre : Formation visant l'intégration du thème de la sexualité à la pratique professionnelle en réadaptation post-AVC auprès des intervenants : une initiative inter-établissements de transfert de connaissance intégré

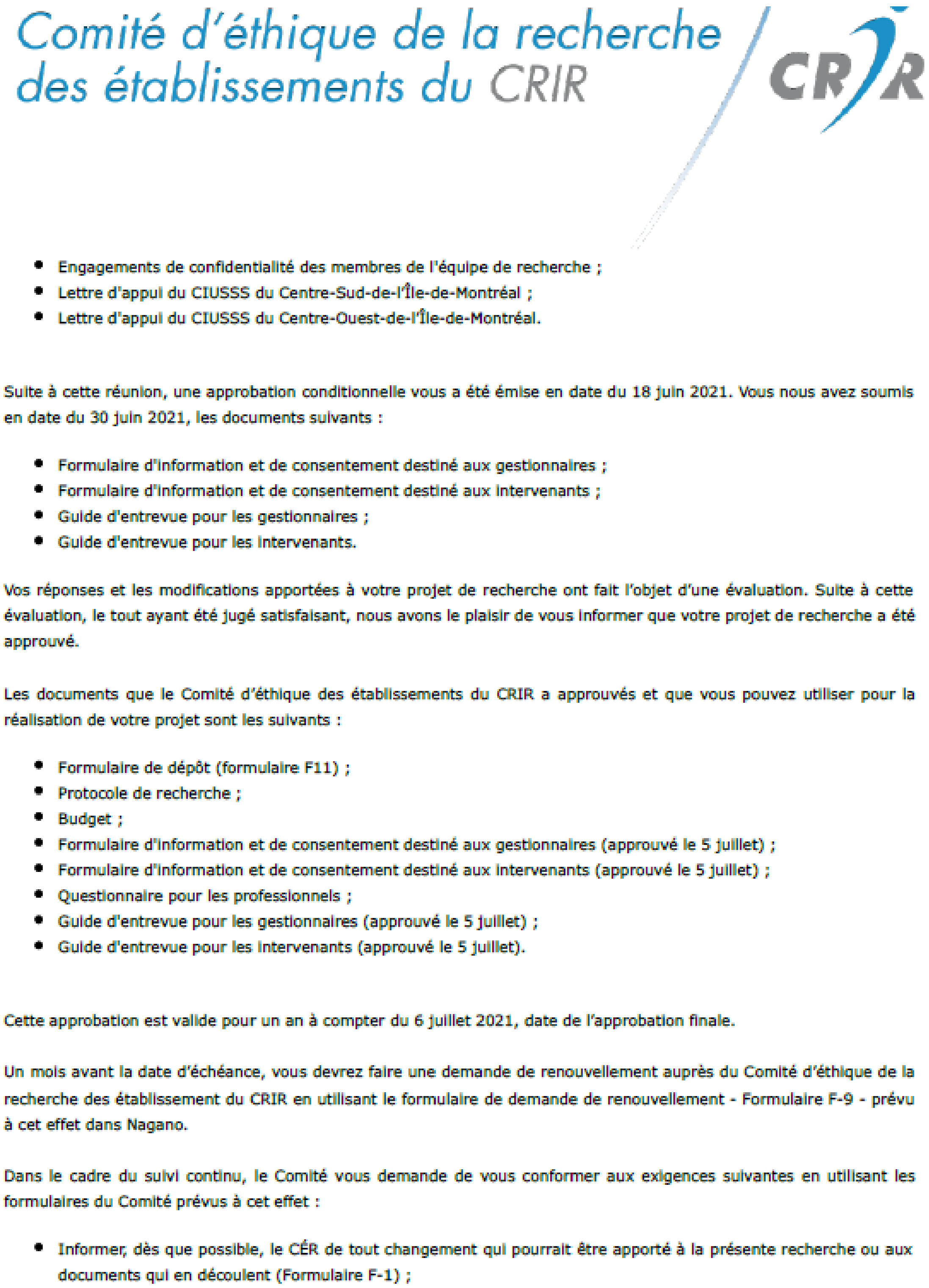
Numéro du projet : MP-50-2022-1277

Madame,

Le Comité d'éthique de la recherche des établissements du CRIR a évalué votre projet de recherche en comité restreint. Lors de cette réunion, les documents suivants ont été examinés :

- Formulaire de dépôt (formulaire F11) ;
- Protocole de recherche ;
- Attestation positive de la convenance institutionnelle du CIUSSS du Centre-Sud-de-l'Île-de-Montréal ;
- Attestation positive de la pré-convenance institutionnelle du CIUSSS du Centre-Ouest-de-l'Île-de-Montréal ;
- Preuve d'octroi (programme Nouvelles Initiatives) ;
- Description du programme de financement Nouvelles Initiatives ;
- Budget ;
- Formulaire d'information et de consentement destiné aux gestionnaires et aux intervenants ;
- Questionnaire pour les professionnels ;
- Guide d'entrevue pour les gestionnaires ;
- Guide d'entrevue pour les intervenants ;

Comité d’éthique de la recherche du CRIR



Comité d’éthique de la recherche des établissements du CRIR

- Engagements de confidentialité des membres de l'équipe de recherche ;
- Lettre d'appui du CIUSSS du Centre-Sud-de-l'Île-de-Montréal ;
- Lettre d'appui du CIUSSS du Centre-Ouest-de-l'Île-de-Montréal.

Suite à cette réunion, une approbation conditionnelle vous a été émise en date du 18 juin 2021. Vous nous avez soumis en date du 30 juin 2021, les documents suivants :

- Formulaire d'information et de consentement destiné aux gestionnaires ;
- Formulaire d'information et de consentement destiné aux intervenants ;
- Guide d'entrevue pour les gestionnaires ;
- Guide d'entrevue pour les intervenants.

Vos réponses et les modifications apportées à votre projet de recherche ont fait l’objet d’une évaluation. Suite à cette évaluation, le tout ayant été jugé satisfaisant, nous avons le plaisir de vous informer que votre projet de recherche a été approuvé.

Les documents que le Comité d’éthique des établissements du CRIR a approuvés et que vous pouvez utiliser pour la réalisation de votre projet sont les suivants :

- Formulaire de dépôt (formulaire F11) ;
- Protocole de recherche ;
- Budget ;
- Formulaire d'information et de consentement destiné aux gestionnaires (approuvé le 5 juillet) ;
- Formulaire d'information et de consentement destiné aux intervenants (approuvé le 5 juillet) ;
- Questionnaire pour les professionnels ;
- Guide d'entrevue pour les gestionnaires (approuvé le 5 juillet) ;
- Guide d'entrevue pour les intervenants (approuvé le 5 juillet).

Cette approbation est valide pour un an à compter du 6 juillet 2021, date de l’approbation finale.

Un mois avant la date d’échéance, vous devrez faire une demande de renouvellement auprès du Comité d’éthique de la recherche des établissement du CRIR en utilisant le formulaire de demande de renouvellement - Formulaire F-9 - prévu à cet effet dans Nagano.

Dans le cadre du suivi continu, le Comité vous demande de vous conformer aux exigences suivantes en utilisant les formulaires du Comité prévus à cet effet :

- Informer, dès que possible, le CÉR de tout changement qui pourrait être apporté à la présente recherche ou aux documents qui en découlent (Formulaire F-1) ;

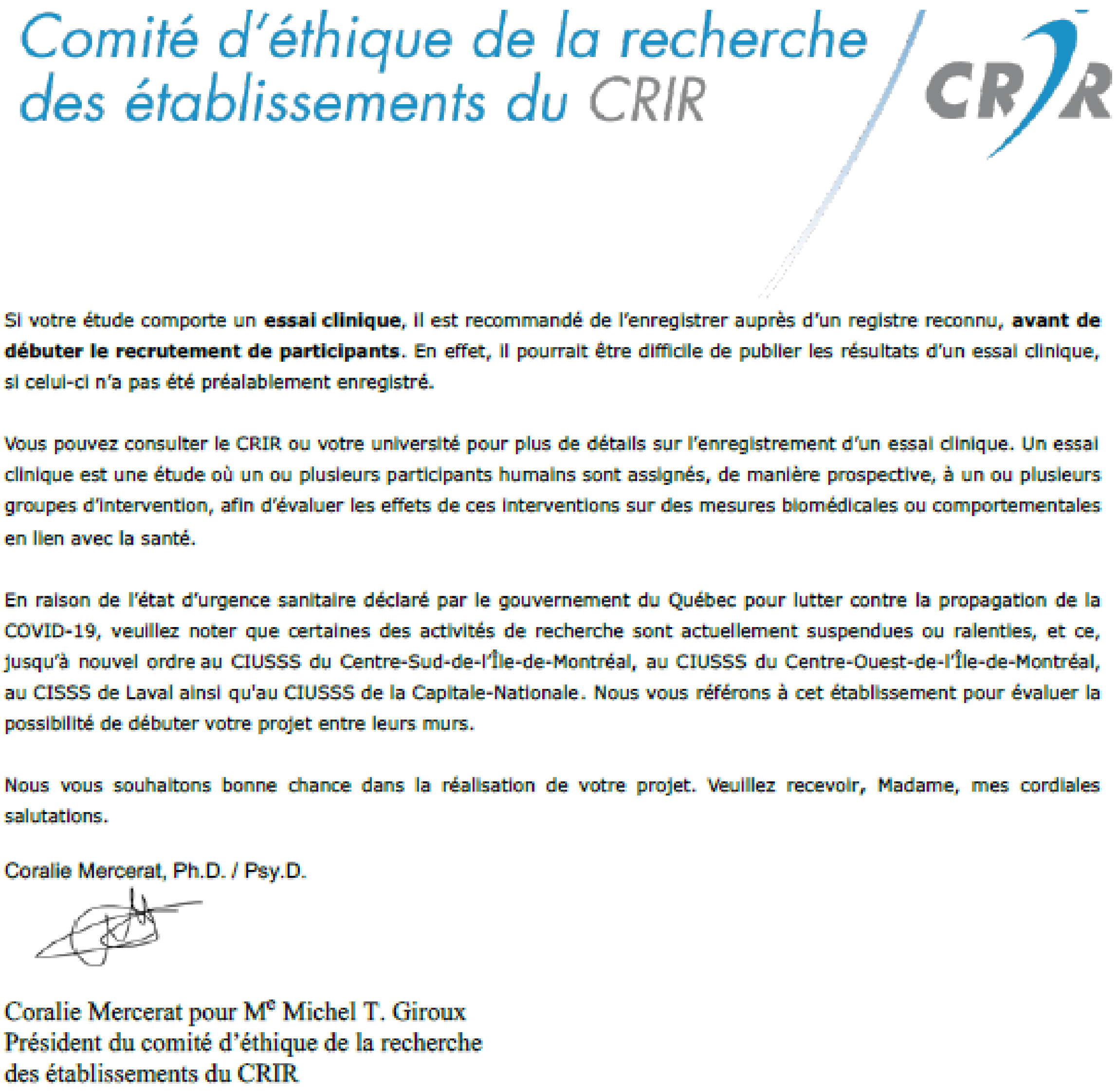
- Notifier, dès que possible, le CÉR de tout incident ou accident lié à la procédure du projet ;
- Notifier, dès que possible, le CÉR de tout nouveau renseignement susceptible d'affecter l'intégrité ou l'éthicité du projet de recherche, ou encore, d'influer sur la décision d'un sujet de recherche quant à sa participation au projet ;
- Notifier, dès que possible, le CÉR de toute suspension ou annulation d'autorisation relative au projet qu'aura formulée un organisme de subvention ou de réglementation ;
- Notifier, dès que possible, le CÉR de tout problème constaté par un tiers au cours d'une activité de surveillance ou de vérification, interne ou externe, qui est susceptible de remettre en question l'intégrité ou l'éthicité du projet ainsi que la décision du CÉR ;
- Notifier, dès que possible, le CÉR de l'interruption prématurée, temporaire ou définitive du projet. Cette modification doit être accompagnée d'un rapport faisant état des motifs à la base de cette interruption et des répercussions sur celles-ci sur les sujets de recherche ;
- Fournir annuellement au CÉR un rapport d'étape l'informant de l'avancement des travaux de recherche ;
- Demander le renouvellement annuel de son certificat d'éthique (Formulaire F-9) ;
- Tenir et conserver, selon la procédure prévue dans la *Politique portant sur laconservation d'une liste des sujets de recherche*, incluse dans le cadre réglementaire des établissements du CRIR, une liste des personnes qui ont accepté de prendre part à la présente étude ;
- Envoyer au CÉR une copie de son rapport de fin de projet / publication ;
- En vertu de l'article 19.2 de la *Loi sur les services de santé et les services sociaux,* obtenir l'autorisation du Directeur des services professionnels de l'établissement sollicité avant d'aller consulter les dossiers des usagers de cet établissement, le cas échéant.

Cette décision s'applique aux sites suivants, une fois que les lettres des personnes formellement mandatées de chaque site auront été émises :

- CIUSSS du Centre-Sud-de-l'Île-de-Montréal ;
- CIUSSS du Centre-Ouest-de-l'Île-de-Montréal ;
- CISSS de Laval ;
- CIUSSS de la Capitale-Nationale

Nous vous rappelons ainsi que vous ne pouvez commencer votre projet avant d'avoir obtenu l'autorisation de la personne formellement mandatée responsable dans les sites participants. Nous acheminerons l'approbation éthique finale de votre projet à la personne formellement mandatée responsable au CIUSSS du Centre-Sud-de-l'Île-de-Montréal, au CIUSSS du Centre-Ouest-de-l'Île-de-Montréal, au CISSS de Laval ainsi qu'au CIUSSS de la Capitale-Nationale pour que vous puissiez obtenir l'autorisation de réaliser votre projet dans les murs de l'établissement.

Le Comité d'éthique de la recherche des établissements du CRIR est désigné par le ministre de la Santé et des Services sociaux aux fins de l'application de l'article 21 du Code civil du Québec et suit les règles émises par l'Énoncé de politique des trois conseils et les Bonnes pratiques cliniques telles qu'élaborées par la Conférence internationale sur l'harmonisation (CIH).



Comité d'éthique de la recherche
des établissements du CRIR

CRIR

Si votre étude comporte un **essai clinique**, il est recommandé de l'enregistrer auprès d'un registre reconnu, **avant de débuter le recrutement de participants**. En effet, il pourrait être difficile de publier les résultats d'un essai clinique, si celui-ci n'a pas été préalablement enregistré.

Vous pouvez consulter le CRIR ou votre université pour plus de détails sur l'enregistrement d'un essai clinique. Un essai clinique est une étude où un ou plusieurs participants humains sont assignés, de manière prospective, à un ou plusieurs groupes d'intervention, afin d'évaluer les effets de ces interventions sur des mesures biomédicales ou comportementales en lien avec la santé.

En raison de l'état d'urgence sanitaire déclaré par le gouvernement du Québec pour lutter contre la propagation de la COVID-19, veuillez noter que certaines des activités de recherche sont actuellement suspendues ou ralenties, et ce, jusqu'à nouvel ordre au CIUSSS du Centre-Sud-de-l'Île-de-Montréal, au CIUSSS du Centre-Ouest-de-l'Île-de-Montréal, au CISSS de Laval ainsi qu'au CIUSSS de la Capitale-Nationale. Nous vous référons à cet établissement pour évaluer la possibilité de débuter votre projet entre leurs murs.

Nous vous souhaitons bonne chance dans la réalisation de votre projet. Veuillez recevoir, Madame, mes cordiales salutations.

Coralie Mercerat, Ph.D. / Psy.D.

Coralie Mercerat pour M^e Michel T. Giroux
Président du comité d'éthique de la recherche
des établissements du CRIR

Annexe 2 - Original questionnaires and qualitative methods used to assess sexuality with a stroke population

Authors	Type of assessment	Study objective(s)	Questions	Scale
Monga, Lawson et Inglis, 1986	Original questionnaire	Assess the impact of CVA on sexual behavior in stroke patients	1. Sexual drive/libido	1) 4 = normal, 3 = diminished, 2 = markedly diminished, 1 = none
			2. Frequency of intercourse	2) 4 = more than once a week, 3 = once a week, 2 = once a month, 1 = none
			3. Enjoyment of sexual activity	3) 4 = very much, 3 = moderate, 2 = mild, 1 = none
			4. Satisfaction with sexual activity	4) 4 = very much, 3 = moderate, 2 = mild, 1 = none
			Male only:	
			1. Erection during sexual activity	4 = normal, 3 = slow normal, 2 = poor, 1 = none
			2. Ejaculation during sexual activity	4 = normal, 3 = premature, 2 = delayed, 1 = none
			Female only:	
			1. Vaginal lubrification during sexual activity	4 = normal, 3 = slow normal, 2 = poor, 1 = none
			2. Orgasm during sexual activity	4 = normal, 3 = premature, 2 = delayed, 1 = none
McCall and Hosenfel, 2008	Original questionnaire	Explore the association of sexual satisfaction with prevalent cardiovascular disease and cardiovascular disease risk factors among sexually active postmenopausal women	"How satisfied are you with your current sexual activities, either with a partner or alone?"	4-point Likert-type scale: 1 = very unsatisfied, 2 = a little unsatisfied, 3 = somewhat satisfied, 4 = very satisfied
		Determine if low sexual satisfaction is predictive of incident cardiovascular disease in women		
Korpelainen et al.,1999 (inspiré de Monga)	Original questionnaire	Assess the impact of stroke on sexual functioning in stroke patients and their spouse	Libido	1 = increased, 2 = no change, 3 = diminished, 4 = markedly diminished, 5 = none
		Evaluate the associations between the changes in sexuality and the various clinical and psychological features of stroke patients	Coital frequency	1 = more than once a week, 2 = once a week, 3 = one or twice a month, 4 = less than once a month, 5 = none
		Clarify the complex and multifactorial etiology of poststroke sexual dysfunction	Erection, ejaculation, vaginal lubrification and orgasm	1 = normal, 2 = slightly diminished, 3 = markedly diminished, 4 = none

			Satisfaction with sexual life	1 = very satisfied, 2 = moderately satisfied, 3 = moderately dissatisfied, 4 = completely dissatisfied
			General attitude toward sexuality	1 = extremely important, 2 = fairly important, 3 = unimportant
			Fear of impotence	1 = no, 2 = yes
			Fear of another stroke	1 = no, 2 = yes
			Ability to discuss sexuality with spouse	1 = yes, with ease, 2 = yes, with trouble, 3 = no
			Unwillingness to participate in sexual activity	1 = no, 2 = yes
Korpelainen et al.,1998	Original questionnaire	Assess the impact of stroke on sexual behavior in stroke patients and their spouse	Libido	Increased, no change, diminished, markedly diminished, ceased
			Coital frequency	More than once a week, once a week, one or twice a month, less than once a month, none
			Erection	Increased, no change, diminished, markedly diminished, ceased
			Ejaculation	Increased, no change, diminished, markedly diminished, ceased
			Vaginal lubrification	Increased, no change, diminished, markedly diminished, ceased
			Satisfaction with sexual life	Very satisfied, moderately satisfied, moderately dissatisfied, completely dissatisfied
Jung, 2008	Original questionnaire	Examine characteristics of sexual problems in stroke patients	Frequency of sexual intercourse	0 = no attempts, 1 = 1-2 times/month, 2 = 3-4 times/month, 3 = 5-6 times/month, 4 = 7-10 times/month, 5 = more than 10 time/month
		Examine the effect of the location of brain lesions on sexual function	Change in sexual desire after the stroke	0 = no desire after stroke, 1 = severely decreased desire after stroke, 2 = decrease desire after stroke, 3 = no change, 4 = increased
			Conditions preventing intercourse	1 to 5 scale
			Methods used to improve sexual function	0 to 5 scale
			sexual information	
			Fear of sexual intercourse after the stroke	0 = no fear, 1 = almost never, 2 = a few times, 3 = sometimes, 4 = most times, 5 = almost always
			Satisfaction with sexual function	1 to 5 scale

			Need for treatment by specialists	
Sjogren and Fugl-Meyer, 1982	Original questionnaire	Study the impact of stroke with hemiplegia on frequencies of sexual intercourse and of leisure activities	Frequency of intercourse	Cessation, decrease, unaltered
Humphrey, 1985	Original questionnaire	Consequence of CVA on sexuality	"Have you felt the need for advice on sexual matter since your husband (wife) left the Wolfson Centre? If so, were you able to find someone to give you advice?"	
Giaquinto et al., 2003	Structured interview	Evaluate and quantify sexual changes 1 year after stroke	1. Number of times per week they engaged in sexual intercourse	
			2. The time at which sexual activity had started again	
			3. Drugs taken by the patient	
	Original questionnaire		Is motor impairment stressful?	Yes, No
			Did the physical impairment oblige you to change your preferred sexual position?	Yes, No, No new position would allow us to have sexual intercourse
			Do you find your sexual life satisfactory?	No in spite of maintained sexual intercourse, No we do not have sexual intercourse, Yes we still have sexual intercourse
			Do you experience frustration in the case of sexual decline?	Yes, I am very frustrated; No, sexual life is not important; The problem does not apply to me
			How much value has a normal sexual life?	Very high for everybody, Very high for healthy people, Low if a person has a disability
			Are you sexually attracted by your partner? (for patient's partner only	Yes, No
			How is your erection? (for male patients)	Normal, Incomplete, Absent
			How is your ejaculation? (for male patients, lubrification for female patients	Normal, precocious, late, absent

Edmans, 1998	Original questionnaire	Investigate whether stroke patients had been able to resume their sexual activity, what information they had found useful and when this was given	Biographical characteristics, that is, gender, age and side of stroke (for patient)	
		Identify whose rehabilitation role should include this subject	Frequency with which they engaged in sexual activity prior to and since the patient's stroke. If sexual activity had deteriorated after the stroke, they were asked to give their reasons for this deterioration	Often, sometimes, rarely, never
			Whether any information regarding returning to sexual activity had been offered to them on the stroke unit or since the patient's discharge.	Written, verbal advice, nothing; Relevant, not relevant
			When they felt such information should be offered	On admission, time at home, before discharge, after discharge
			Whether they felt it was clear whom to discuss the subject with	
			Whether they would prefer private consultations alone or with their partner	Definitely yes, probably yes, probably no, definitely no
			Whether they felt resuming sexual activity should be discussed routinely as part of stroke rehabilitation	Definitely yes, probably yes, probably no, definitely no
de Freitas et al., 2017	Original questionnaire	Determine the association of body function disabilities evaluate according to the "body function" dimension of the International Classification of Functioning, Disability and Health (ICF) stroke core sets with the referral of stroke-affected subjects to rehabilitation services in the city of Joao Pessoa-Paraiba	Vestibular functions	Disability in the body functions or not
			Emotional functions	
			Memory functions	
			Muscle strength	
			Attention function	
			Function relating to muscle tone	
			Perception functions	
			Pain sensation	
			Functions relating to voluntary movement control	
			Vision functions	
			Tactile functions	
			Mental language functions	

			Proprioceptive functions	
			Defecation functions	
			Orientation functions	
			Functions relating to joint stability	
			Functions relating to involuntary movement reflexes	
			Sexual functions	
			Auditory functions	
Choi-Know and Kim, 2002 (inspiré de Monga)	Original questionnaire	Investigate the relationship between poststroke emotional incontinence and sexual activity	Libido	No change or diminished (if so, they asked if there were any causes other than stroke)
			Coital frequency	1 = more than once a week, 2 = once a week, 3 = one to three time a month, 4 = less than once a month
			Erectile function/vaginal lubrification	No change or diminished (if so, they asked if there were any causes other than stroke)
Cheung, 2002	Original questionnaire	Assess the impact of stroke on sexual functioning in a cohort of stable Chinese patients with mild or no disability	Libido after stroke	Increased, Unchanged, Decrease or absent
		Explore the associations between changes in sexuality and the various clinical and psychosocial factors	Coital frequency before stroke	Twice per week or more, once per week, once or twice per month, less than once per month, absent
			Coital frequency after stroke	Twice per week or more, once per week, once or twice per month, less than once per month, absent
			Erection before stroke	Normal, Diminished, Absent
			Erection after stroke	Normal, Diminished, Absent
			Ejaculation before stroke	Normal, Diminished, Absent
			Ejaculation after stroke	Normal, Diminished, Absent
			Vaginal lubrification before stroke	Normal, Diminished, Absent
			Vaginal lubrification before stroke	Normal, Diminished, Absent
			Orgasm before stroke	Normal, Diminished, Absent
			Orgasm after stroke	Normal, Diminished, Absent
			Satisfaction before stroke	Satisfactory, Dissatisfactory, Unsure

			Satisfaction after stroke	Satisfactory, Dissatisfactory, Unsure
			Psychological factors:	
			Marital status	Married, Divorced, Widow/widower, Single
			Importance of sexuality	Important, Not important, Unsure
			Fear of impotence	Yes, No, Unsure
			Fear of recurrent stroke	Yes, No, Unsure
			Belief in stroke affecting sexual functions	Yes, No, Unsure
			Ability to discuss sexuality with the spouse or partner	Yes with ease, Yes with trouble, No
			Willingness to participate in sexual activity	Yes, No, Unsure
Carod and al., 1999	Original questionnaire	Measure the variables (depression, disability, or psychological) that could interfere in the sexual life of stroke survivors and their spouses	Libido	
			Impotence	
			Sexual satisfaction	
			Changes in their sexual life with partner	
Aloni et al., 1993	Original questionnaire	Study change in sexual performance in post-stroke male patients	Frequency of intercourse (before and after stroke) (4 questions)	Once a week, once in two weeks, once a month, less than once a month
			Identifying the changes (2 questions)	
			Desire (7 questions)	
			Erection (8 questions)	Duration: over 10 min, 5-10min, 1-4, Less than 1 min
			Ejaculation (2 questions)	
			Orgasm (satisfaction) (1 question)	
Aloni et al., 1994	Original questionnaire	Investigate sexual function in post-stroke females	Desire	Increase, decrease, no change
			Lubrification	Increase, decrease, no change
			Orgasm	Decrease, no change
			Mens. Period	Change, no change
Berry et al., 2017	Original questionnaire	Examine how positive and negative relationship changes post-stroke are associated with a couple's relationship satisfaction	10 items: current relationship satisfaction, changes in relationship satisfaction, 5 negatives and 3 positive relationship factors that changed since the stroke	Likert-scale

		Assess the need of support	*Negative relationship factors:*	
			growing further apart since the stroke	
			not taking as much time to enjoy each other's company	
			Positive relationship factor:	
			Growing closer since the stroke	
			Current relationship satisfaction:	
			Intimacy	
			Supporting health habits	
			Changes in relationship satisfaction:	
			Grateful for their partner	
			Need for mote information	
Akinpelu et al., 2013 (inspiré de Korpelainen, 1999)	Original questionnaire	Survey sexual dysfunction among stroke survivors attending a hospital in Southwestern Nigeria	*Sexual function:*	
		Determine the influence of socio-demographic, clinical and psychological factors on the dysfunction	Libido	1 = increased, 2 = no change, 3 = diminished, 4 = markedly diminished, 5 = none
			Coital frequency	1 = more than once a week, 2 = once a week, 3 = one or twice a month, 4 = less than once a month, 5 = none
			Erection	1 = normal, 2 = slightly diminished, 3 = markedly diminished, 4 = none
			Ejaculation	1 = normal, 2 = slightly diminished, 3 = markedly diminished, 4 = none
			Vaginal lubrification	1 = normal, 2 = slightly diminished, 3 = markedly diminished, 4 = none
			Orgasm	1 = normal, 2 = slightly diminished, 3 = markedly diminished, 4 = none
			Sexual satisfaction	1 = very satisfied, 2 = moderately satisfied, 3 = moderately dissatisfied, 4 = completely dissatisfied
			Psychological factors:	
			General attitude towards sexuality	1 = extremely important, 2 = fairly important, 3 = unimportant

			Fear of impotence	1 = no, 2 = yes
			Fear of another stroke	1 = no, 2 = yes
			Ability to discuss sexuality with spouse	1 = yes, with ease, 2 = yes, with trouble, 3 = no
			Unwillingness to participate in sexual activity	1 = no, 2 = yes
Argawal and Jain, 1989	Original questionnaire	Evaluate male sexual functions in stroke patients	Libido before and after stroke	1 = very disinterested, 2 = disinterested, 3 = interested, 4 = very interested
		Analyse the role of left or right hemispheric involvement on sexual dysfunction	Frequency of coitus before and after stroke	same, decreased, increased
Boldrini et al., 1991	Structured Interview	1. Measure changes regarding aspects of sexual behavior and hemiparesis	Behavioral features of sexual functions as influenced by the stroke:	
		2. Measure changes in sexual life experienced by the spouses of stroke victims	1. Frequency of intercourse after the stroke	unchanged or increased, decreased, ceased
		3. Measure possible differences between the two genders concerning sexuality after CVA	2. Interval between stroke and renewal of intercourse	during the first three months, between three and six months, after six months
		4. Measure the association between changes in sexuality and clinical features of hemiparetic patients.	3. Foreplay	changed, unchanged
			4. Positions assumed during intercourse	changed, unchanged
			5. Changes in erection in men	difficult or normal erection before the stroke and difficult or normal erection after the stroke
			6. Change in ejaculation in men	difficult or normal ejaculation before the stroke and difficult or normal ejaculation after the stroke
			7. Changes in orgasm in women	presence or absence of orgasmic dysfunction before the stroke and presence or absence of orgasmic dysfunction after the stroke
			8. Disturbances during sex play in women	presence or absence of vaginismus or lack of vaginal lubrification before and after the stroke
			Patient's feelings about sexual life:	
			1. Overall feelings about sexual life after stroke	Changed or unchanged

			2. Changes in satisfaction derived from intercourse	Presence or absence of satisfaction as a rule before the stroke and presence or absence of satisfaction as a rule after the stroke
			Sexual assessment of patients' spouses:	
			1. Frequency of intercourse after the stroke	unchanged or increased, decreased, ceased
			2. Estimation of overall psychologic change in patient after stroke	changed, unchanged
			3. Feelings about sexual life after the stroke	changed, unchanged
			4. Changes in satisfaction derived from intercourse	Presence or absence of satisfaction as a rule before the stroke and presence or absence of satisfaction as a rule after the stroke
Tamam, 2008 (inspiré de Monga et Korpelainen)	Original questionnaire	Assess the impact of stroke on sexual functioning in a stable cohort of Turkish stroke patients with mild or no disability	Libido	1 = increased, 2 = no change, 3 = diminished, 4 = markedly diminished, 5 = none
		Assess the relationship between post-stroke sexuality and a number of socio-demographic, clinical and laboratory variables	Coital frequency	1 = more than once a week, 2 = once a week, 3 = one or twice a month, 4 = less than once a month, 5 = none
			Erection, ejaculation, vaginal lubrification and orgasm	1 = normal, 2 = slightly diminished, 3 = markedly diminished, 4 = none
			Satisfaction with sexual life	1 = very satisfied, 2 = moderately satisfied, 3 = moderately dissatisfied, 4 = completely dissatisfied
			General attitude toward sexuality	1 = extremely important, 2 = fairly important, 3 = unimportant
			Fear of impotence	1 = no, 2 = yes
			Fear of another stroke	1 = no, 2 = yes
			Ability to discuss sexuality with spouse	1 = yes, with ease, 2 = yes, with trouble, 3 = no
			Unwillingness to participate in sexual activity	1 = no, 2 = yes
Song, 2011 (questionnaire of McCabe and Taleperos)	Original questionnaire	Examine whether a sexual rehabilitation intervention program is effective with respect to sexual knowledge and satisfaction, and	Deep kissing	Score from 1 to 5 according to the frequency over the past month: never, once, 2-5 times, 6-20 times, more than 20 times
			Nude cuddling	
			Oral sex	

		frequency of sexual activity at 1 month after intervention	Sexual intercourse	
Aloni et al., 1992	Original questionnaire	Study a vacuum tumescence constriction therapy as a non-invasive method for use by a population with traumatic or nontraumatic neurologic disorder	Desire	
			Quality of patient's erection	
			Ability to achieve orgasm	
			Ability to achieve and maintain penetration for a substantial length of time	
			Ability to ejaculate	
Kim, 2008 (questionnaire of McCabe and Taleperos)	Original questionnaire	Investigate the influence of sexual frequency and sense of control on depression in Korean men after stroke	*Independent sexual activities:*	Score from 1 to 5 according to the frequency over the past month : never, once, 2-5 times, 6-20 times, more than 20 times
			Masturbation	
			Viewing erotic movies/magazines	
			Imagination	
			Mutual sexual activities:	
			Deep kissing	
			Nude cuddling	
			Oral sex	
			Sexual intercourse	
Howes et al., 2005	Original questionnaire	Examine the perceived effect of acquired brain injury on body image and psycho-emotional functioning	Appetite	1 = strong negative feeling, 3 = no feelings either way, 5 strong negative feeling
			Physical stamina	
			Reflexes	
			Muscular strength	
			energy level	
			Thighs	
			Biceps	
			body build	
			Physical co-ordination	
			Buttock	
			Agility	
			Shoulder width	
			Arms	

			Chest	
			Legs	
			Hips	
			Physique	
			Sex drive	
			Sex organs	
			Stomach	
			Health sex activities	
			Body hair	
			Face	
			Weight	
Dusenbury and al., 2020	Original questionnaire	Analyze factors affecting sexual activity in individuals with and without stroke, ages 40-59 years	Number of times the individual engaged in a vaginal or anal sex over the last year	Seven categories ranging from "never" to "365 times or more"
Na and al., 2020	Original questionnaire	Review the postulated factors contributing to poststroke sexual dysfunction (PSSD) and explore the underecognition by presenting a questionnaire study as well as examining existing literature	*Poststroke physical deficits:*	
			Sensorimotor or perceptual deficits	
			Spasticity	
			Autonomic dysfunctions	
			Urinary incontinence	
			Cognitive dysfunction	
			Communication issues	
			Catheters	
			Hygiene	
			Comorbidities or known vascular risk factors:	
			Hypertension	
			Diabetes	
			Dyslipidemia	
			Chronic smoking	
			High BMI	
			Side effects of medications:	

			Antihypertensive (beta blockers, calcium channel blockers, diuretics)	
			Antidepressants especially SSRIs	
			Psychological factors:	
			Depression	
			Fear or recurrence of stroke	
			Post stroke fatigue	
			Fear of partner rejection	
			Pre-existing dysfunction	
			Social factors:	
			Role change	
			Spousal attitude changes	
			Reduced social contact	
			Post-stroke coping skills	
Habot, 1989	Original questionnaire	Study sexual performance and satisfaction among male post-CVA	Frequency of sexual intercourse	
			Satisfaction with sexual intercourse	
Epprecht, 2018	Original questionnaire	Determine the prevalence of sexual dysfunction after an aneurysmal subarachnoid hemorrhage in patients with otherwise favorable neurologic outcomes	Whether their current sexual experience had:	improved, worsened, remained unchanged
Stead, 2019	Original questionnaire	Describe some of the changes in intimate connection that caregivers can experience with their partners with aphasia.	Why they wanted to attend the retreat	
		Discuss one community-based program designed to aid couples in their recovery and reconnection	What they hoped to get from the retreat	
			Whether relationship roles had changed since acquiring aphasia	
			Benefits of the retreat	
Sjrogen, 1981	Structured interview	To what degree do coital habits change as a result of stroke with hemiplegia?	1. How often sexual problem in partnership?	Alternative answer: often, occasionally, rarely, never

		What is the prevalence of registrable erectile and orgasmic dysfunction in hemiplegia?	2. How often erectile problems (males)?	Alternative answer: often, occasionally, rarely, never
		To what extend do hemiplegia/hemiparetic subjects feel satisfied with sexual life post-stroke?	3. How often morning erection?	Alternative answer: often, occasionally, rarely, never
			4. Do you achieve orgasm?	Alternative answer: often, occasionally, rarely, never
			5. Is erection spontaneous during sex-play (males)?	Alternative answer: often, occasionally, rarely, never
			6. Is orgasm spontaneous?	Alternative answer: often, occasionally, rarely, never
			7. Frequency of intercourse is	Alternative answer: satisfactory, rather satisfactory, rather unsatisfactory, unsatisfactory
			8. Duration of foreplay is?	Alternative answer: satisfactory, rather satisfactory, rather unsatisfactory, unsatisfactory
			9. Duration of total sex-play is	Alternative answer: satisfactory, rather satisfactory, rather unsatisfactory, unsatisfactory
			10. Frequency of intercourse?	
			11. Duration of foreplay?	
			12. Duration of total sex-play?	
Sjogren et al., 1983	Structured interview	Explore further aspects of sexual function, responsiveness, and fulfilment in the same stroke victims and to relate the findings to prevalence of performance orientated attitudes and to sexually stigmatic tendencies	A. Function	
			1. General caressing (touching, hugging)	were also asked about degree of liking and degree of satisfaction with frequency
			2. Deep kissing	
			3. P caresses S's breast	
			4. S caresses P's breast	
			5. Manual caressing of S's genital by P	
			6. Oral caressing of S's genital by P	
			7. Manual caressing of P'S genitals by S	
			8. Oral caressing of P'S genitals by S	
			9. Orgasmic spectatoring	
			10 Erectile spectatoring (male only)	

			11. Ejaculatory problems (males only)	
			B. Fulfilment	
			1. Sex life, in general	If reduction of pleasure, they were asked reasons. They were also asked if they had been given opportunity for or has themselves sought sexual concealing after stroke
			2. Foreplay, duration	
			3. Sex-play, duration	
			4. Intercourse, frequency	
			5. Intercourse, as such	
			C. Responsiveness	
			1. Mutual verbal communication on sexuality	
			2. S's reaction to P's sexual initiatives	
			3. P's reaction to S's sexual initiatives	
			4. P's emotional involvement during sex activities	
			5. P's shown interest in mutual sexuality	
			Sexual stigmatism:	
			Disabled males can never fully satisfy their partner sexually	
			Disabled females can never fully satisfy their partner sexually	
			Males who are interested in disabled females are insecure of their masculinity	
			Females who marry disabled males want to avoid competition for spouse	
			Female who are attracted to disabled males want to dominate their partners sexually	
			Disabled individuals are less interested in sex than are the ablebodied	
			Individuals who are physically incapable of intercourse have little or no thought of sex	
			The healthiest way for the disabled t deal with diminished sexual capacity is to choose other goals	

			A disabled individual's partner should not initiate sex	
			Performance orientation:	
			Greater number of coital techniques guaranteed better sexual life	
			Orgasm cannot be achieved from non-genital areas	
			Erection is necessary for male sexual satisfaction	
			Orgasm is always the goal of sexuality	
			Partners' simultaneous orgasm are important	
Sjogren, 1983	Structured interview	Study changes in several parameters of sexual behaviour and to probe whether the pituitary-gonadal axis malfunction in male hemiplegics	Duration of foreplay	
		Analyse effects of antihypertensive medication on erection of male hemiplegics	Duration of sex-play	
			Frequency of intercourse	
			Frequency of erectile difficulties (males)	
			Frequency of orgasm	
			Shown interest in mutual sexuality	
			Thought of mutual sexuality	
Fugl-Meyer and Jaasko, 1980	Structured interview	Analyse whether the frequency of coitus is changed in subjects who have suffered stroke with resulting hemi motor deficit	Whether the stroke had led to a permanent change in frequency of sexual intercourse	If so, the change could be rated as decrease or cessation (no subject ad an increase)
			Disturbed partnership communication (rated by the examiner after observation, not ask to the subject)	2 = no disturbance, 1 = some evidence of custodial attitudes 0 = marked interpersonal disturbance
Coslett et al. , 1986	Structured interview	Study the impact of right hemisphere stroke on sexual function	Rate their interest in or desire for sexual activity before and after the stroke	0 = no interest, 4 = maximal interest or desire
			Estimate frequency of intercourse before and after the stroke	Same, Increase, Decrease
Buzzelli et al., 1997	Structured interview	1. Quantify the sexual change by comparison between data collected after one month and after one year	1. Number of sexual intercourses per week	

		after stroke, both from the patients and their partners		
		2. investigate the relationship among sexual behavior, age, education, years of marriage, depression and disability	2. The time at which sexual life started again	
			3. Changes in sexual desire	
			4. Changes in sexual positions	
			5. Satisfaction	
			6. Frustration in the case of sexual decline	
			7. Drugs taken by the patient	
			8. The importance given to a normal sexual life	
Bugnicourt, 2014	Structured interview	Assess the prevalence of impaired sexual activity (ISA) after stroke in young patients	"Since your stroke, have you suffered from sexual impairment (a decline in libido, erectile dysfunction or poor ejaculation) or a lack of sexual satisfactions?" and the participant was invited to comment further on his/her sexual disorder	
		Determine factors associated with the development of ISA in this population		
Bray et al., 1981	Structured interview	Present the impacts of stroke in sexual functioning	*Pre- and postroke levels of sexual desire and function:*	
			Men:	
			Sexual desire present	
			Erection	
			Ejaculation	
			Women:	
			Sexual desire present	
			Menstruation	
			Orgasm	
			Men and women:	
			Importance of sexual functioning	very, Limited, None
Allsup-Jackson, 1981	Structured interview	Impact of stroke in sexual dysfunction	a. Biographical	
			b. Medical history:	

			c. Pre and post personality characteristics	
			d. Social activities	
			e. Sexual functioning:	
			Frequency of sexual contact	
			Frequency of coitus	
			Erection	
			Ejaculation	
Yilmaz et al., 2015	Semi-structured interview	Define the thoughts, emotions, experiences, and perceptions of women in sexual life after stroke	1. Physical, emotional, and spiritual changes experienced after stroke	
		Determine how women are affected physically and emotionally by stroke	Physical changes and psychological exposure	
			Anxiety and fear	
			Failure in adjustment to poststroke period and sadness	
			Spiritual changes	
			2. Negative effects of changes after stroke on women as housewives and mothers ‘failures in household chores	
			3. Changes of sexual life in poststroke period	
			4. Support from healthcare providers in coping with emotional and sexual challenges	
Thomas, 2016	Semi-structured interview	Describe a case to demonstrate barriers to sexual activity after a stroke and how occupational therapy and the interprofessional team address limitations in engagement in sexual activities	Identify their perspectives on the difficulties they have been experiencing	
Schmitz and Finkelstein, 2010	Semi-structured interview	Examine the perspectives and experiences of stroke survivors and partner regarding sexual issues and perceived rehabilitation needs	"I am interested in your experience of adjusting to stroke. Tell me a bit about your stroke and what you remember about the days and weeks following it. "	
			"Would you describe for me how having a stroke has affected your life?"	

			"From you experience, how would you say your stroke has affected your relationships with your partner (spouse) and family?"	
			"What kinds of questions do you think that many stroke survivors and their partners might have about sex after stroke?"	
			"Would you describe for me the types of information or guidance, if any, you have received after your stroke from health care professionals that dealt with relationship or sexual concerns?"	
			"What kind of information do you feel was (or would have been) most helpful to you? Follow-up: Unhelpful? Please explain."	
			"From your experience, describe any barriers or road blocks that prevented you from getting information or help when you needed it."	
			"Thinking back to you process of adjusting to your stroke, at what point in time do you feel information was (or would have been) most helpful? Follow-up: Least helpful time? Please explain."	
			"Among those health care professionals you have worked with after your stroke, could you tell me who would have been most comfortable talking to about sexual concerns and why?"	
			"Would you describe for me what kinds of things would make it easier for you to talk about sexual concerns with your health care provider?"	
Nilsson and al., 2017	Semi-structured interview	Explore experiences of sexuality 6 years after stroke, including communication with health care professionals concerning sexuality	"Can you tell me about your sexual life at present?"	
			"Have you experienced any changes in your sexual life since your stroke and, if so, what changes?"	

			"If you have experienced any changes in sexuality, and if so, how have you handled these?"	
			"Could you describe what kind of information, guidance, or interventions you have received from health care professionals concerning sexuality after stroke?"	
			"What would your preferences, if any, be concerning information, guidance, or interventions on sexuality?"	
Mitchel-Pedersen, 1994	Semi-structured interview	"spotlighting the reality" of a couple's sexual relationship following one partner's stoke	**Individual interview: Survivor**	
			Health history:	
			1. “Thinking back over the past seven days how many drinks of alcohol did you have each day? Let's start with yesterday”	
			2. “Do you smoke?”	yes, no
			3. “How many packs a day do you smoke?”	
			4. “How long have you smoked?”	
			Sexual functioning status:	
			5. Preamble: “Many people following a stroke have questions or concerns about their sexual well-being”. I'm wondering if you have any.”	
			Sexual response:	
			*Present a graph of sexual mountain	
			6. “Does that picture accurately describe your sexual feelings now?”	yes, no
			7. “If, "No", draw what your picture is now”	
			8. “Now draw what it was like 6 months or so before the stroke”	
			If female, ask:	
			9. “With respect to specific changes in your body's sexual response since the	

			stroke occurred, would you comment about:	
			a. Sexual feeling widespread throughout your body?	less, same, more
			b. Number of areas where you feel sexual sensation	less, same, more
			c. Length of time it takes for you to feel aroused	less, same, more
			d. length of time for your vagina to become moist	less, same, more
			e. amount of moisture apparent in your vagina”	less, same, more
			10. “Do you notice any changes in the "release of tension" moment (use word used by client in describing sexual "mountain")? If "Yes", describe”	yes, no
			11. “Do you notice any changes in how long it takes for the sexual feelings to go away after the "release of tension" moment? If, "Yes", describe”	yes, no
			12. “Has intercourse been, at any time in the past, painful for you? If, "Yes", when?”	yes, no
			13. “Is it painful at the present time?”	yes, no
			14. “If, "Yes", how would you describe the pain?”	
			If male:	
			Preamble: ‘Many men experience swelling of the penis, or erection, in many different situations. I'm wondering if you would describe your own response in these various situations, using the following scale.”	Place a line on a 0 to 10 scale: 0 = absolutely no selling of the penis (an absolutely flaccid penis), 10 = fully swollen, totally erect penis. For further clarification, suggest that 5 = a penis that bends readily to the touch while 7 or 8 = would not be easily bent
			15. “On waking in the morning” (before and after stroke)	
			16. “During sleep” (before and after stroke)	
			17. ‘With partner in ordinary lovemaking” (before and after stroke)	

			18. ‘Reading erotic literature or seeing erotic films” (before and after stroke)	
			19. “Away on holiday” (before and after stroke)	
			20. “Self-stimulation” (before and after stroke)	
			21. “Other” (before and after stroke)	
			22. “With respect to specific changes in your body's sexual response since the stroke occurred, would you comment about:	
			a. Sexual feeling widespread throughout your body?	less, same, more
			b. Number of areas where you feel sexual sensation	less, same, more
			c. Length of time it takes for you to feel aroused	less, same, more
			d. length of time it takes for you to have an erection”	less, same, more
			23. “Do you notice any changes in the "release of tension" moment (use word used by client in describing sexual "mountain")? If "Yes", describe”	yes, no
			24. “Do you notice any changes in how long it takes for the sexual feelings to go away after the "release of tension" moment? If, "Yes", describe”	yes, no
			25. “Have you notices any change, which you would attribute primarily to the stroke, in the force of the fluid coming out? If, "Yes", describe”	yes, no
			26. “Is the amount of fluid coming out about the same as before the stroke? If, "Yes", describe”	yes, no
			27. “Have you noticed any changes in your feelings as the fluid comes out? If, "Yes", describe”	yes, no
			Male and female survivors:	
			Sexual activities:	

			28. “What did your sexual activity routinely include 6 months before the stroke ?”	
			29. “What does your sexual activity routinely include now?”	
			30. “Would you say there has been a change in frequency of any of these activities since the stroke? If, "Yes", describe”	yes, no
			Sexual behaviour:	
			31. Preamble: “many people feel that during a difficult time they shouldn't let their partner know when they want to be sexual. Has this been a concern for you? If, "Yes", describe”	yes, no
			32. “Many people are afraid that having intercourse will bring on another stroke. I'm wondering if this is one of your concerns. If, "Yes", describe”	yes, no
			Sexual interest:	
			33. “Do you want sexual activity as frequently as you did before the stroke? Describe”	More, about the same, less
			Bowel and bladder hygiene:	
			34. “Many people have some difficulty after a stroke in managing their bladder and bowels. I'm wondering how this as been for you. If, "Yes", describe”	yes, no
			Sexual self-view:	
			35. “How do you think your partner sees you ?”	More attractive, about the same, less attractive
			36. “Do you have other concerns about your sexual relationship? If, "Yes", describe”	yes, no
			37. “At any time throughout you experience with this stoke, did you, at any time, ask question about your sexual concerns of any health professional?”	

			38. “If, "Yes", whom did you ask?”	
			39. “If, "Yes", was that person able to be of help?”	
			40. “If, "No", can you say why you felt unable to ask?”	
			41. “Since the stroke, have you ever been asked by a health professional about the possibility of your having sexual concerns?”	
			42. “If, "Yes", by whom?”	
			43. “If, "No", would you have liked someone to ask?”	
			44. “If, "Yes", with whom would you have felt comfortable to discuss this?”	doctor, nurse, therapist, social worker, pastoral care worker, other
			45. “How long, after the stroke, would this have been acceptable to you?”	
			Individual interview: Partner	
			Health history:	
			1. Alcohol	
			2. “Do you smoke?”	
			3. “How many packs a day do you smoke ?”	
			4. “How long have you smoked?”	
			Sexual functioning status:	
			5. Preamble: “Many people whose partners have had a stroke have questions or concerns about their sexual well-being. I'm wondering if you have any.”	
			Sexual response:	
			*Present a graph of sexual mountain	
			6. “Does that picture accurately describe your sexual feelings now?”	yes, no
			7. “If, "No", draw what your picture is now”	
			8. “Now draw what it was like 6 months or so before the stroke”	

			If female, ask:	
			9. “With respect to specific changes in your body's sexual response since your partner stroke occurred, would you comment about:	
			a. Sexual feeling widespread throughout your body?	less, same, more
			b. Number of areas where you feel sexual sensation	less, same, more
			c. Length of time it takes for you to feel aroused	less, same, more
			d. length of time for your vagina to become moist	less, same, more
			e. amount of moisture apparent in your vagina”	less, same, more
			10. “Do you have any pain during intercourse?”	Yes, no
			11. “If, "Yes", describe”	
			12. “Do you notice any changes in the "release of tension" moment (use word used by client in describing sexual "mountain")? If "Yes", describe”	yes, no
			13. “Do you notice any changes in how long it takes for the sexual feelings to go away after the "release of tension" moment? If, "Yes", describe”	yes, no
			If male:	
			Preamble: “Many men experience swelling of the penis, or erection, in many different situations. I'm wondering if you would describe your own response in these various situations, using the following scale.”	Place a line on a 0 to 10 scale: 0 = absolutely no selling of the penis (an absolutely flaccid penis), 10 = fully swollen, totally erect penis. For further clarification, suggest that 5 = a penis that bends readily to the touch while 7 or 8 = would not be easily bent
			14. “On waking in the morning” (before and after partner's stroke)	
			15. “During sleep” (before and after partner's stroke)	

			16. “With partner in ordinary lovemaking” (before and after partner's stroke)	
			17. “Reading erotic literature or seeing erotic films” (before and after partner's stroke)	
			18. “Away on holiday” (before and after partner's stroke)	
			19. “Self-stimulation” (before and after partner's stroke)	
			20. “Other” (before and after partner's stroke)	
			21. “With respect to specific changes in your body's sexual response since your partner's stroke occurred, would you comment about:	less, same, more
			a. Sexual feeling widespread throughout your body?	less, same, more
			b. Number of areas where you feel sexual sensation	less, same, more
			c. Length of time it takes for you to feel aroused	less, same, more
			d. length of time it takes for you to have an erection”	less, same, more
			22. “Do you notice any changes in the "release of tension" moment (use word used by client in describing sexual "mountain")? If "Yes", describe”	yes, no
			23. “Do you notice any changes in how long it takes for the sexual feelings to go away after the "release of tension" moment? If, "Yes", describe”	yes, no
			Male and female partners:	
			Sexual activities:	
			24. “What would you say was part of your sexual activity 6 months before the stroke ?”	
			25. “What would you say is part of your sexual activity now?”	

			26. “Would you say there has been a change in frequency of any of these activities since the stroke? If, "Yes", describe”	
			Sexual behaviour:	
			27. Preamble: “Many people feel that during a difficult time they shouldn't let their partner know when they want to be sexual. Has this been a concern for you? If, "Yes", describe”	
			28. “Many people are afraid that having intercourse will bring on another stroke. I'm wondering if this is one of your concerns. If, "Yes", describe”	
			Sexual interest:	
			29. “Many people whose partners have had a stroke, no longer feel the same sexually towards that partner. I'm wondering how this is for you.”	less attracted, about the same, more attracted
			30. “Many people whose partners have had a stroke describe a personality change in their partner. Have you notice any changes in your partner? If, "Yes", describe”	yes, no
			31. “Many people after a stroke experience some changes in how much sexual activity they want. I'm wondering how this is for you.”	
			32. “Do you want sexual activity as frequently as you did before the stroke? Describe”	More, about the same, less
			Bowel and bladder hygiene:	
			34. “Many people have some difficulty after a stroke in worrying about their partner's bladder and bowel problems/related to sexual activity. I'm wondering how this as been for you. If, "Yes", describe”	yes, no
			Sexual self-view:	

			34. “I'm wondering how you think your partner sees you”	More attractive, about the same, less attractive
			35. “Do you have other concerns about your sexual relationship? If, "Yes", describe”	yes, no
			36. “At any time throughout you experience with this stoke, did you, at any time, ask question about your sexual concerns of any health professional ?”	doctor, nurse, therapist, social worker, pastoral care worker, other
			37. “If, "Yes", whom did you ask?”	
			38. “If, "Yes", was that person able to be of help?”	
			39. “If, "No", can you say why you felt unable to ask?”	
			40. “Since the stroke, have you ever been asked by a health professional about the possibility of your having sexual concerns?”	
			41. “If, "Yes", by whom?”	
			42. “If, "No", would you have liked someone to ask?”	
			43. “If, "Yes", with whom would you have felt comfortable to discuss this?”	
			44. “How long, after the stroke, would this have been acceptable to you?”	
Millenbruch, 2009	Semi-structured interview	1. Describe how survivors defined and managed their sexuality after stroke	*General questions*	
		2. Describe how sexuality informed QOL from survivors' perspectives	1. “Tell me about what happened when you had your stroke?”	
		3. Describe relationships between sexual self-schema and QOL	PROBE: Do you have any thoughts about what may have caused your stroke?	
		4. Develop a multidimensional typology of sexuality in relation to QOL after stroke	PROBE: How old were you when you had your stroke?	
			PROBE: Did you have any other health problems/conditions before you had your stroke? Did these affect your sexuality ?	

			PROBE: Before your stroke, did you take any medication that affected your sexuality?	
			PROBE: Have you ever found that alcohol or nonprescribed drugs affected your sexuality prior to the stroke?	
			2. “Since your stroke, have you developed any other health problems?”	
			PROBE: Do you feel any of these conditions affect your sexuality?	
			PROBE: Other than the physical problems we've already talked about as a result of your stroke, has the stroke changed the way your body work in other ways?	
			PROBE: Can you describe?	
			PROBE: Have these changes made a difference in your sexuality? Tell me about that?	
			PROBE: Do any of the medications that you are now taking affect your sexuality?	
			PROBE: What medication are you currently prescribed? What meds are you taking?	
			PROBE: Have you found that alcohol or nonprescribed drugs affect your sexuality?	
			3. “Tell me about your life before you had your stroke”	
			PROBE: talk about your work, family, friends, leisure activities, etc.	
			PROBE: Telle me about the quality of life before the stroke	
			PROBE: What ere the good things about your life?	
			PROBE: Were there things about your life that were not so good?	

			PROBE: In general, how satisfied were you with the quality of your life before the stroke?	
			4. “Tell me about your life now”	
			PROBE: For example, can you talk about your work, family, friends, leisure activities, etc.?	
			PROBE: Tell me about the quality of your life now	
			PROBE: What are the good things about your life?	
			PROBE: Are there difficulties?	
			PROBE: In general, how satisfied were you with the quality of your life now?	
			Sexuality before and after the stroke	
			1. “If you had to choose a word to describe your sexuality before the stroke, what might that word have been?”	
			PROBE: Can you explain?	
			2. “If you had to choose a word to describe your sexuality after the stroke, what might that would be ?”	
			PROBE: Can you explain?	
			3. “So, before your stroke, you would have used the word _____ to describe your sexuality. Some people might use other word. For example, they might use words like "spiritual" or "emotional" to describe how they think about their sexuality. Do you have any thoughts or feeling about other words that you might have used to describe your sexuality before the stroke ?”	
			PROBE: What about now, after the stroke?	
			4. “Before the stroke, were there things about yourself that were important to how you thought about your sexuality?”	

			(you body, personality, work or accomplishments, appearance, relationships, activities)	
			5. “What about now, since the stroke? Are there things about yourself that are important to how you think about your sexuality?” (you body, personality, work or accomplishments, appearance, relationships, activities)	
			6. “Before the stroke, did you make a conscious effort to maintain, enhance, or express your sexuality?”	
			PROBE: How did you do that?	
			7. “What about now, after the stroke? Do you make a conscious effort to maintain, enhance, or express your sexuality?”	
			PROBE: Can you explain?	
			8. “Were you sexually active before the stroke?”	
			9. “Whether or not you were sexually active, were you satisfied with the role sexuality played in your life ?”	
			10. “Are you sexually active now ?”	
			11. “Are you satisfied with the role that sexuality plays in your life now?”	
			12. “Were you in a committed relationship before the stroke?”	
			PROBE: Did sexuality play a part in that relationship?	
			PROBE: Do you think your partner was satisfied with the role sexuality played in this relationship?	
			13. “Are you in a committed relationship now?”	
			PROBE: Does sexuality play a part in that relationship?	
			PROBE: Do you think your partner is satisfied with the role sexuality plays in your relationship today?	

			14. “Sometimes our thought about sexuality may be influenced by how others look at us or relate to us”	
			PROBE: How do you think others might have thought about you or described you in terms of your sexuality before the stroke?	
			PROBE: how do you think others think about you or describe you now in terms of your sexuality?	
			PROBE: In general, how do you think people who have had strokes are viewed by the general public?	
			PROBE: As sexual persons?	
			15. “Have your thoughts about yourself as a man or a woman changed since the stroke?”	
			PROBE: if yes, can you describe how?	
			PROBE: If no, can you explain?	
			16. “Has the stroke changed your ability to communicate with people?”	
			PROBE: If so, have these changes made a difference in your sexuality? Tell me about that	
			17. (Ask only if no partner) “Some people think that they are sexual only if they have a sexual partner and are sexually active. I know you said that you don't have a sexual partner now. What do you think about this?”	
			18. “Have there been any other changes in your body or your abilities or in any other area that we haven't talked about and that are important to your sexuality?”	
			19. “Many people think that being sexual is part of having a god life. Other people disagree. What do you think?“	

			PROBE: Has that changed since you had your stroke?	
			20. “Some people say that health care providers aren't very good at talking with stroke survivors about sexuality. What's been your experience?”	
			PROBE: Did you ask any health car provider for information about sexuality? What happened?	
			PROBE: Did any health care provider volunteer information about sexuality? What was that like?	
			PROBE: Can you think of any time when health care providers may have said something to you about sexuality after the stroke? What happened?	
			21. “Have any health care providers talked with you about quality of life?”	
			PROBE: Can you give any examples/ or explain?	
			22. “Being in this study gives you the opportunity to speak directly to health care providers about sexuality. What advice would you give to doctors, nurses, or other providers about talking with stroke survivors about their sexuality?”	
			PROBE: What advice would you give talking with stroke survivors about their quality of life?	
			23. “If you were going to talk with a health care provider about your sexuality, who would you be most comfortable with (doctor, nurse, psychologist, social worker, physical therapist, occupational therapist)?”	
			PROBE: Would you feel more comfortable talking about your sexuality with someone who is not a health care provider, e.g., a pastor or a priest? Other?	

			PROBE: Do you think it matters to men/women whether the person they talk with about sexuality is a man or a woman? Gay or straight? What about your preference? What do you think?	
			24. When health care providers talk to stroke survivors about sexuality, they usually talk to the patient alone. Which do you think is better? To talk to the patient alone, to talk to the spouse/partner alone, to talk to both together, or some other combination?	
			PROBE: Can you explain?	
			25. “What about support groups for couples after stroke? Do you think they would help with sexuality and/or quality of life concerns, issues or problems after stroke?”	
			PROBE: Do you think they would be helpful for you?	
			26. “When do you think is the most appropriate time to bring up the topic of sexuality to someone who has had a stroke?”	
			PROBE: Who should introduce the topic of sexuality, you as a stroke survivor or the health care provider?	
			PROBE: Do you think the topic of sexuality should be brought up while you are in the hospital, outpatient clinic, during follow-up doctor visits, or at another time? Can you explain?	
			27. “Do you have any other thought about how nurses and health care providers can help survivors with their sexuality after a stroke?”	
			28. “Being in this study also give you the opportunity to speak directly to stroke survivors about sexuality. If you were to	

			give advice to them about sexuality after stroke, what might taht advice be?”	
			PROBE: What advice would you give about quality of life after stroke?	
			Questions about sexuality and quality of life broadly and about the interview	
			1. “Suppose I were to come and talk with you again in five years about your sexuality. How do you think you would answer these questions then?”	
			PROBE: Suppose I ask you about your quality of life five years from now? What do you think it will be like?	
			2. “Please tell me what it was like for you to do the interview today?”	
			PROBE: Can you think of anything I could do differently in these interviews to make it better or is there anything I forget to ask you about?	
			3. “Before I turn the tape recorder off, is there anything else that you want to include in the interview? “	
McCarthy and Bauer, 2015	Semi-structured interview	How do age and relationship duration affect couples' experiences with stroke?	“Is there anything you would like to add about how the stroke has disrupted your life?”	
			“What about your spouse's life?”	
			“What about your life as a couple?”	
			What about your spouse's life ?	
			What about your life as a couple ?	
Lever and Pryor, 2017	Semi-structured interview	Explore the impact of stroke on female sexuality from the perspective of women who have had a stroke	Being a female	
			Intimacy	
			Relationships	
Lemieux and al., 2001	Semi-structured interview	Investigate how stroke changed sexuality for people with aphasia and their spouses	*Joint questions for the couple:*	
		Investigate their needs regarding sexual dysfunction and whether they	1. "What are your sleeping arrangements?"	

		wanted access to services to address these needs		
			2. "Is there a caregiver in your home at night? Do they interfere with your privacy?"	
			3. "What were the frequencies of sexual activity before the stroke?"	
			4. "Have you resumed any sexual activity since the stroke?"	
			5. "What has happened?"	
			6. "What are the frequencies of sexual activity since the stroke?"	
			7. "Do you think that the spouse who had a stroke might have another stroke, hearth attack, or die during sex?"	
			8. "Has anyone asked you wheter your sexuality has changed because of the stroke? If so, who?"	
			9. "Would you have liked someone to talk about sex after stroke?"	
			10. "What would you like to know about sex after stroke?"	
			11. "Who would you like to talk to about sex after stroke?"	
			13. "Have you ever discussed sex openly before?"	
			Content covered in the aphasic spouse interview and in the Non-aphasic spouse questionnaire:	
			1. Importance of sex pre and post stroke	
			2. Importance of sex compared to other activities pre and post stroke	
			3. Desire for sex pre and post stroke for both males and females	
			4. Satisfaction with sexual activity pre and post stroke	
			5. Estimate of change in spouse's desire for sex post stroke	

			6. For males: ability to have erections pre and post stroke	
			7. For males: ability to ejaculate pre and post stroke	
			8. For females: pain on sexual intercourse (re: lubrification) pre and post stroke	
			9. For females: orgasm ability pre and post stroke	
			10. Experience of emotional ability and its effect on sexual activity	
			11. The effect of aphasia in sexual activity	
			12. Impact of caregiving on sexual relationship	
Kattari, 2014	Semi-structured interview	Examine the experiences of adults with physical disabilities regarding negotiations with their current, former and potential sexual partners about sexual activities	Disability(ies)	
			Level of confidence around sexuality	
			Experiences discussing their disability(ies) with their sexual partners	
			How they feel their level of sexual satisfaction might be associated with these conversations	
Hawton, 1984	Semi-structured interview	Determine the effects that strokes in men may have on their sexual interest and response, and on their sexual relationships, and to elucidate the factors which predict whether or not a man is likely to resume sexual activity following a stroke	Whether the interest in sex had return	
			Regained ability to obtain an erection	
			If sexual intercourse had resumed (for men who had an active sexual relationship before their strokes)	
			Difficulties in sexual response or sexual activity	
			Whether new positions for sexual intercourse had been tried to combat any physical effects of the stroke and whether these had been found helpful	
			Whether the man and his partner had discussed the effects of the stroke on their sexual relationship	
			Medication	

			Significant symptoms of depression or anxiety	
Goddess and al., 1979	Semi-structured interview	Poststroke sexual activity of CVA patient	Changes in sexuality	
			Libido	
Beal et Millenbruch, 2015	Semi-structured interview	Explore perceptions of poststroke sexuality in a woman of childbearing age	Participants' stories of the stroke	
			Perceptions of pre- and poststroke sexuality	
			Perceptions of pre- and poststroke quality of life	
			Treatment and realization (admission to hospital, inpatient stay, coming home, coping with change)	
			Adjustment	
McCormick et al., 1986	Semi-structured interview I	Report results of discussions about poststroke sexuality with stroke patients or with their sexual partners	Patient health education	
			Performance fears	
			Sexual conditioning (role)	
			Acceptance of change	
			Coital positioning	
McCarthy et al., 2020	Semi-structured interview	Enhance our understanding about interpersonal relationship challenges in this population and identify lessons for practice in social work and related helping professions	Typical day of giving or receiving care	
			General relationship functioning	
			Factors that challenged or strengthened interviewees' relationship	
			Advice for maintaining a healthy relationship during stroke recovery	
Pryor et Lever, 2020	Semi-structured interview	Provide insights into the nature of female sexuality from the perspective of one group of women following a stroke	Stories of having a stroke	
			Personal experiences of being female	
			Intimacy	
			Relationships	

Annexe 3 – Matrices of change objectives, methods and strategies for environmental performance objectives

Performance objectives **Determinants**	**1. Clinicians will have access to continuing professional development regarding post-stroke sexual rehabilitation**	**2. Clinicians will have access to clinical tools and resources related to post-stroke sexual rehabilitation (screening, assessment, intervention, referrals)**	**3. Clinicians will have access to a working environment suitable to address sexuality**	**4. Clinicians will have access to human resources complementary to their discipline**	**5. Clinicians will have access to support from their managers and organization to integrate sexuality into their practice**	**Methods* Theory and technique tool (Johnston et al., 2020)** **Taxonomy of behaviour change intervention (Kok et al., 2016)**	**Strategies**
Environmental context and resources	1.1.1 Clinicians will have access to professional development opportunities regarding sexual rehabilitation	2.1.1 Sexuality will be included in assessment and intervention canvas that are routinely used by clinicians. 2.1.2 Screening tools for need of sexual rehabilitation will be accessible in	3.1.1 Clinicians will have access to a room that respects' confidentiality and that is suitable for provision of sexual rehabilitation services. 3.1.2 The environment	4.1.1 Organizations and managers will hire human resources in sufficient number to answer the clients' (and clinicians') needs.	5.1.1 Human and financial resources will be sufficiently available to answer clients' rehabilitation needs.	Social support Prompts/cues Remove aversive stimulus Restructuring the physical environment Restructuring the social environment Avoidance/reducing exposure to cues for the behaviour Adding objects to the environment	Development and diffusion of a training Community of practice during the implementation of the program Modification of existing tools in the organization to include sexuality

		clinicians' work environment. 2.1.3 Assessment tools regarding sexuality will be accessible in clinicians' work environment. 2.1.4 Intervention tools regarding sexual rehabilitation will be accessible in clinicians' work environment. 2.1.5 Referral tools will be accessible in clinicians' work environment.	should be easily accessible and close to the clinicians' usual working environment.			Systems change Participatory problem solving Advocacy and lobbying Modeling Technical assistance	Constitution of an interdisciplinary committee, including managers, to restructure the physical and social environment Provision of a repository of sexual rehabilitation assessment tools Provision of a repository of sexual rehabilitation intervention tools Sensitizing managers on the importance of having sufficient human resources to address sexuality Advocacy and lobbying with managers and directors to receive sufficient funding
Social influences				4.2.1 Clinicians will be able to call on other professionals within their organization to offer	5.2.1 Clinicians will feel encouraged to address sexuality in their practice	Social support (unspecified) Social support (practical) Social comparison Information about others' approval	Appoint sexuality champions in disciplinary teams Hiring enough clinicians in the

				interdisciplinary sexual rehabilitation when needed. 4.2.2 Clinicians will have access to clinicians outside the organization that their clients can have access to (physically and/or financially), for referrals.	by their managers.	Social reward	rehabilitation program Hiring or maintaining specialized resources in sexuality Collaboration with specialized clinicians outside the organization Procedure of mentoring for clinicians Procedure for referrals for specialized sexuality services Verbal persuasion and reinforcement by managers Organizational objectives for implementation of sexual rehabilitation Routine audits of clinicians' performance
						Enhancing network linkages Developing new social network Linkages Use of lay health workers; peer education	

*Domains are founded on the Theoretical Domains Framework (Cane et al., 2012) and were targeted according to the influencing factors outlined in Auger and collaborators's (2023) study.

**the program's performance objectives were elaborated with the advisory group.

Annexe 4 – Matrices of change objectives, methods and strategies for behavioural performance objectives

Performance objectives Determinants	6. At least one clinician will carry out a screening of the needs for sexual rehabilitation services with each client	7. Clinicians will offer minimal services to each of their clients when needed;	8. Clinicians will assess the sexual rehabilitation needs of the clientele when needed;	9. With clients who need it, clinicians will develop and apply a disciplinary and/or interdisciplinary intervention plan that meets the clients' own objectives;	10. Clinicians will refer their clients to the right resource when they deem their intervention complete (or having reached their personal/professional limit)	Methods* Theory and technique tool (Johnston et al., 2020) Taxonomy of behaviour change intervention (Kok et al., 2016)	Strategies
Knowledge	6.1.1 Clinicians will know at least one method to detect the needs of sexual rehabilitation services. 6.1.2 Clinicians will know how to use a method to detect the needs of sexual rehabilitation services. 6.1.3 For each client, clinicians will know who has addressed, or who will address, sexuality among the	7.1.1 Clinicians will know what the potential consequences of stroke on sexuality are. 7.1.2 Clinicians will know what are the minimum services to offer to their clients. 7.1.3 Clinicians	8.1.1 Clinicians will know at least one method to assess the needs of their clients. 8.1.2 Clinicians will know how and when to use the assessment method and tools they have access to.	9.1.1 Clinicians will know how to contextualize the intervention methods they already use to sexual rehabilitation.	10.1.1 Clinicians will know the referral procedure for their client to have access to the designated other clinician.	Instruction on how to perform behaviour Information about health consequences Information about social and environmental consequences Chunking Discussion Elaboration Providing cues	Presentation of certain methods for detecting, assessing and intervening regarding sexuality post-stroke Explanation and demonstration of use of certain tools Checklist of services founded on Canadian stroke rehabilitation guidelines Discussion and elaboration with

	interdisciplinary team (when applicable).	will know how and when to offer these services.					clinicians about how they would realize a sexual rehabilitation screening, assessment or intervention Provision of educative resources on sexuality post-stroke Problem-solving of case studies
Skills	6.2.1 Clinicians will be able to detect the needs of sexual rehabilitation services.	7.2.1 Clinicians will be able to offer the minimum services. 7.2.2 Clinicians will be able to conclude if their clients need more than the minimum services.	8.2.1 Clinicians will be able to assess the sexual rehabilitation needs of their clients.	9.2.1 Clinicians will be able to use sexual rehabilitation intervention methods.		Instruction on how to perform behaviour Behavioural practice/rehearsal Graded tasks Set graded tasks Guided practice Self-monitoring of behavior Planning coping responses Facilitation Feedback Reinforcement	Explanation and demonstration of targeted clinical activities Discussion regarding pros and cons of performances Dyadic role play for clinical activities occurring between a clinician and a client Case histories graded in terms of complexity and clinical activities to be performed and representative of clinical practice

							Assessment and exchange after the role play or actual practice (self-made, by the partner, and in-group) Clinical tools available in the working environment
Professional Role and Identity		7.3.1 Clinicians will offer the minimum services in respect of their own professional discipline.	8.3.1 Clinicians will know how to assess the sexual rehabilitation needs in concordance with their professional field of practice and limits.	9.3.1 Clinicians will know their disciplinary contribution to sexual rehabilitation, and the related intervention methods. 9.3.2 Clinicians will know how and when to collaborate with their colleagues regarding sexual rehabilitation	10.3.1 Clinicians will be able to identify when their personal or professional limit is reached regarding sexual rehabilitation. 10.3.2 Clinicians will know to which colleague to refer their clients to when needed.	Social comparison Credible source Social support Discussion Elaboration	Chart of professional roles Discussions between clinicians of a same discipline regarding professional role in sexual rehabilitation Explanation of the disciplinary role by clinicians with interdisciplinary colleagues and discussions Problem-solving in clinical case studies
Beliefs about Capabilities	6.4.1 Clinicians will feel capable to detect the needs of sexual rehabilitation with their clients.	7.4.1 Clinicians will feel capable to offer the minimum	8.4.1 Clinicians will feel capable to assess the sexual rehabilitation	9.4.1 Clinicians will feel capable to realize sexual rehabilitation interventions with their clients.		Problem solving Instruction on how to perform behaviour Demonstration of the behaviour	Dyadic role play for clinical activities occurring between a

		services to their clients.	needs of their clients.			Behavioural practice/rehearsal Graded tasks Verbal persuasion about capability Focus on past success Self-talk	clinician and a client Case histories graded in terms of complexity and clinical activities to be performed and representative of clinical practice Guided assessment and exchange after the role play or actual practice (self-made, by the partner, and in-group) Persuasion regarding positive aspects of performance and reflexion about aspects to improve
						Guided practice Enactive mastery experiences Verbal persuasion Reattribution training Self-monitoring of behavior Set graded tasks Planning coping responses Feedback Reinforcement	
Goals	6.5.1 Clinicians will consider that sexuality should be addressed among the topics of stroke rehabilitation.	7.5.1 Clinicians will plan to offer the minimal amount of required services in line with other contextual priorities.				Goal setting (behaviour) Goal setting (outcome) Review behaviour goal(s) Discrepancy between current behaviour and goal Review outcome goal(s)	Testimonials from post-stroke people (live or video) Information provision and discussion with clinicians regarding priorities Self-assessment regarding

						Self-reevaluation Environmental reevaluation	priorities and values regarding practice and sexuality
Memory, Attention and Decision processes	6.6.1 Clinicians will think about detecting the needs of sexual rehabilitation services with their clients.					Prompts/cues Conserving mental resources Cue altering Implementation intentions Stimulus control Planning coping responses	Cues in when to address sexuality in typical stroke rehabilitation follow-up Adding sexuality to routinely used clinical tools Discussion and elaboration regarding how to integrate sexuality in clients' rehabilitation in situations of overload.
Emotions	6.7.1 Clinicians will feel comfortable enough to detect the needs of sexual rehabilitation with their clients.	7.7.1 Clinicians will feel comfortable enough to provide general education regarding sexuality after a stroke.	8.7.1 Clinicians will feel comfortable enough to assess the sexual rehabilitation needs of their clients.	9.7.1 Clinicians will feel comfortable enough to intervene regarding the sexual rehabilitation needs of their clients.	10.7.1 Clinicians will feel comfortable to refer their clients to a specialized resource.	Reduce negative emotions Framing/reframing Anticipated regret Self-reevaluation Environmental reevaluation Shifting perspective Direct experience Elaboration Repeated exposure Cultural similarity	Testimonials from post-stroke people (live or video) and discussion regarding risks of discomfort and potential consequences Dyadic role play for clinical activities occurring between a

								clinician and a client Case histories graded in terms of complexity and clinical activities to be performed and representative of clinical practice Guided assessment and exchange after the role play (self-made, by the partner, and in-group) Persuasion regarding positive aspects of performance and reflexion about aspects to improve

Annexe 5 – Répertoire des rôles professionnels liés au sujet de la sexualité

Discipline	Rôles et contributions liés à la sexualité suggérées*	Champ d'exercice selon ordres et/ou associations du Québec
Éducation spécialisée	• Lien thérapeutique privilégié • Exploration des besoins, préoccupations et questionnements liés à la sexualité au cours d'interventions informelles • Contributions par leurs observations et impressions professionnelles aux autres évaluations disciplinaires • Favoriser l'application et la généralisation des stratégies et enseignements, incluant au niveau de la sexualité (application hors contexte de la sexualité, ex. lors d'une visite à domicile) • Contribution à l'enseignement des impacts potentiels de l'AVC sur la sexualité • Exploration avec le client d'autres stratégies complémentaires aux autres déjà formulées avec d'autres professionnels, une fois que le client en est rendu à expérimenter des activités sexuelles dans son quotidien.	Son rôle consiste à observer et à évaluer les besoins, les capacités, les habitudes de vie et les comportements de personnes en difficulté d'adaptation psychosociale. L'éducateur spécialisé peut aussi procéder au dépistage, à l'estimation, à la détection ainsi qu'à l'appréciation de troubles non diagnostiqués. Il doit aussi évaluer le risque suicidaire et la dangerosité que présente une personne en situation de crise. Il consigne les données au dossier et rédige les rapports d'évolution en employant la méthode désignée par son organisation. L'éducateur spécialisé a l'obligation de déterminer un plan d'intervention pour chaque client qui lui est confié dans le cadre d'un processus d'intervention planifié.
Ergothérapie	• Adaptation des activités sexuelles souhaitées • Adaptation des environnements pertinents pour les activités sexuelles (ex. chambre à coucher, salle de bain) • Aides techniques, attelles/orthèses, coussins/appuis, adaptation du fauteuil roulant, et jouets sexuels • Positionnement • Stratégies de gestion de l'énergie, de protection des articulations, de gestion de la douleur	L'exercice de l'ergothérapie consiste à évaluer les habiletés fonctionnelles, à déterminer et mettre en œuvre un plan de traitement et d'intervention, à développer, restaurer ou maintenir les aptitudes, à compenser les incapacités, à diminuer les situations de handicap et à adapter l'environnement dans le but de favoriser l'autonomie optimale de l'être humain en interaction avec son environnement

	- Entraînement de certaines capacités nécessaires aux activités sexuelles telles que le contrôle moteur, l'endurance, l'équilibre, mouvements du membre supérieur en visant généralisation aux activités liées à la sexualité - Rééducation sensitive, incluant de la douleur - Enseignement auprès du.des partenaire.s et des proches	
Kinésiologie	- Entraînement des capacités physiques pour favoriser la participation aux activités dont celles liées à la sexualité - Image corporelle, confiance en soi - Favoriser poids santé et diminution du syndrome métabolique (i.e. hypertension, diabète, hypercholestérolémie)?	Le kinésiologue évalue la condition physique et ses déterminants ainsi que la dynamique du mouvement d'une personne qui présente ou non des facteurs pathologiques. Il établit un plan de traitement et d'intervention par le moyen de l'activité physique puis en assure sa réalisation dans le but de maintenir ou de rétablir la santé. Ses fonctions s'étalent de la dimension fonctionnelle à la performance, et ce, selon des fondements biopsychosociaux.
Médecine de famille	- Se prononcer sur capacités physiologiques à participer à la sexualité (ex. effort maximal) - Santé sexuelle, contraception - Prescription d'évaluations de la réponse sexuelle physiologique (Ex. désir, excitation, orgasme) et de médication associée	L'exercice de la médecine consiste à évaluer et diagnostiquer toute déficience de la santé, à prévenir et traiter les maladies dans le but de maintenir la santé ou de la rétablir chez l'être humain en interaction avec son environnement
Nutrition	- Favoriser une alimentation équilibrée et suffisante pour le fonctionnement corporel général, incluant pour la sexualité?	Évaluer l'état nutritionnel d'une personne, déterminer et assurer la mise en oeuvre d'une stratégie d'intervention visant à adapter l'alimentation en fonction des besoins pour maintenir ou rétablir la santé ;
Orthophonie	- Entraînement de la communication verbale et non-verbale. Par exemple, en prenant en compte la pragmatique : entraînement dans des conversations usuelles et à partir de là on espère une généralisation vers les aptitudes relationnelles, capacité à séduire, etc.	L'exercice de l'orthophonie et de l'audiologie consiste à évaluer les fonctions de l'audition, du langage, de la voix et de la parole, déterminer un plan de traitement et d'intervention et en assurer la mise en œuvre dans le but d'améliorer ou de rétablir la communication de l'être humain en interaction avec son environnement

	- Favoriser la communication et ainsi nourrir les aspects relationnels tels que l'intimité, la complicité, la compréhension mutuelle, etc. - Favoriser – faciliter l'expression des besoins, essayer de comprendre ce que les clients désirent aborder. - Orthophonie peut soutenir le processus des interventions liées à la sexualité pour les autres intervenants. Donner les outils et les moyens pour communiquer à l'équipe clinique et aux proches - Tout simplement parler du sujet de la sexualité, ventiler. Offrir l'opportunité d'en parler au cas où les clients le désirent.	
Physiothérapie	- Positionnement assis et couché - Entraînement des déplacements, mobilité au lit et transferts - Entraînement de capacités physiques nécessaires (aussi) aux activités liées à la sexualité. À l'opposé, réduction des limitations physiques telles que des contractures, hypotonies, etc. - Attelles, orthèses, aides techniques, et leur inclusion dans les activités sexuelles. - Normalisation du tonus, de la douleur, etc. - Rééducation périnéale et pelvienne	évaluer les déficiences et les incapacités de la fonction physique reliées aux systèmes neurologique, musculosquelettique et cardiorespiratoire, déterminer un plan de traitement et réaliser les interventions dans le but d'obtenir un rendement fonctionnel optimal
Psychologie	- Psychothérapie - Possibilité de suivi ou de référence à des ressources spécialisées si abus sexuels - Sujets pouvant être abordés : image corporelle, intimité relationnelle et communication, estime de soi, deuils et acceptation de sa condition actuelle, accueillir et normaliser les émotions vécues, affirmation de soi, dynamique du couple, valeurs - Donner le *safe space* au patient pour le dévoilement, former une alliance thérapeutique, coaching sur le processus de réadaptation et interventions faites par autrui.	L'exercice de la psychologie consiste à évaluer le fonctionnement psychologique et mental ainsi qu'à déterminer, recommander et effectuer des interventions et des traitements dans le but de favoriser la santé psychologique et de rétablir la santé mentale de l'être humain en interaction avec son environnement

	• Éducation, soutien, recommandations, renforcer ce qui est fait par d'autres. • Faciliter l'expression du besoin et le clarifier • Écoute, réassurance, relation d'aide.	
Neuropsychologie	• Plusieurs neuropsychologues en réadaptation prennent également en charge les rôles et responsabilités liés à la discipline « Psychologie » • Évaluation des trouble neuropsychologiques et éducation psychologique pour permettre une meilleure compréhension de soi, des atteintes cognitives et des fonctions préservées. • Aider à départager le rôle des atteintes cérébrales, de conditions psychologiques ou médicales et de personnalité dans la présentation du client • Suggestion de stratégies pour limiter l'impact de troubles neurocognitifs sur le fonctionnement dans les activités liées à la sexualité.	l'évaluation des troubles neuropsychologiques vise à établir un lien entre l'affection clinique et une altération possible des fonctions cérébrales ou fonctions mentales supérieures, soit à conclure à la présence d'un trouble de ces fonctions et, si nécessaire, établir un lien cerveau-comportement, ce lien ne se réduisant pas à situer « géographiquement » dans le cerveau la ou les dysfonctions identifiées.
Service social	Accès privilégié aux partenaires et à la famille (i.e. proches) Donner un safe-space aux clients et aux partenaires pour partager les questionnements, inquiétudes, etc., discussion en profondeur. Encourager la communication Mettre en évidence la détresse des partenaires Accompagnement et gestion des émotions et des sentiments en lien avec les difficultés vécues Exploration des rôles des partenaires du couple et redéfinition des rôles en lien avec la condition de santé. Évaluer le besoin d'une référence du couple en thérapie conjugale Notions d'intimité, estime de soi Référer vers ressources.	L'exercice du travail social consiste à évaluer le fonctionnement social, à déterminer un plan d'intervention et en assurer la mise en œuvre ainsi qu'à soutenir et rétablir le fonctionnement social de la personne en réciprocité avec son milieu dans le but de favoriser le développement optimal de l'être humain en interaction avec son environnement;
Sexologie	• Relation d'aide • Psychothérapie (si certifié) • Évaluation des troubles sexuels (si certifié)	L'exercice de la sexologie consiste à évaluer le comportement et le développement sexuels de la personne, à déterminer,

	- Exploration des habitudes antérieures liées à la sexualité - Évaluation du développement/ajustement sexuel - Adaptation des activités sexuelles désirées	recommander et effectuer des interventions et des traitements dans le but de favoriser un meilleur équilibre sexuel chez l'être humain en interaction avec son environnement
Soins infirmiers	- Gestion des incontinences urinaire et fécale (incluant gaz) - Gestion des cathéters et autres équipements médicaux durant les activités sexuelles - Enseignement sur saines HDV, contraception et prévention ITSS - Effectuer et ajuster les traitements médicaux, selon une ordonnance. et/ou 'évaluation de la condition physique et mentale - Enseignement lié à la médication - Collaboration étroite avec MD et équipe traitante - Gestion de l'aspect «milieu de vie» de la réadaptation lorsque à l'interne. Les patients sont toujours à l'étage hormis au moment des thérapies. - Gestion des comportements appropriés et inappropriés sur l'étage (hors des autres thérapies) en collaboration avec l'équipe ou les autres thérapeutes.	L'exercice infirmier consiste à évaluer l'état de santé, à déterminer et assurer la réalisation du plan de soins et de traitements infirmiers, à prodiguer les soins et les traitements infirmiers et médicaux dans le but de maintenir et de rétablir la santé de l'être humain en interaction avec son environnement, à prévenir la maladie ainsi qu'à fournir les soins palliatifs
Médecine spécialisée		

Gynécologie	- Troubles de la fonction sexuelle
	  - Dyspareunie
	  - Vaginisme
	  - Inhibition du désir sexuel
	  - Anorgasmie
	- Infections gynécologiques
	- Agression sexuelle
	- Promouvoir saines HDV au niveau sexualité
		Le champ de pratique des obstétriciens-gynécologues inclut les soins préventifs aux femmes en santé, l'évaluation des déterminants sociaux de la santé de la femme, la prévention des maladies par la prestation de conseils sur la santé sexuelle et la contraception, et le diagnostic et le traitement chirurgical et médical avancé d'affections touchant les femmes et leur appareil reproducteur. Les obstétriciens-gynécologues font partie intégrante des services offerts aux femmes et à leurs proches pendant la grossesse et la naissance, ce qui comprend la prestation de soins directs ainsi que

		la consultation auprès d’autres professionnels de la santé en cas de grossesse compliquée ou d’affection médicale pendant leur grossesse. Compétences : Physiologie (Fonction sexuelle); Diagnostic des troubles de la fonction sexuelle
Neurologie	Évaluations neurologiques et neurophysiologiques selon le portrait clinique du patient	Les neurologues diagnostiquent et prennent en charge des maladies touchant le système nerveux. Ils recueillent des informations au moyen d’une anamnèse et d’un examen physique afin de localiser la lésion neurologique, puis ils combinent ces résultats cliniques à ceux des examens paracliniques du système nerveux, notamment des examens de neuroimagerie et des tests électrophysiologiques, afin de déterminer la cause de la maladie neurologique aiguë ou chronique. L’évaluation clinique peut comprendre le prélèvement de liquide céphalorachidien par ponction lombaire et l’interprétation des résultats de l’analyse du liquide céphalorachidien. Les neurologues assurent un suivi continu de patients atteints de maladies neurologiques, mettent en place un traitement ciblé, évaluent l’efficacité et l’innocuité du traitement et déterminent quand le traitement doit être intensifié. Comme de nombreuses affections neurologiques sont évolutives, les neurologues aident les patients à optimiser leur capacité fonctionnelle et leur qualité de vie et facilitent la transition vers des objectifs de soins palliatifs, s’il y a lieu.
Physiatrie	• Principes de prise en charge en physiatrie en présence des enjeux suivants liés à la réadaptation : Santé et dysfonction sexuelle et reproductive	Les physiatres veillent à maximiser l’autonomie fonctionnelle et la qualité de vie des patients en utilisant comme cadre la Classification internationale du

		fonctionnement, du handicap et de la santé (CIF). L’approche thérapeutique en physiatrie peut être pharmacologique, non pharmacologique ou interventionnelle. Les traitements non pharmacologiques comprennent l’information et les conseils fournis au patient, les stratégies de réadaptation pulmonaire non invasives, la prescription d’exercices, les orthèses et prothèses, l’équipement adapté et les aides à la mobilité. Les physiatres réalisent des interventions diagnostiques et thérapeutiques, comme des tests électrophysiologiques et des injections visant à soulager la douleur et la spasticité, et ils interprètent les résultats obtenus. Ils utilisent des technologies de pointe, comme la robotique, des prothèses et orthèses à microprocesseurs et la réalité virtuelle pour aider les patients à améliorer leur niveau fonctionnel.
Urologie	• Fertilité, fonction sexuelle et fonction gonadique chez l’homme • Troubles qui touchent l’andrologie, y compris le dysfonctionnement sexuel, l’infertilité masculine et l'hypogonadisme	Les urologues prennent en charge les aspects médicaux et chirurgicaux de diverses maladies et divers troubles congénitaux ou acquis touchant les reins, les glandes surrénales, les uretères, la vessie, la prostate, l’urètre et les organes génitaux externes de l’homme. Cela inclut les troubles liés à l’embryologie, au développement et à la croissance, à la différenciation sexuelle, au fonctionnement de la vessie et aux affections inflammatoires, infectieuses, néoplasiques, obstructives ou traumatiques de l’appareil génito-urinaire chez l’homme et la femme, de même que les troubles de la fonction sexuelle et de la fertilité chez l’homme. Les interventions diagnostiques réalisées par les urologues comprennent les évaluations de la fonction

		mictionnelle et de la fonction érectile, les biopsies de l'appareil génito-urinaire et l'endoscopie diagnostique des voies urinaires supérieures et inférieures. Les urologues ont recours à différentes techniques d'intervention. Ils réalisent des interventions minimalement invasives, notamment des chirurgies par laparoscopie et des endoscopies thérapeutiques des voies urinaires supérieures et inférieures, des interventions sur les organes génitaux, ainsi que des interventions par voie ouverte dans l'abdomen, le rétropéritoine et la cavité pelvienne.

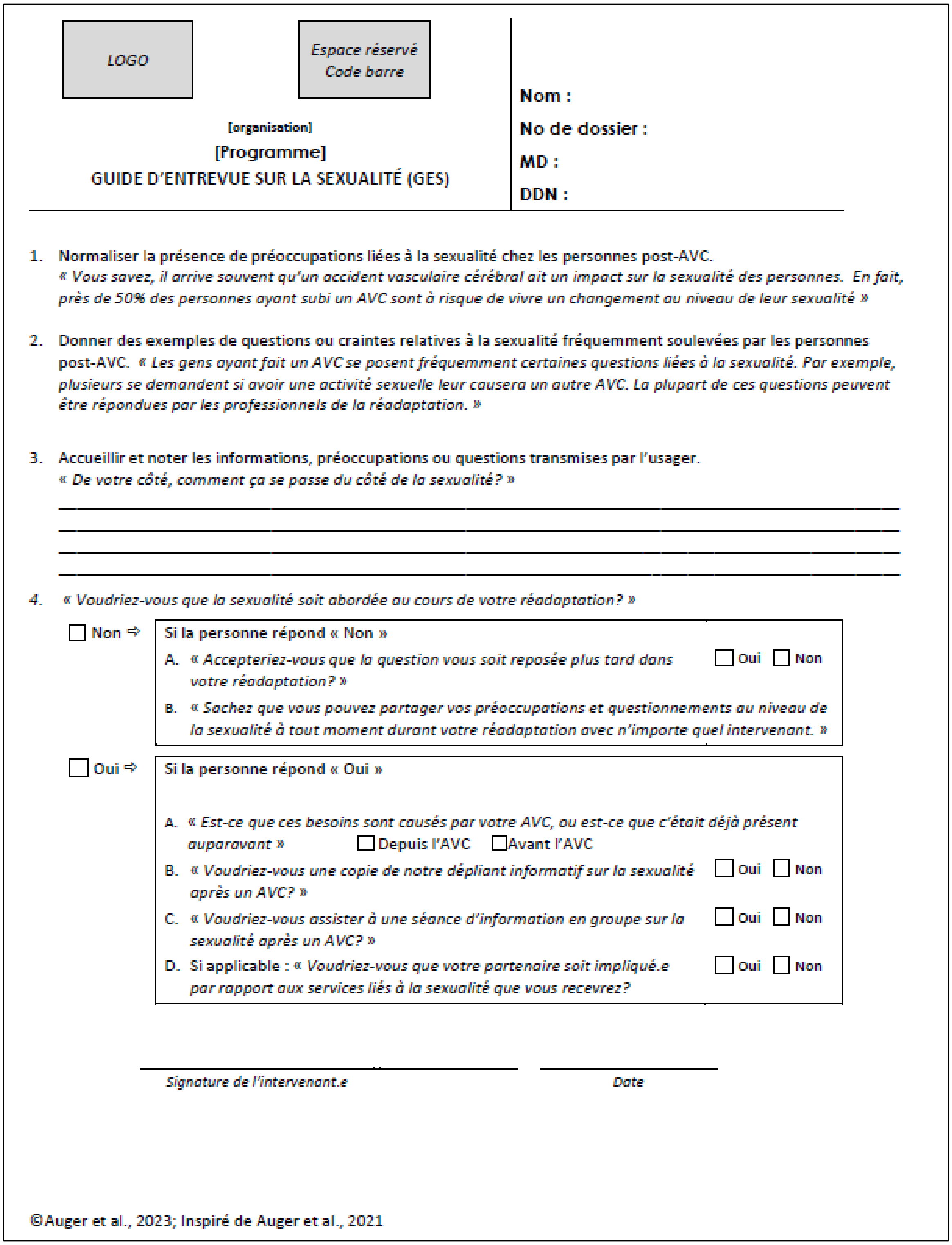
*Les rôles et contributions liés à la sexualité suggérés le sont à titre indicatif seulement. Ces suggestions ne sauraient se substituer au jugement professionnel des intervenant.e.s qui les utilisent. Les rôles et les contributions liés à la sexualité pourraient varier parmi les professionnel.le.s d'une même discipline selon leur niveau perçu de connaissances, de confort et/de compétences, leur milieu de pratique, et les autres professionnels avec qui il.elle.s interviennent, entre autres.

S'appliquant à toutes les professions :

« L'information, la promotion de la santé et la prévention du suicide, de la maladie, des accidents et des problèmes sociaux auprès des individus, des familles et des collectivités font également partie de l'exercice de la profession du membre d'un ordre dans la mesure où elles sont reliées à ses activités professionnelles. »

Pour l'ensemble des professions du domaine de la santé mentale et des relations humaines, l'information, la promotion de la santé, la prévention du suicide, de la maladie, des accidents et des problèmes sociaux font également partie de l'exercice de la profession auprès des individus, des familles et des collectivités.

Annexe 6 – Le Guide d'entrevue sur la sexualité 2.0



LOGO

Espace réservé
Code barre

[organisation]
[Programme]
GUIDE D'ENTREVUE SUR LA SEXUALITÉ (GES)

Nom :
No de dossier :
MD :
DDN :

1. Normaliser la présence de préoccupations liées à la sexualité chez les personnes post-AVC.
« Vous savez, il arrive souvent qu'un accident vasculaire cérébral ait un impact sur la sexualité des personnes. En fait, près de 50% des personnes ayant subi un AVC sont à risque de vivre un changement au niveau de leur sexualité »

2. Donner des exemples de questions ou craintes relatives à la sexualité fréquemment soulevées par les personnes post-AVC. *« Les gens ayant fait un AVC se posent fréquemment certaines questions liées à la sexualité. Par exemple, plusieurs se demandent si avoir une activité sexuelle leur causera un autre AVC. La plupart de ces questions peuvent être répondues par les professionnels de la réadaptation. »*

3. Accueillir et noter les informations, préoccupations ou questions transmises par l'usager.
« De votre côté, comment ça se passe du côté de la sexualité? »
____
____
____
____

4. *« Voudriez-vous que la sexualité soit abordée au cours de votre réadaptation? »*

☐ Non ⇨ Si la personne répond « Non »

A. *« Accepteriez-vous que la question vous soit reposée plus tard dans votre réadaptation? »* ☐ Oui ☐ Non

B. *« Sachez que vous pouvez partager vos préoccupations et questionnements au niveau de la sexualité à tout moment durant votre réadaptation avec n'importe quel intervenant. »*

☐ Oui ⇨ Si la personne répond « Oui »

A. *« Est-ce que ces besoins sont causés par votre AVC, ou est-ce que c'était déjà présent auparavant »* ☐ Depuis l'AVC ☐ Avant l'AVC

B. *« Voudriez-vous une copie de notre dépliant informatif sur la sexualité après un AVC? »* ☐ Oui ☐ Non

C. *« Voudriez-vous assister à une séance d'information en groupe sur la sexualité après un AVC? »* ☐ Oui ☐ Non

D. Si applicable : *« Voudriez-vous que votre partenaire soit impliqué.e par rapport aux services liés à la sexualité que vous recevrez?* ☐ Oui ☐ Non

Signature de l'intervenant.e *Date*

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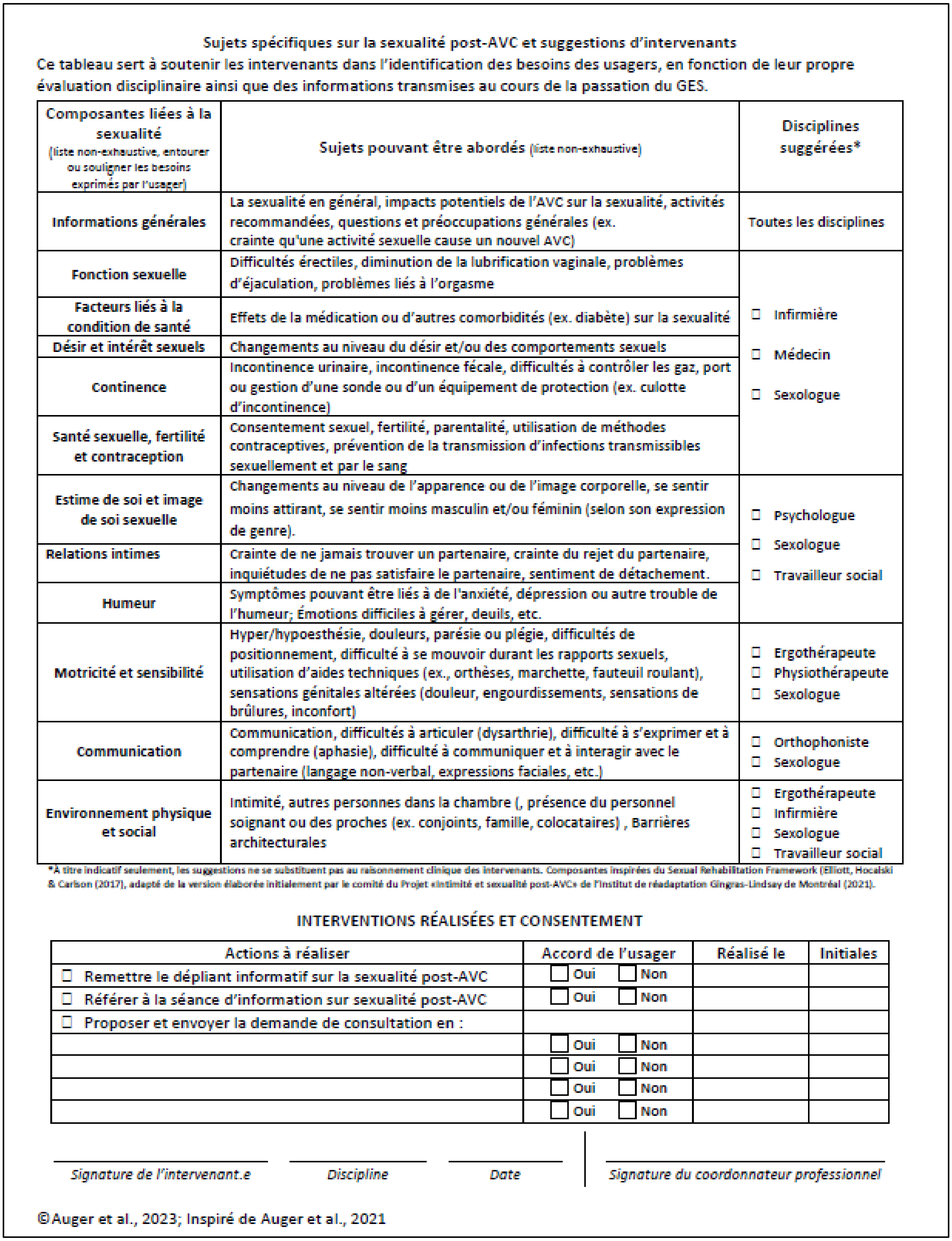

Sujets spécifiques sur la sexualité post-AVC et suggestions d'intervenants

Ce tableau sert à soutenir les intervenants dans l'identification des besoins des usagers, en fonction de leur propre évaluation disciplinaire ainsi que des informations transmises au cours de la passation du GES.

Composantes liées à la sexualité (liste non-exhaustive, entourer ou souligner les besoins exprimés par l'usager)	Sujets pouvant être abordés (liste non-exhaustive)	Disciplines suggérées*
Informations générales	La sexualité en général, impacts potentiels de l'AVC sur la sexualité, activités recommandées, questions et préoccupations générales (ex. crainte qu'une activité sexuelle cause un nouvel AVC)	Toutes les disciplines
Fonction sexuelle	Difficultés érectiles, diminution de la lubrification vaginale, problèmes d'éjaculation, problèmes liés à l'orgasme	☐ Infirmière ☐ Médecin ☐ Sexologue
Facteurs liés à la condition de santé	Effets de la médication ou d'autres comorbidités (ex. diabète) sur la sexualité	
Désir et intérêt sexuels	Changements au niveau du désir et/ou des comportements sexuels	
Continence	Incontinence urinaire, incontinence fécale, difficultés à contrôler les gaz, port ou gestion d'une sonde ou d'un équipement de protection (ex. culotte d'incontinence)	
Santé sexuelle, fertilité et contraception	Consentement sexuel, fertilité, parentalité, utilisation de méthodes contraceptives, prévention de la transmission d'infections transmissibles sexuellement et par le sang	
Estime de soi et image de soi sexuelle	Changements au niveau de l'apparence ou de l'image corporelle, se sentir moins attirant, se sentir moins masculin et/ou féminin (selon son expression de genre).	☐ Psychologue ☐ Sexologue ☐ Travailleur social
Relations intimes	Crainte de ne jamais trouver un partenaire, crainte du rejet du partenaire, inquiétudes de ne pas satisfaire le partenaire, sentiment de détachement.	
Humeur	Symptômes pouvant être liés à de l'anxiété, dépression ou autre trouble de l'humeur; Émotions difficiles à gérer, deuils, etc.	
Motricité et sensibilité	Hyper/hypoesthésie, douleurs, parésie ou plégie, difficultés de positionnement, difficulté à se mouvoir durant les rapports sexuels, utilisation d'aides techniques (ex., orthèses, marchette, fauteuil roulant), sensations génitales altérées (douleur, engourdissements, sensations de brûlures, inconfort)	☐ Ergothérapeute ☐ Physiothérapeute ☐ Sexologue
Communication	Communication, difficultés à articuler (dysarthrie), difficulté à s'exprimer et à comprendre (aphasie), difficulté à communiquer et à interagir avec le partenaire (langage non-verbal, expressions faciales, etc.)	☐ Orthophoniste ☐ Sexologue
Environnement physique et social	Intimité, autres personnes dans la chambre (, présence du personnel soignant ou des proches (ex. conjoints, famille, colocataires) , Barrières architecturales	☐ Ergothérapeute ☐ Infirmière ☐ Sexologue ☐ Travailleur social

*À titre indicatif seulement, les suggestions ne se substituent pas au raisonnement clinique des intervenants. Composantes inspirées du Sexual Rehabilitation Framework (Elliott, Hocalski & Carlson (2017), adapté de la version élaborée initialement par le comité du Projet «Intimité et sexualité post-AVC» de l'Institut de réadaptation Gingras-Lindsay de Montréal (2021).

INTERVENTIONS RÉALISÉES ET CONSENTEMENT

Actions à réaliser	Accord de l'usager	Réalisé le	Initiales
☐ Remettre le dépliant informatif sur la sexualité post-AVC	☐ Oui ☐ Non		
☐ Référer à la séance d'information sur sexualité post-AVC	☐ Oui ☐ Non		
☐ Proposer et envoyer la demande de consultation en :			
	☐ Oui ☐ Non		
	☐ Oui ☐ Non		
	☐ Oui ☐ Non		
	☐ Oui ☐ Non		

Signature de l'intervenant.e | *Discipline* | *Date* | *Signature du coordonnateur professionnel*

Annexe 7 – Dépliant informatif sur la sexualité post-AVC

Pour le/la partenaire

Est-il possible d'être à la fois soignant et partenaire sexuel ?

Le rôle de proche aidant peut avoir un impact sur l'intimité et la sexualité. Certaines personnes pourraient bien vivre le fait d'être soignant et partenaire sexuel, tandis que d'autres pourraient avoir besoin de séparer ces deux rôles. Ces possibilités sont légitimes et doivent être centrées sur les besoins de chacun des partenaires dans le couple.

Trouvez des moments de plaisir à passer ensemble – riez, parlez et connectez-vous autour de vos intérêts et souvenirs communs. Redonnez de la valeur à la séduction, la tendresse et la sensualité. N'oubliez pas qu'il est important que vous continuiez à participer à des activités que vous aimez et que vous passiez un peu de temps seul sans vous sentir coupable. En prenant soin de vous, vous serez mieux à même de vous occuper de votre partenaire.

N'hésitez pas à poser vos questions ou partager vos préoccupations avec les intervenants de l'équipe. Ils sont présents pour vous aussi!

L'importance d'en parler

Dès que vous êtes prêts, prenez le temps de poser vos questions et parler de vos préoccupations avec les intervenants et votre partenaire. Cela leur permettra de mieux vous accompagner dans la recherche de solutions tout au long du processus de réadaptation et d'adaptation à votre nouvelle réalité. Tout comme il est possible de s'ajuster pour la marche ou l'habillage par exemple, il est possible de s'ajuster pour les activités sexuelles et intimes.

Vous êtes l'expert de vous-même et le meilleur générateur de solutions.

Respectez votre propre rythme.

Chaque personne est différente et il n'y a pas une seule solution qui convient à tous. Les moments opportuns d'aborder l'intimité et la sexualité sont également différents pour chacun. Il est important de vous rappeler que vous êtes la personne qui connaît le mieux vos forces et vos besoins. Faites-vous alors confiance lors de l'exploration de stratégies qui vous seront propres et qui seront les plus pertinentes à votre situation.

Pas encore prêt(e) pour en parler?

Vous pouvez choisir les moments qui vous conviennent le mieux pour aborder l'intimité et la sexualité. N'hésitez pas à en parler avec les intervenants que vous côtoyez en réadaptation. Vous pouvez également attendre de rencontrer votre médecin de famille ou tout autre professionnel de confiance.

Plusieurs ressources existent dans la communauté et en services privés :

- Pour trouver un(e) sexologue, contactez L'Ordre professionnel des sexologues du Québec : 438-386-6777
- Clinique de sexologie de l'UQAM : 455 René-Lévesque Est, Montréal, H2L 4Y2, 514-987-3000 # 4453
- Pour trouver un(e) psychologue, contactez L'Ordre des psychologues du Québec : 514-738-1223
- Clinique universitaire de psychologie de l'Université de Montréal : 514-343-7725
- Appelez l'Accueil psychosocial de votre CLSC

Pour davantage d'informations, vous pouvez consulter :

- www.strokengine.ca
- www.coeuretavc.ca

Sources

- Comité d'experts du *Projet sur l'intimité et la sexualité post-AVC* de l'Institut de réadaptation Gingras-Lindsay de Montréal (2021)
- Dépliant de l'Hôpital Villa Medica
- McDermott, A. et Rochette, A. (2021, 1er février). *Sexualité.* INFO AVC, https://strokengine.ca/fr/consequences/sexuality/

Intimité et sexualité après un AVC

(Accident Vasculaire Cérébral)

Dépliant d'informations pour les usagers et les partenaires

Centre intégré universitaire de santé et de services sociaux du Centre-Sud-de-l'Île-de-Montréal
Québec

Illustration par Yolaine Huard

Intimité et sexualité

L'intimité et la sexualité sont des notions centrales de l'être humain tout au long de la vie. Elles peuvent être vécues avec ou sans partenaire. Elles englobent non seulement les activités sexuelles, mais également les notions de relations, désir, plaisir et proximité.

Considérant que les activités sexuelles sont liées à un meilleur fonctionnement physique et psychologique, ainsi qu'à une meilleure qualité de vie, elles doivent être considérées en réadaptation.

À qui puis-je parler de la sexualité?

Vous pouvez parler de sexualité avec tous les membres de votre équipe de soins. N'hésitez pas à vous renseigner auprès d'eux sur vos préoccupations ou vos questions.

- **Éducateur spécialisé**
- **Ergothérapeute**
- **Infirmier**
- **Médecin**
- **Neuropsychologue**
- **Orthophoniste**
- **Physiothérapeute**
- **Sexologue**
- **Travailleur social**

Changements

De nombreuses personnes vivent des changements après un AVC qui peuvent affecter la sphère intime et sexuelle, incluant :

Physiques

- Fatigue
- Faiblesse, raideur, tension ou paralysie musculaire
- Douleur
- Mobilité réduite
- Sensibilité réduite
- Incontinence urinaire et/ou fécale
- Troubles du langage (aphasie)
- Troubles de la parole (dysarthrie)
- Difficultés érectiles
- Diminution de la lubrification vaginale
- Problèmes d'éjaculation
- Problèmes liés à l'orgasme

Psychologiques

- Dépression, anxiété et changements d'humeur
- Perte de mémoire
- Changements dans l'apparence physique et l'image corporelle
- Diminution de l'estime de soi
- Insécurités
- Peur du rejet du partenaire
- Diminution de la libido (désir)

Questions fréquentes

Je crains que l'activité sexuelle provoque un autre AVC. Est-ce possible?

Rien ne prouve que les relations sexuelles peuvent davantage provoquer un autre AVC en comparaison à d'autres activités de la vie de tous les jours.

Combien de temps dois-je attendre après un AVC avant de reprendre une activité sexuelle?

Vous pouvez reprendre les activités sexuelles et intimes dès que vous vous sentez à l'aise. Allez-y à votre rythme. Il est tout à fait normal de se sentir nerveux à l'idée d'avoir des relations sexuelles après un AVC. Il est aussi fréquent que les personnes perdent tout intérêt pour les relations sexuelles après un AVC. Il est important de parler avec votre partenaire de vos sentiments et de vos préoccupations suite aux changements que vous avez subis. Il peut être utile de commencer par réintroduire des activités familières et moins exigeantes dans votre relation, comme les câlins, les massages, les baisers ou les caresses.

Je prends de nouveaux médicaments. Les médicaments peuvent-ils avoir un impact sur mon fonctionnement sexuel ?

Certains médicaments peuvent avoir un impact sur les activités sexuelles et intimes. Si vous avez des inquiétudes ou des questions concernant vos médicaments, parlez-en à votre médecin. N'arrêtez pas de prendre vos médicaments sans consulter votre médecin.

Existe-t-il des traitements permettant de recouvrer sa fonction sexuelle ?

Il existe des médicaments ou des thérapies pour traiter des troubles sexuels spécifiques. Consultez votre médecin avant d'utiliser tout médicament pour la fonction sexuelle. Il existe également des aides techniques ou des dispositifs spéciaux pour faciliter les activités sexuelles et intimes.

Annexe 8 – Signets de sensibilisation sur la sexualité post-AVC

AVC et sexualité

Un accident vasculaire cérébral (AVC) peut avoir un impact sur la sexualité. La sexualité peut faire partie de la réadaptation post-AVC.

Vous avez des questions ou des préoccupations sur la sexualité suite à un AVC?

Selon vos préférences, vous pouvez :

- En parler avec un intervenant en qui vous avez confiance.
- Utiliser les ressources éducatives sur la sexualité post-AVC de l'établissement où vous recevez des soins.
- Consulter les ressources éducatives en ligne en utilisant le code QR ou l'adresse web ci-dessous.

Adresse web : XXXXXXXXXXX
(code QR)

AVC et sexualité

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Adresse web : XXXXXXXXXXX
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- Consulter les ressources éducatives en ligne en utilisant le code QR ou l'adresse web ci-dessous.

Adresse web : XXXXXXXXXXX
(code QR)

Annexe 9 – Affiche de sensibilisation sur la sexualité post-AVC

L’AVC peut amener des changements au niveau la sexualité et de l’intimité

Vos intervenants peuvent vous aider.

Pour plus d’informations

Espace pour
code QR

Annexe 10 – Support visuel powerpoint d’une séance d’éducation sur la sexualité post-AVC

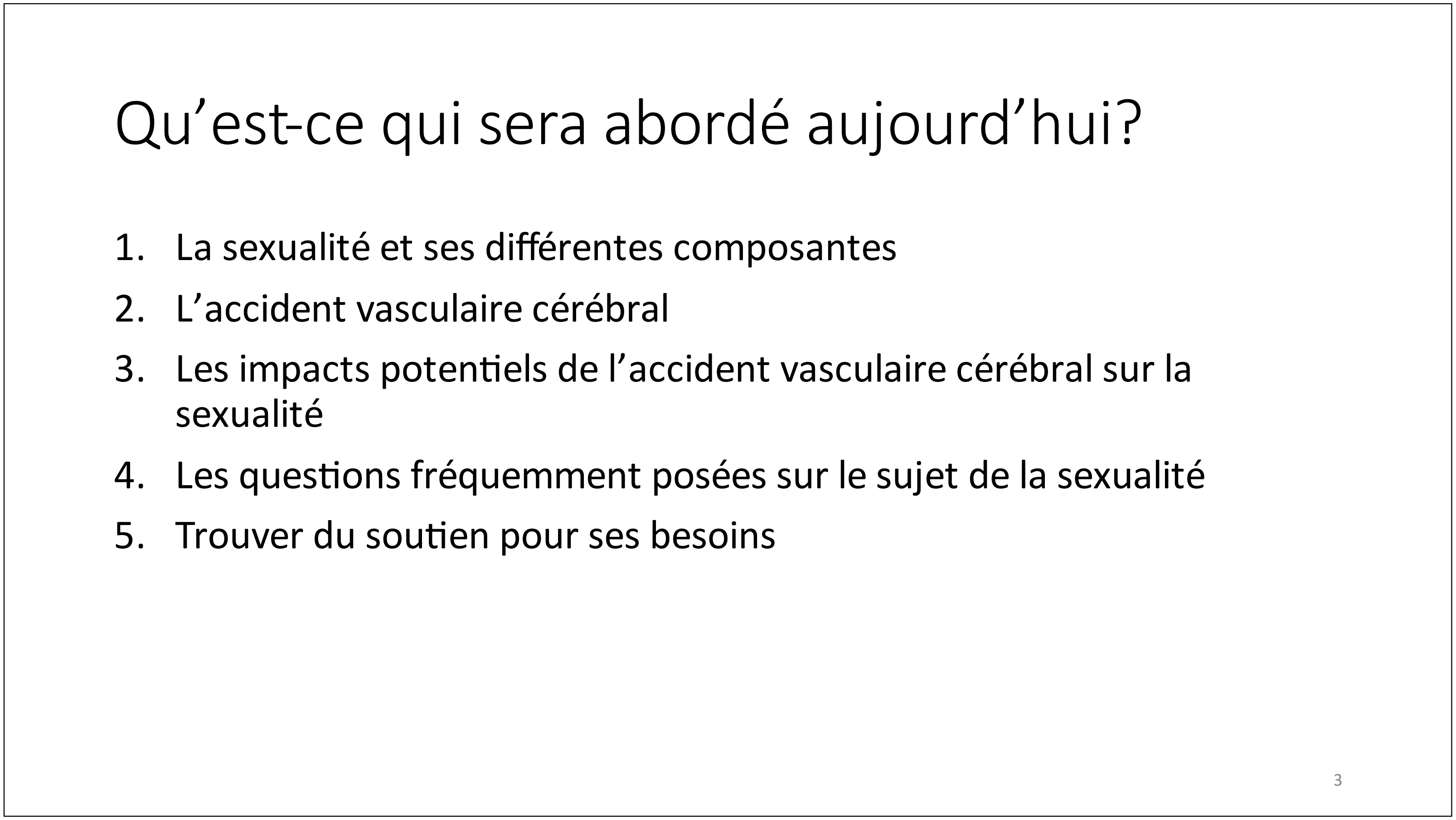
La sexualité après un AVC

Par

[À modifier au besoin]

Contenu de la présentation élaboré par
Louis-Pierre Auger, M. Sc.

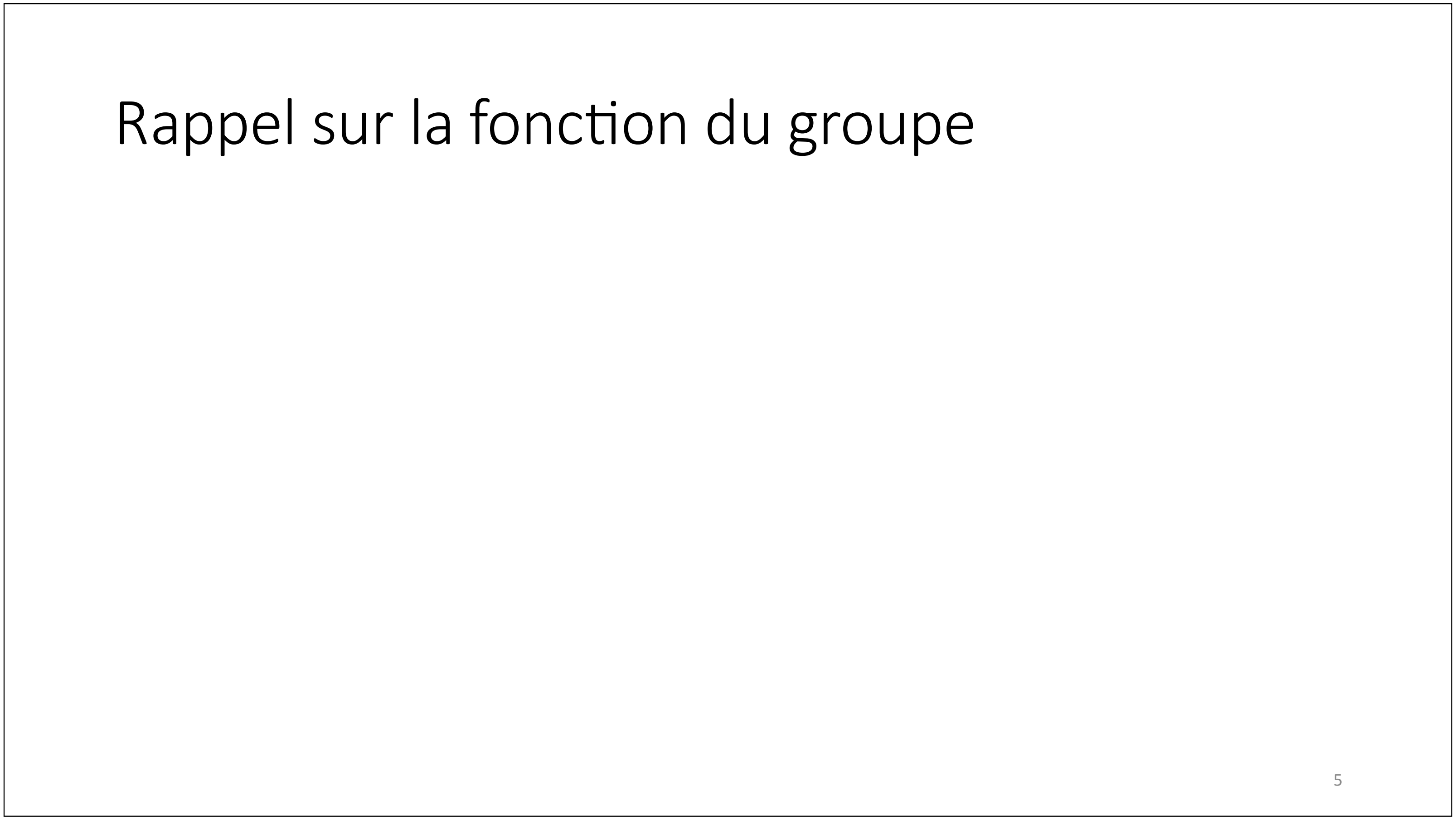
Présentation des animateur.rice.s



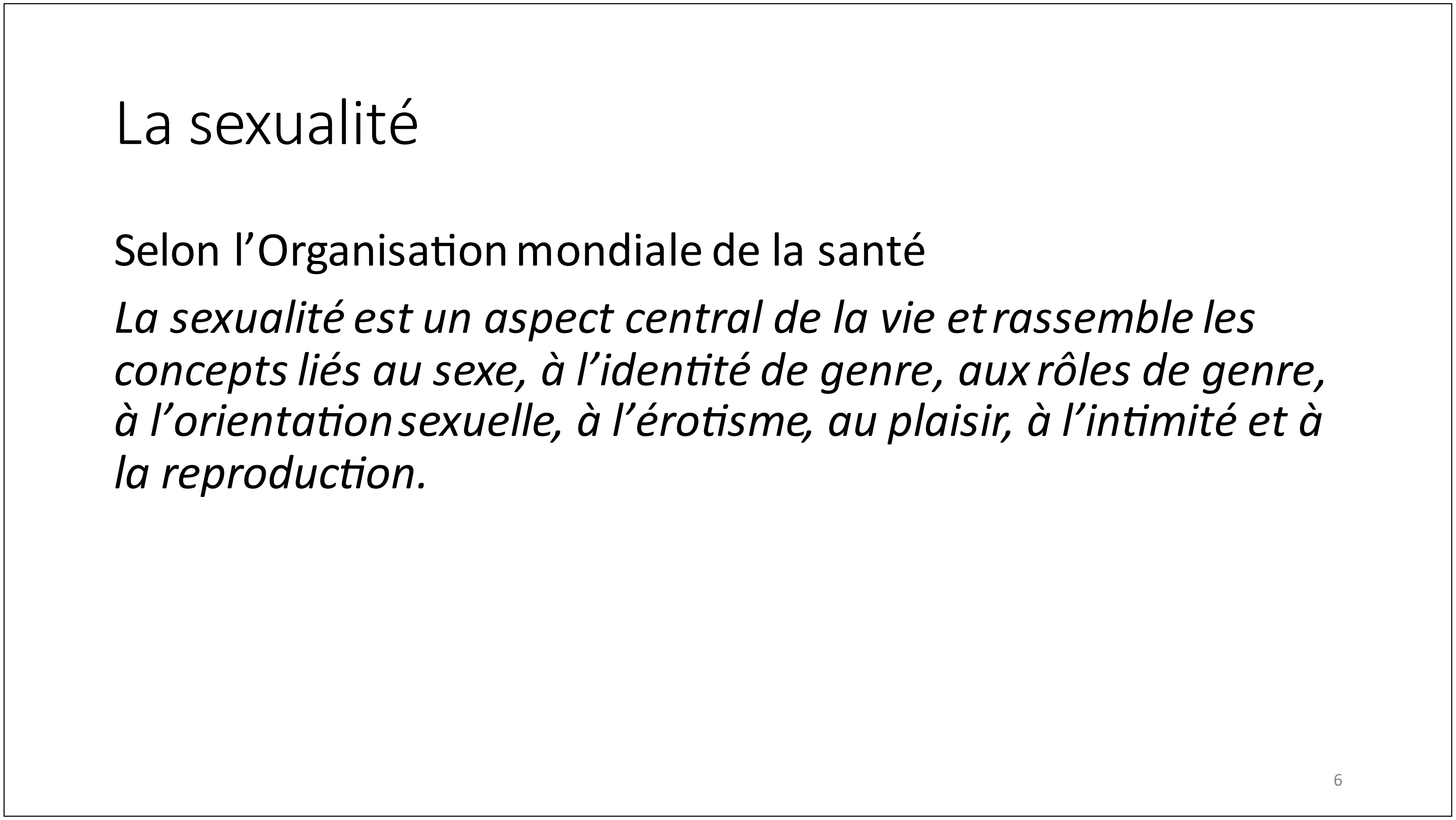
Qu’est-ce qui sera abordé aujourd’hui?

1. La sexualité et ses différentes composantes
2. L’accident vasculaire cérébral
3. Les impacts potentiels de l’accident vasculaire cérébral sur la sexualité
4. Les questions fréquemment posées sur le sujet de la sexualité
5. Trouver du soutien pour ses besoins

Questions ou éléments importants à ajouter?



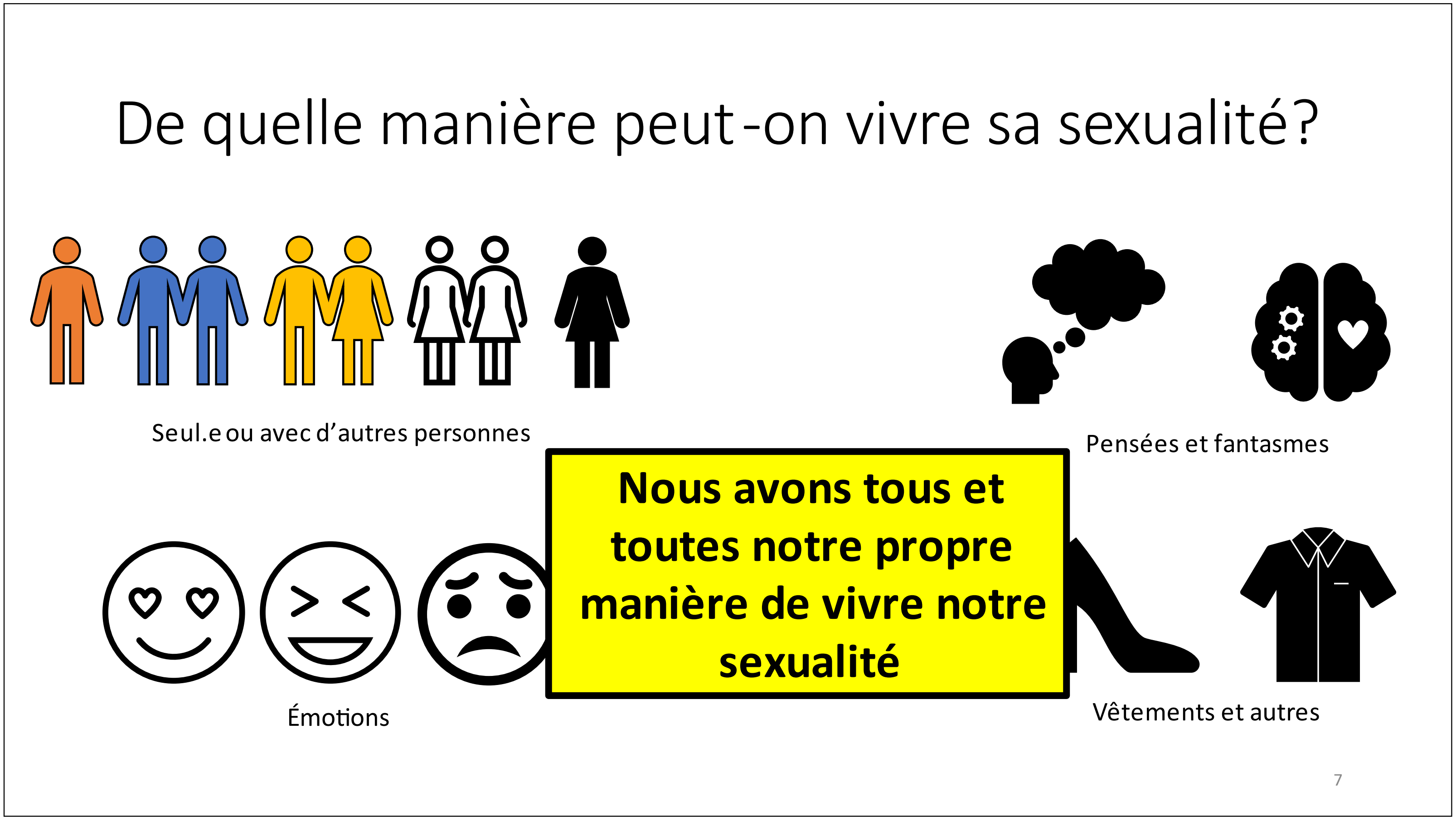
Rappel sur la fonction du groupe



La sexualité

Selon l’Organisation mondiale de la santé

La sexualité est un aspect central de la vie et rassemble les concepts liés au sexe, à l’identité de genre, aux rôles de genre, à l’orientation sexuelle, à l’érotisme, au plaisir, à l’intimité et à la reproduction.



De quelle manière peut-on vivre sa sexualité?

Seul.e ou avec d'autres personnes

Pensées et fantasmes

Nous avons tous et toutes notre propre manière de vivre notre sexualité

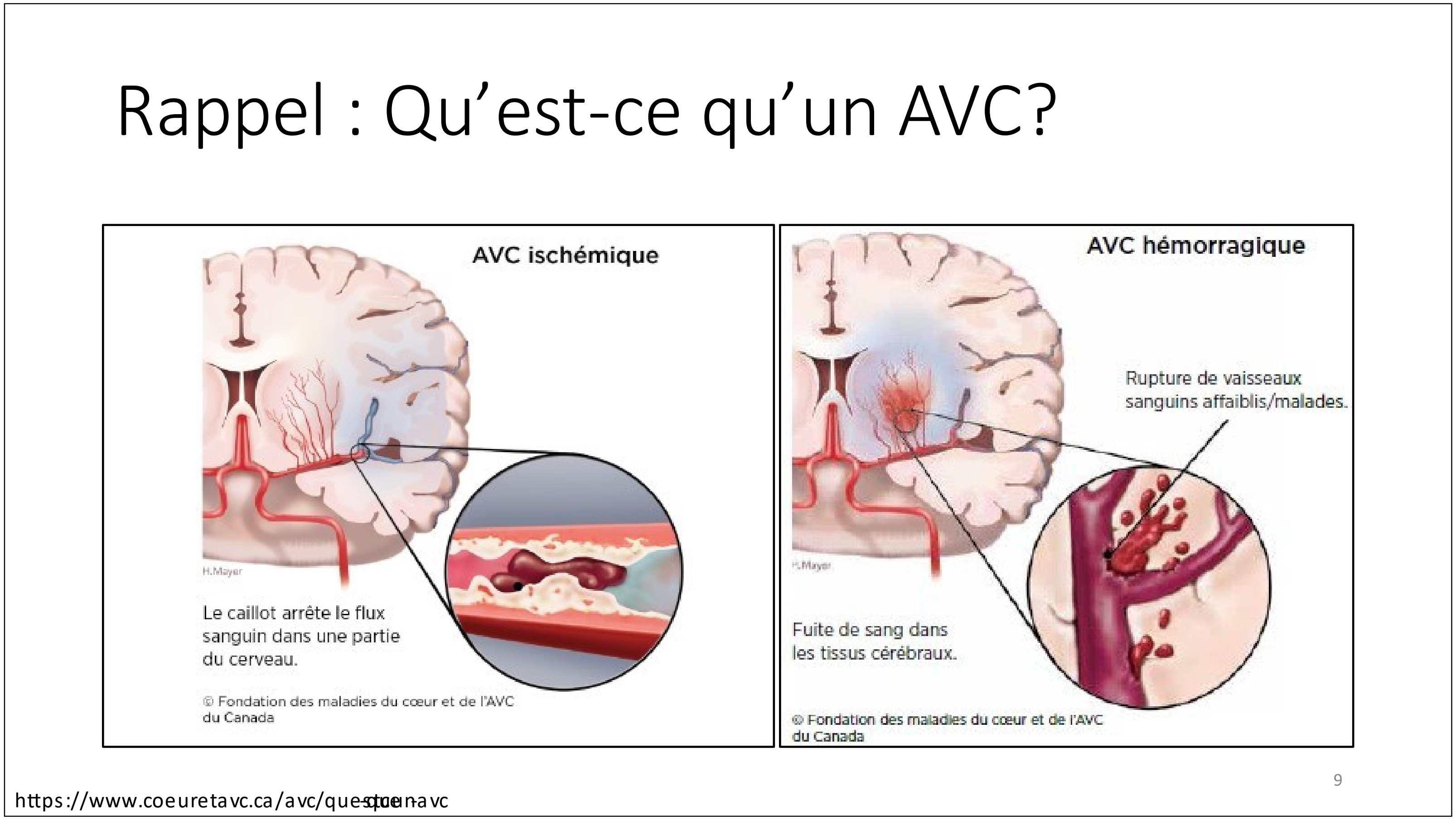
Émotions

Vêtements et autres

Rappel : Qu'est-ce qu'un AVC?

- Un AVC est un type de **lésion du cerveau**.
- Un AVC **se produit lorsque le sang ne circule pas** dans une zone du cerveau.
- La circulation sanguine peut être interrompue par **l'éclatement d'un vaisseau sanguin** (AVC hémorragique), ou par un **caillot de sang** ou un **vaisseau sanguin obstrué** (AVC ischémique).
- Cela limite l'**oxygène** et les **nutriments** à la partie du cerveau affectée, et provoque des **lésions ou la mort des cellules** au niveau de cette zone affectée.
- L'effet de l'AVC sur le corps dépend de **la partie du cerveau** qui a été affectée et de **l'importance des lésions cérébrales**.

https://strokengine.ca/fr/ressources/pour-patients-et-familles/#recent-stroke



Rappel : Qu’est-ce qu’un AVC?

AVC ischémique

Le caillot arrête le flux sanguin dans une partie du cerveau.

© Fondation des maladies du cœur et de l'AVC du Canada

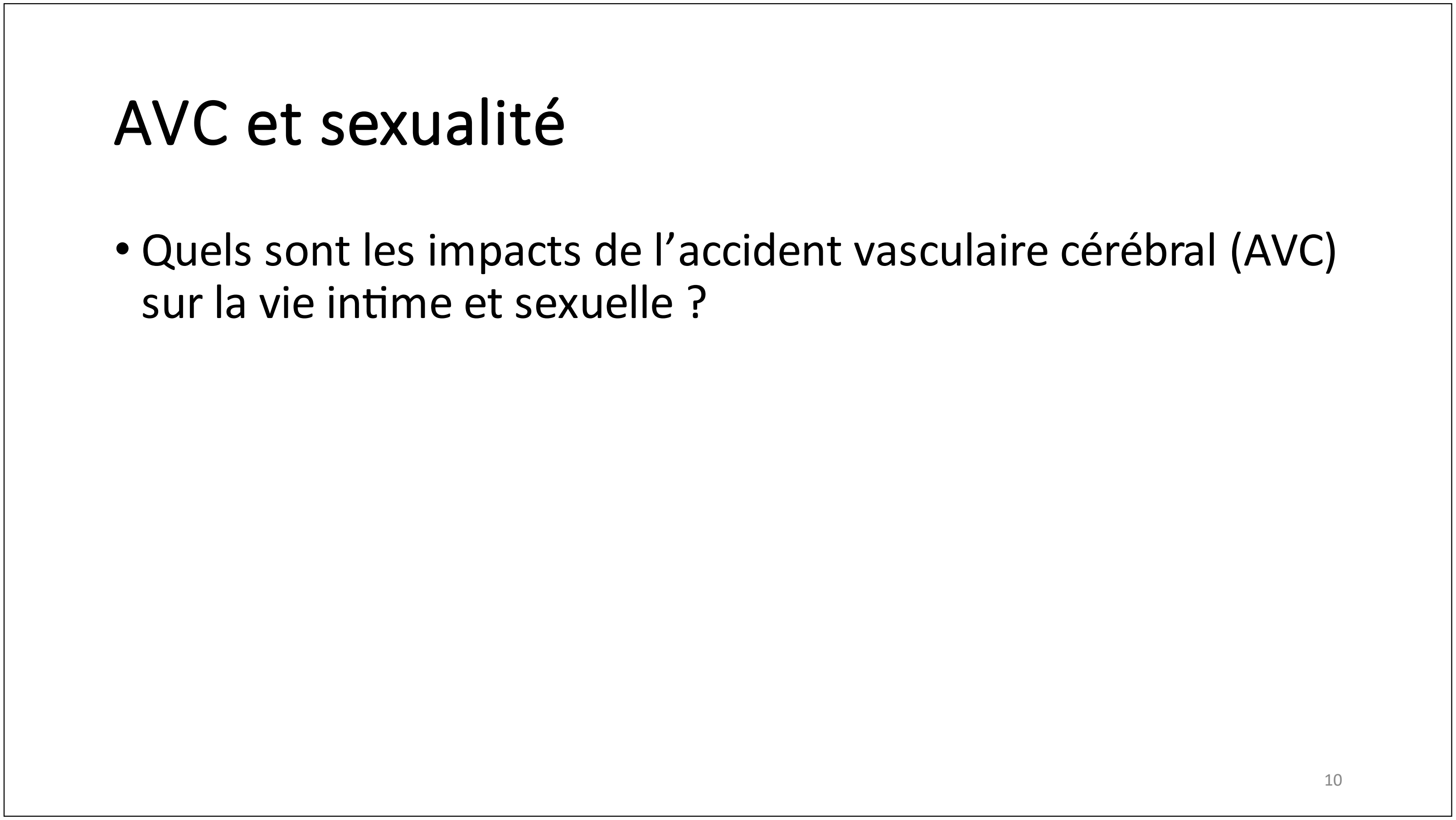
AVC hémorragique

Rupture de vaisseaux sanguins affaiblis/malades.

Fuite de sang dans les tissus cérébraux.

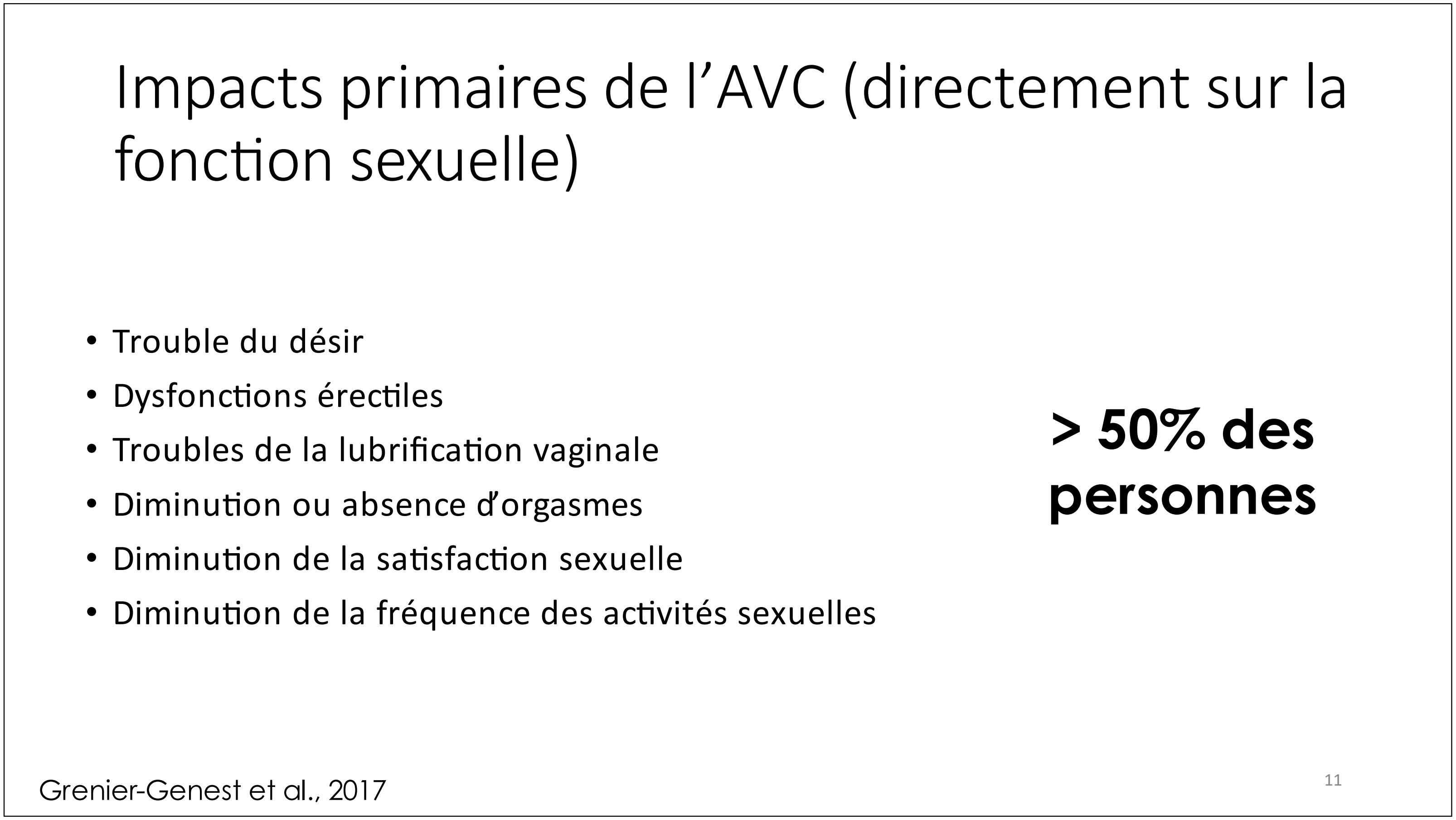
© Fondation des maladies du cœur et de l'AVC du Canada

https://www.coeuretavc.ca/avc/quest-ce-quun-avc



AVC et sexualité

- Quels sont les impacts de l’accident vasculaire cérébral (AVC) sur la vie intime et sexuelle ?



Impacts primaires de l'AVC (directement sur la fonction sexuelle)

- Trouble du désir
- Dysfonctions érectiles
- Troubles de la lubrification vaginale
- Diminution ou absence d'orgasmes
- Diminution de la satisfaction sexuelle
- Diminution de la fréquence des activités sexuelles

> 50% des personnes

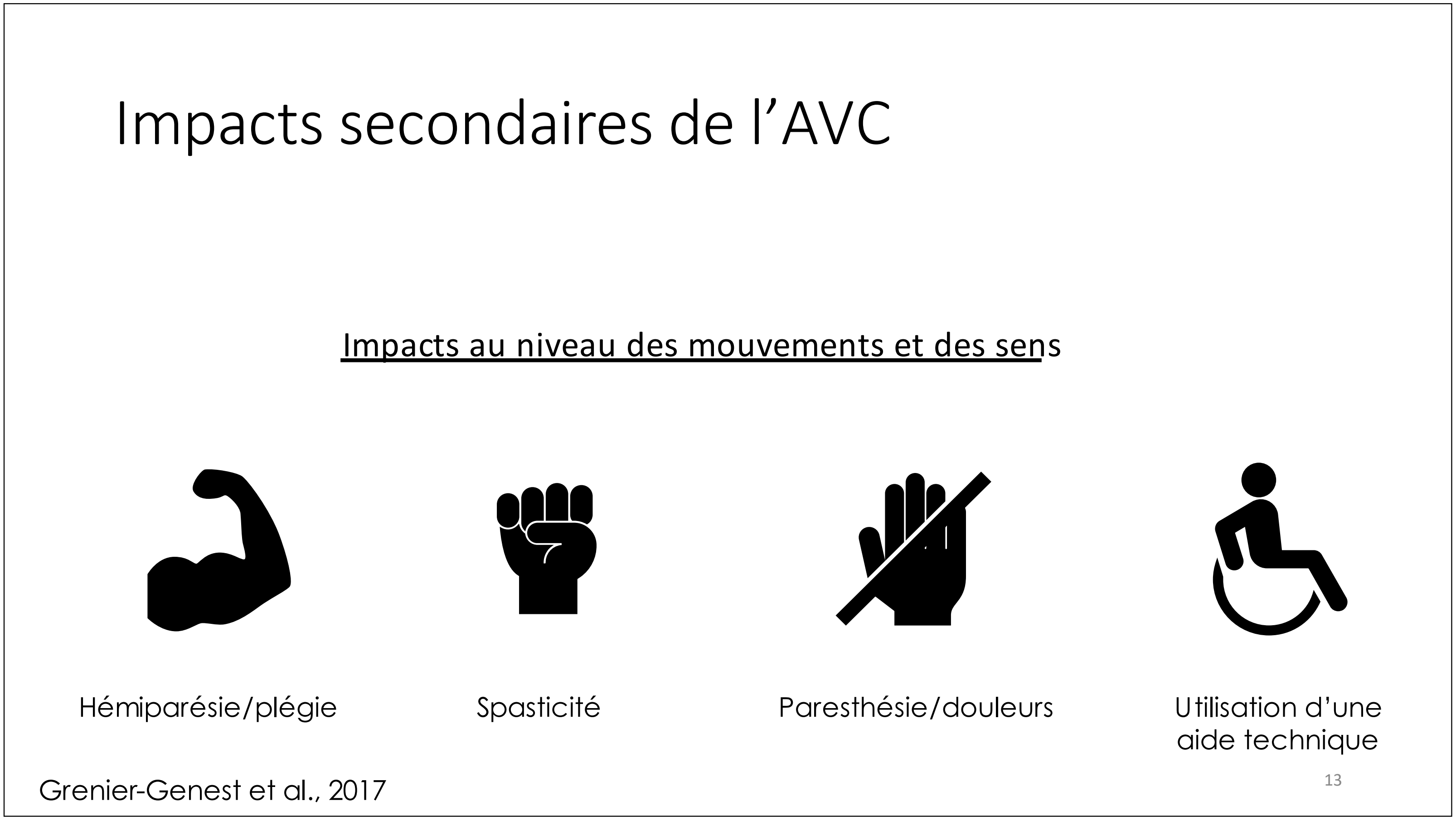
Grenier-Genest et al., 2017

Impacts de la médication sur la vie intime et sexuelle

Certains médicaments fréquemment prescrits après un AVC peuvent influencer la fonction sexuelle, particulièrement le niveau de désir et/ou l'excitation sexuelle (ex. érection, lubrification vaginale), dont :

- **Anticoagulants**
- **Antidépresseurs**
- **Hypotenseurs**

American Stroke Association
https://www.stroke.org/en/about-stroke/effects-of-stroke/emotional-effects-of-stroke/intimacy-after-stroke



Impacts secondaires de l’AVC

Impacts au niveau des mouvements et des sens

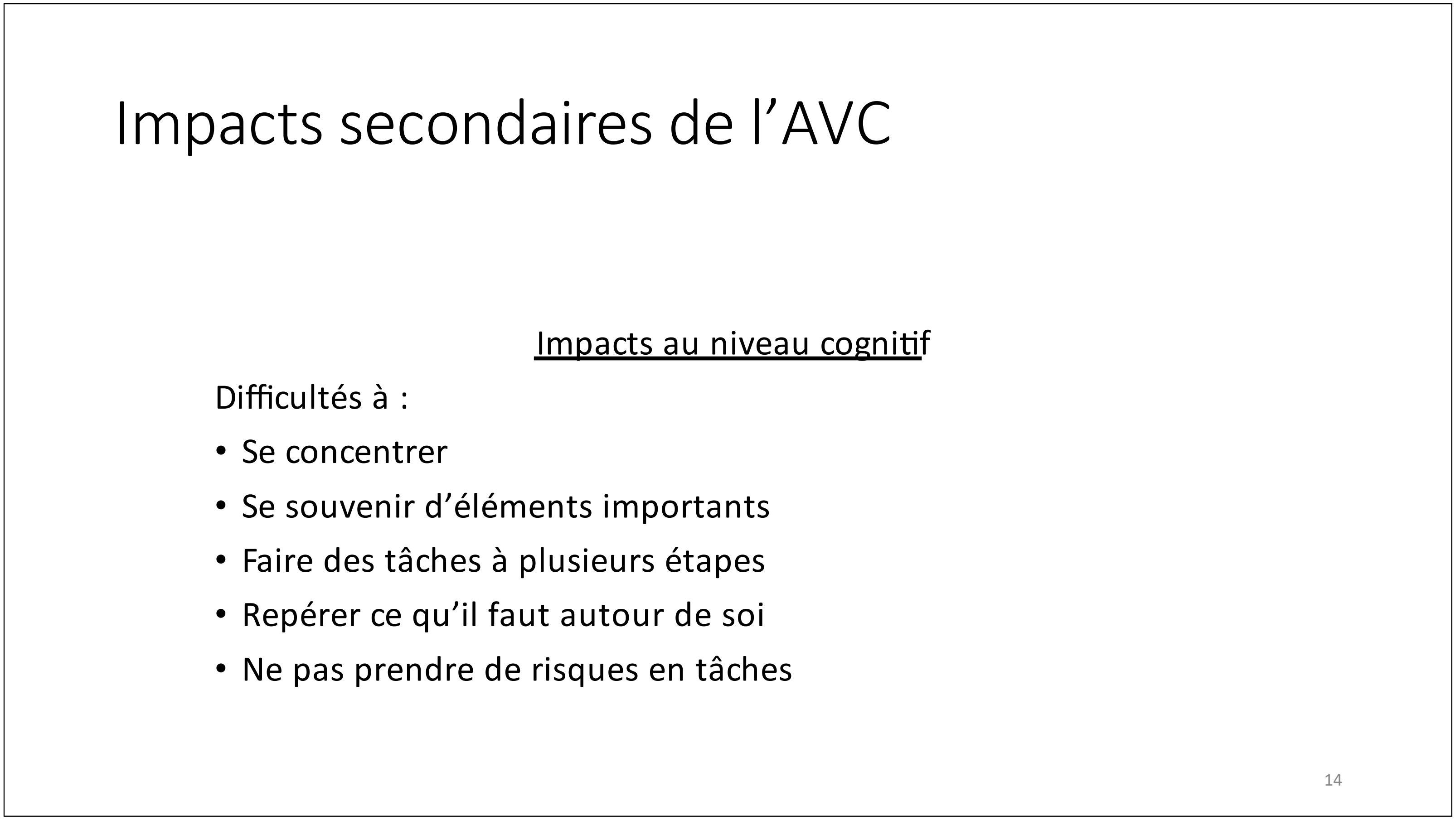
Hémiparésie/plégie

Spasticité

Paresthésie/douleurs

Utilisation d’une aide technique

Grenier-Genest et al., 2017

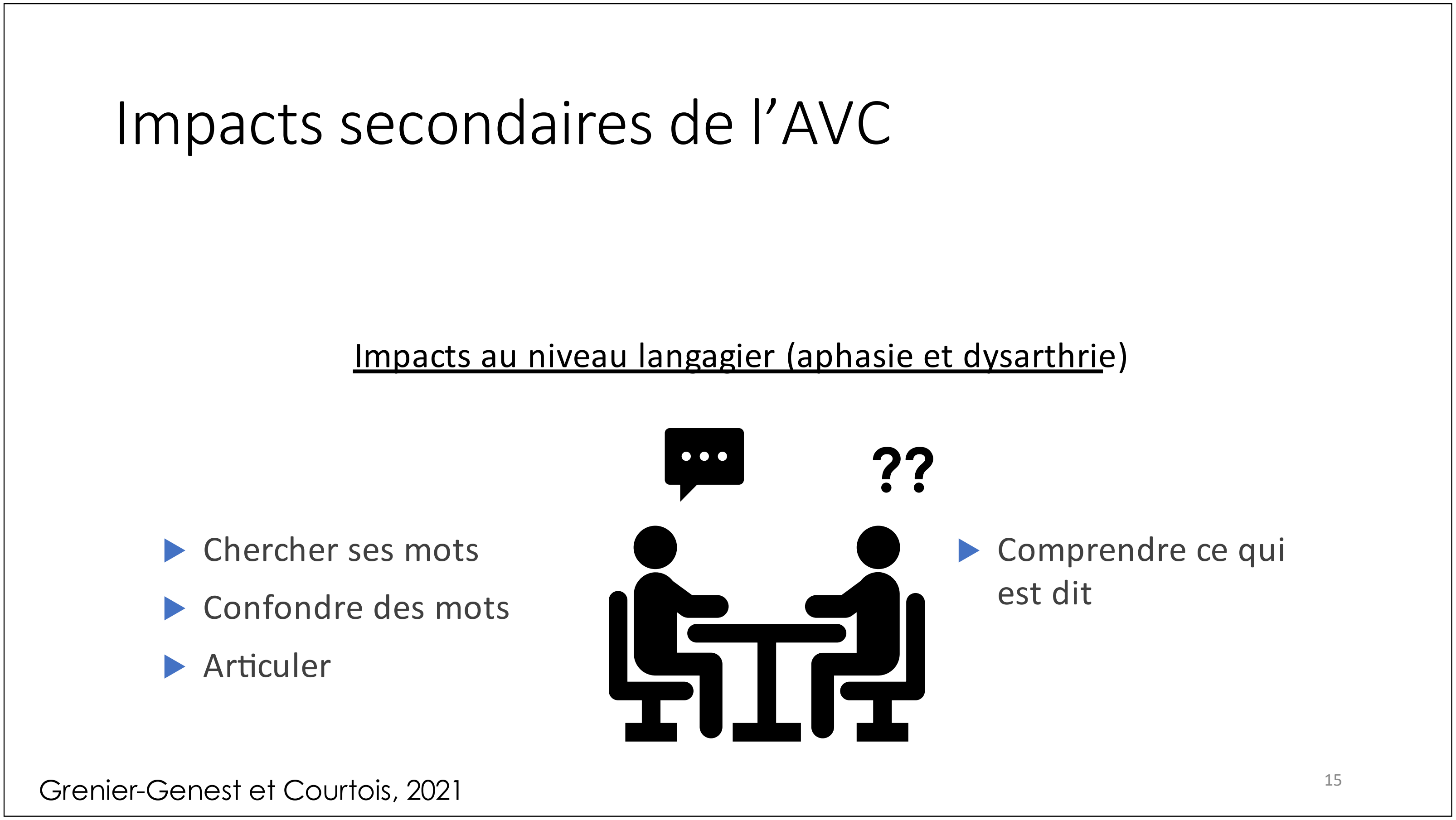


Impacts secondaires de l’AVC

Impacts au niveau cognitif

Difficultés à :

- Se concentrer
- Se souvenir d’éléments importants
- Faire des tâches à plusieurs étapes
- Repérer ce qu’il faut autour de soi
- Ne pas prendre de risques en tâches



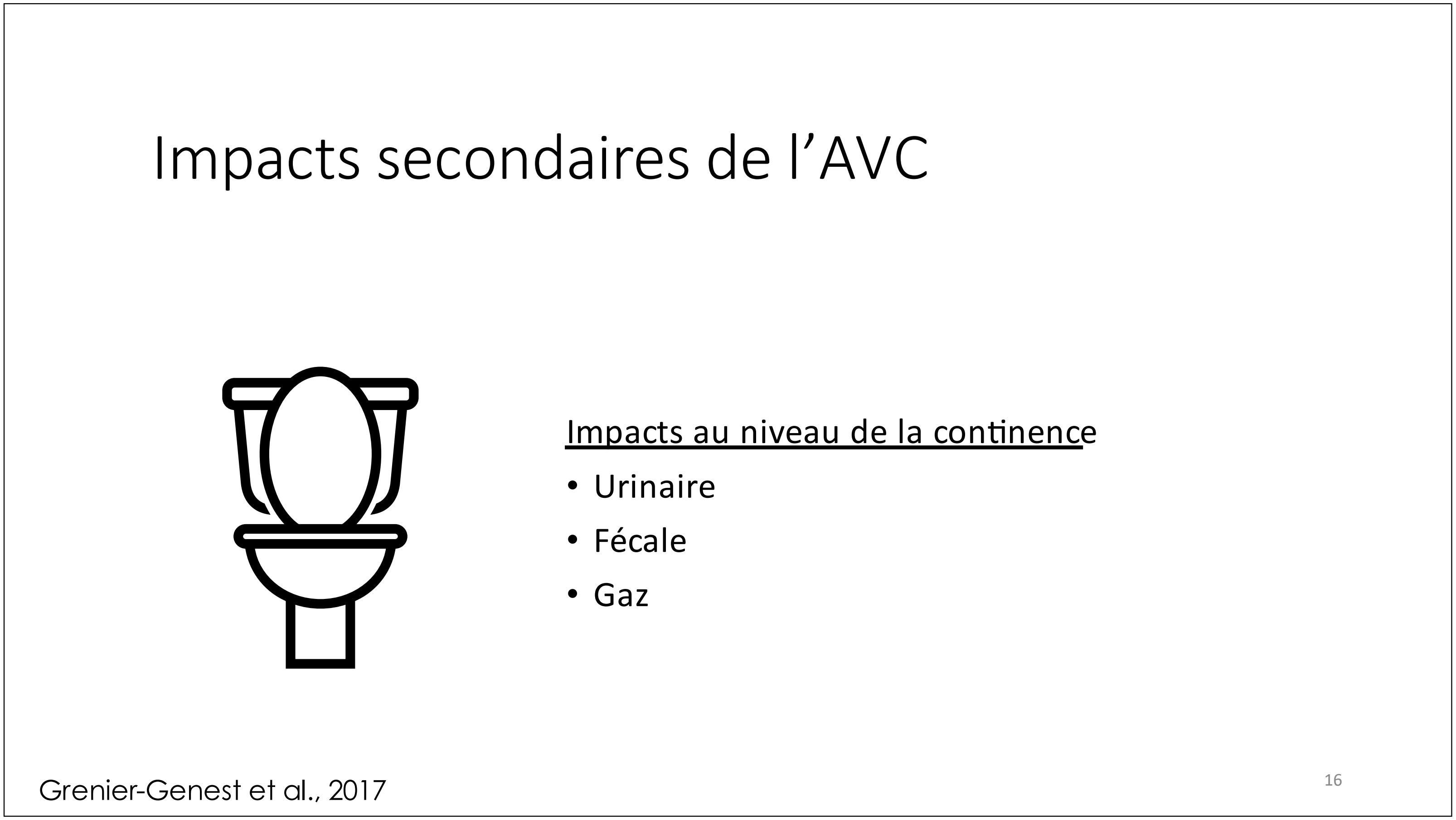
Impacts secondaires de l’AVC

Impacts au niveau langagier (aphasie et dysarthrie)

- Chercher ses mots
- Confondre des mots
- Articuler

- Comprendre ce qui est dit

Grenier-Genest et Courtois, 2021

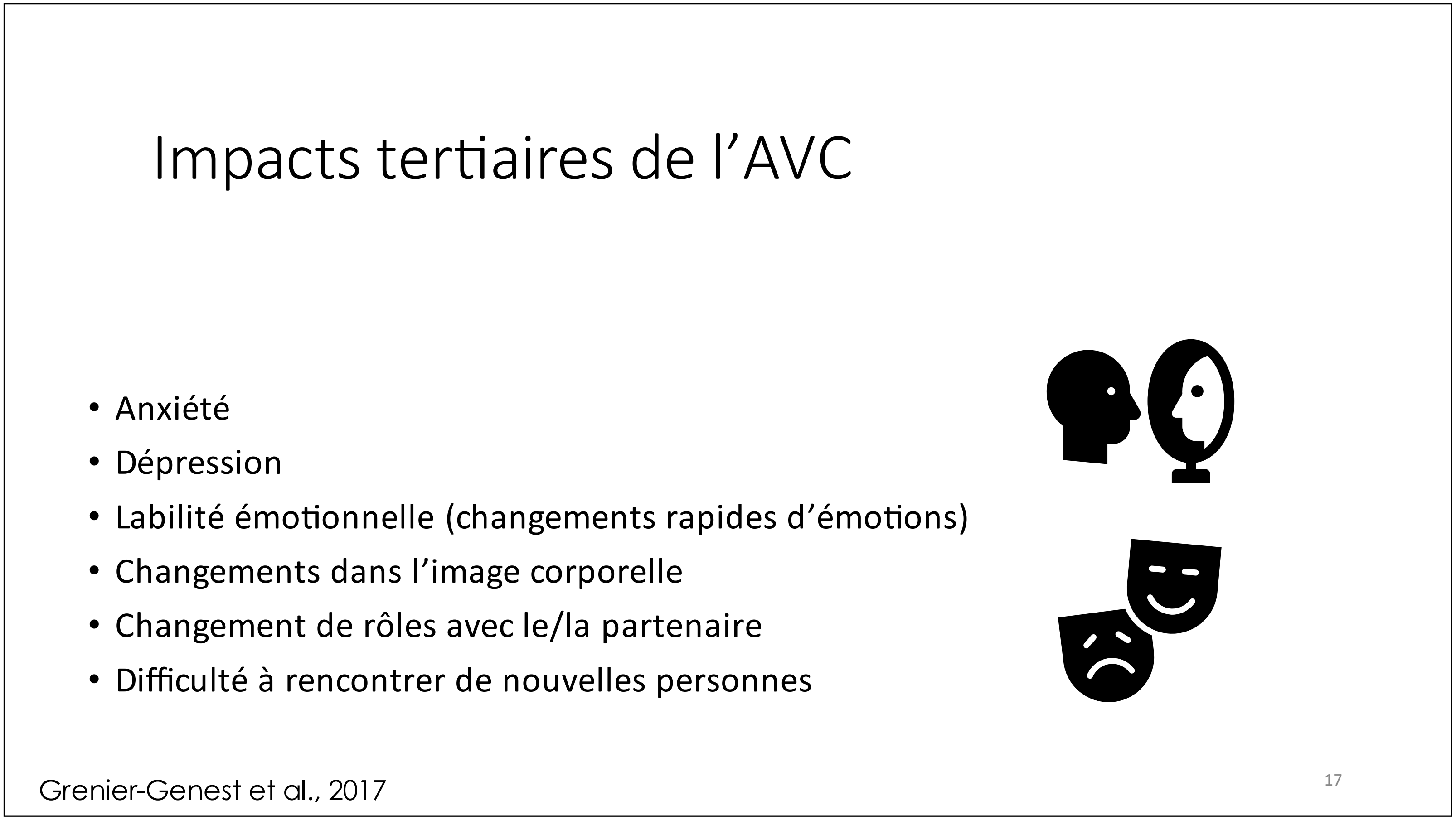


Impacts secondaires de l’AVC

<u>Impacts au niveau de la continence</u>

- Urinaire
- Fécale
- Gaz

Grenier-Genest et al., 2017



Impacts tertiaires de l’AVC

- Anxiété
- Dépression
- Labilité émotionnelle (changements rapides d’émotions)
- Changements dans l’image corporelle
- Changement de rôles avec le/la partenaire
- Difficulté à rencontrer de nouvelles personnes

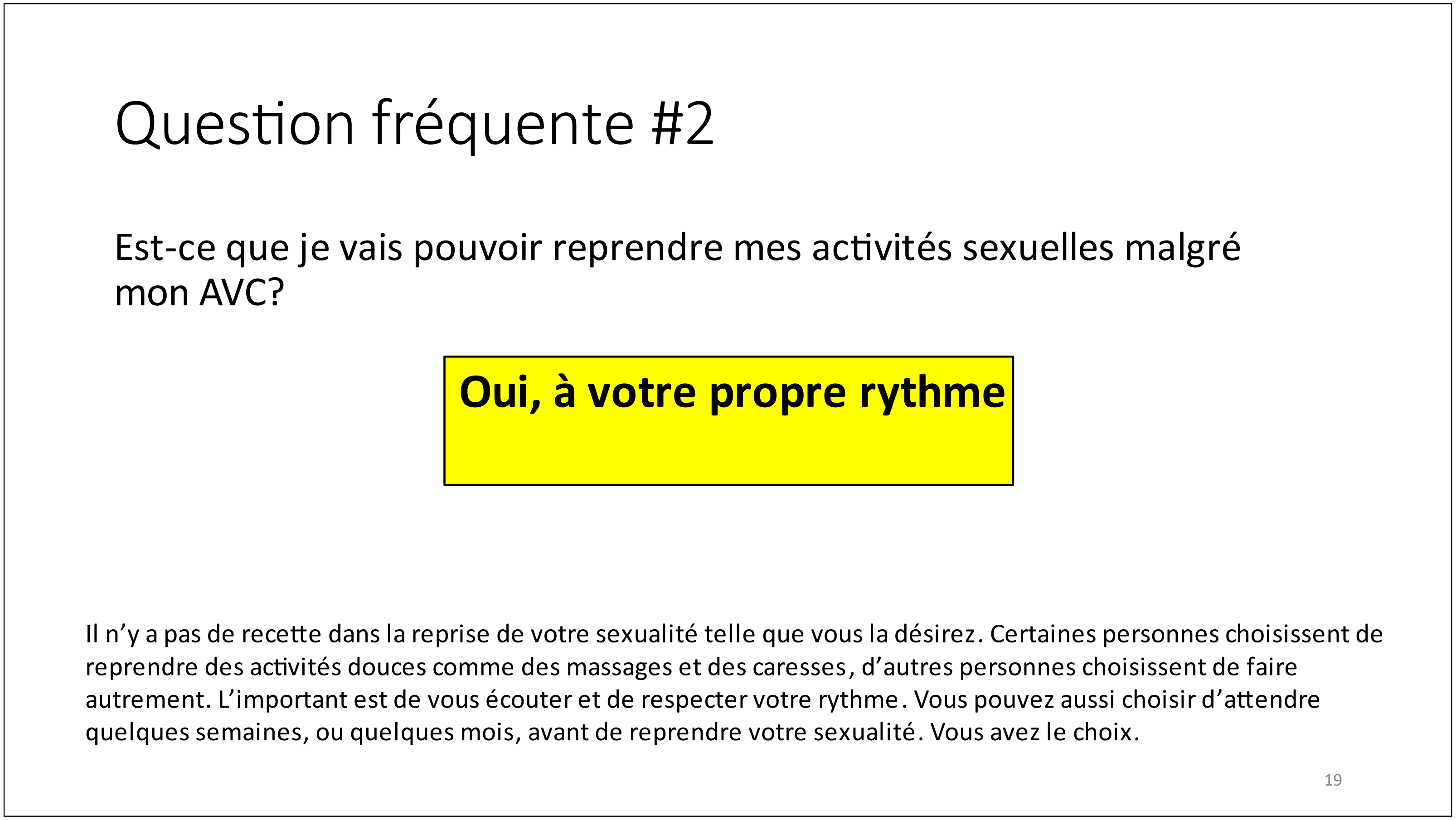
Grenier-Genest et al., 2017

Question fréquente #1

Est-ce qu'une activité sexuelle pourrait me causer un autre AVC?

Non, pas plus qu'une autre activité

*La recherche n'associe pas un plus grand risque de faire un AVC en ayant un activité sexuelle que pour toute autre activité de la vie quotidienne. Si vous avez des questions en lien avec votre condition de santé, parlez en à un professionnel de la santé

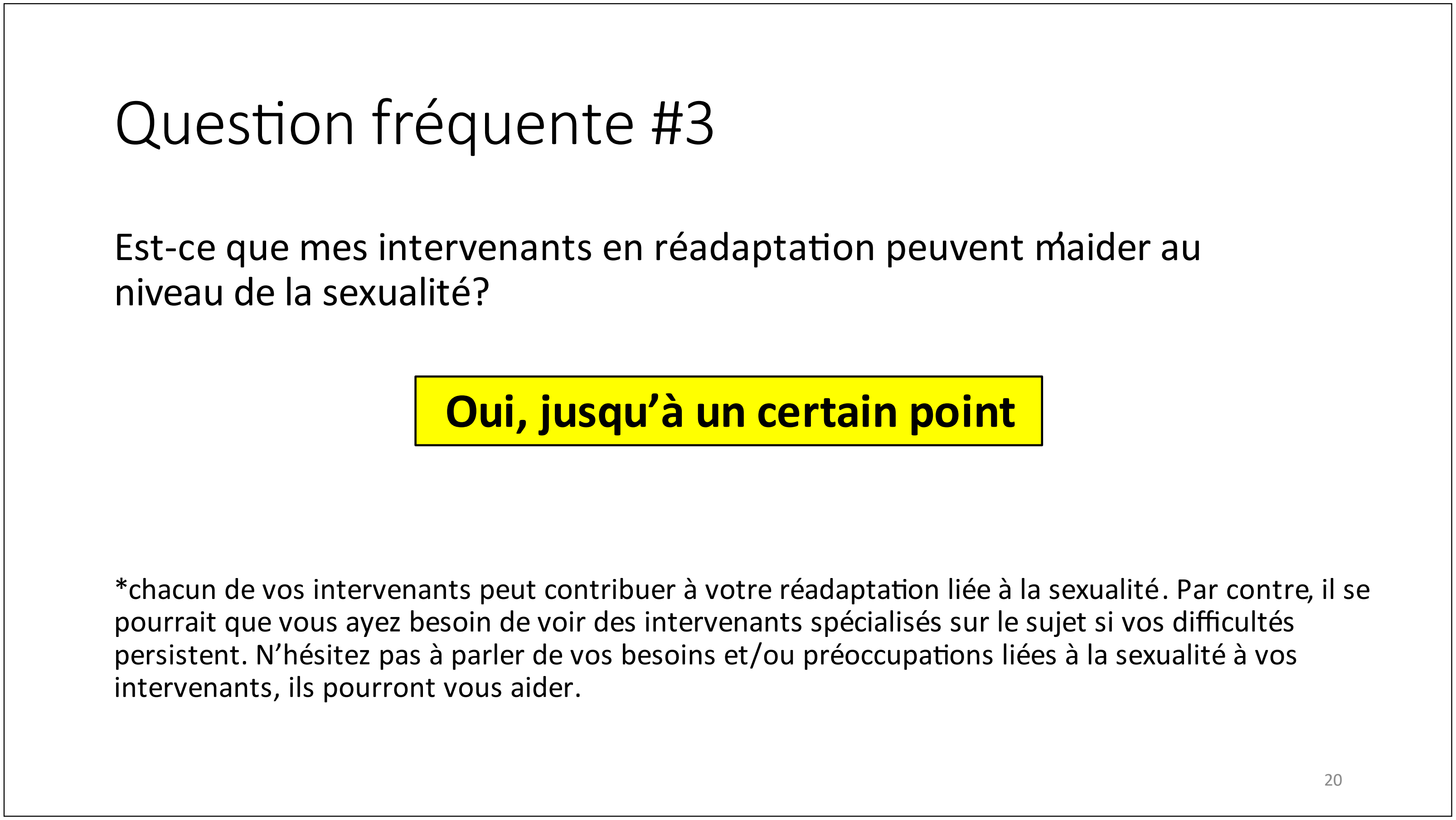


Question fréquente #2

Est-ce que je vais pouvoir reprendre mes activités sexuelles malgré mon AVC?

Oui, à votre propre rythme

Il n’y a pas de recette dans la reprise de votre sexualité telle que vous la désirez. Certaines personnes choisissent de reprendre des activités douces comme des massages et des caresses, d’autres personnes choisissent de faire autrement. L’important est de vous écouter et de respecter votre rythme. Vous pouvez aussi choisir d’attendre quelques semaines, ou quelques mois, avant de reprendre votre sexualité. Vous avez le choix.



Question fréquente #3

Est-ce que mes intervenants en réadaptation peuvent m’aider au niveau de la sexualité?

Oui, jusqu’à un certain point

*chacun de vos intervenants peut contribuer à votre réadaptation liée à la sexualité. Par contre, il se pourrait que vous ayez besoin de voir des intervenants spécialisés sur le sujet si vos difficultés persistent. N’hésitez pas à parler de vos besoins et/ou préoccupations liées à la sexualité à vos intervenants, ils pourront vous aider.

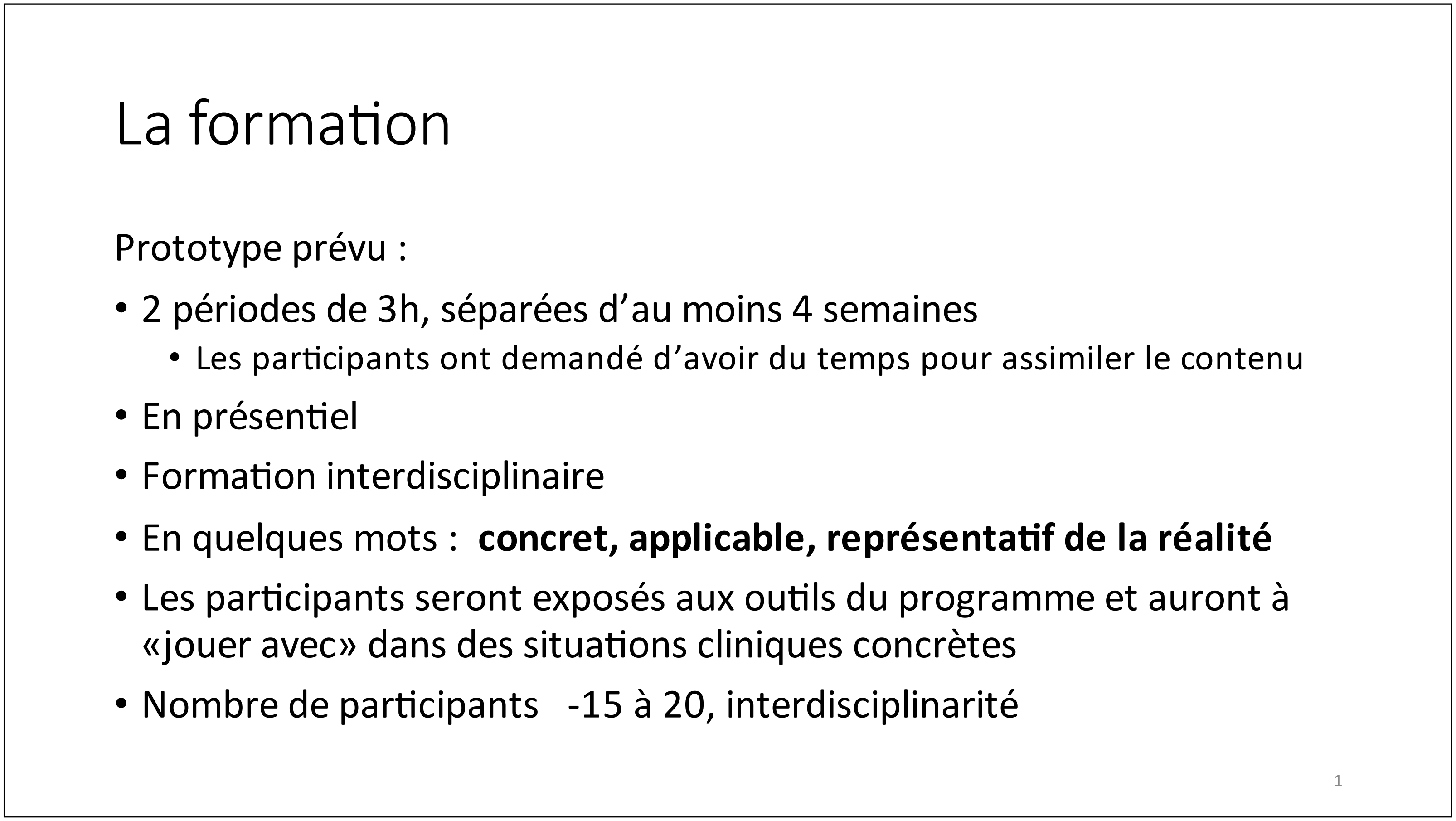
Autres questions?

Espace pour discussion et échanges

Merci!

*Des ressources plus détaillées peuvent vous être fournies sur demandes

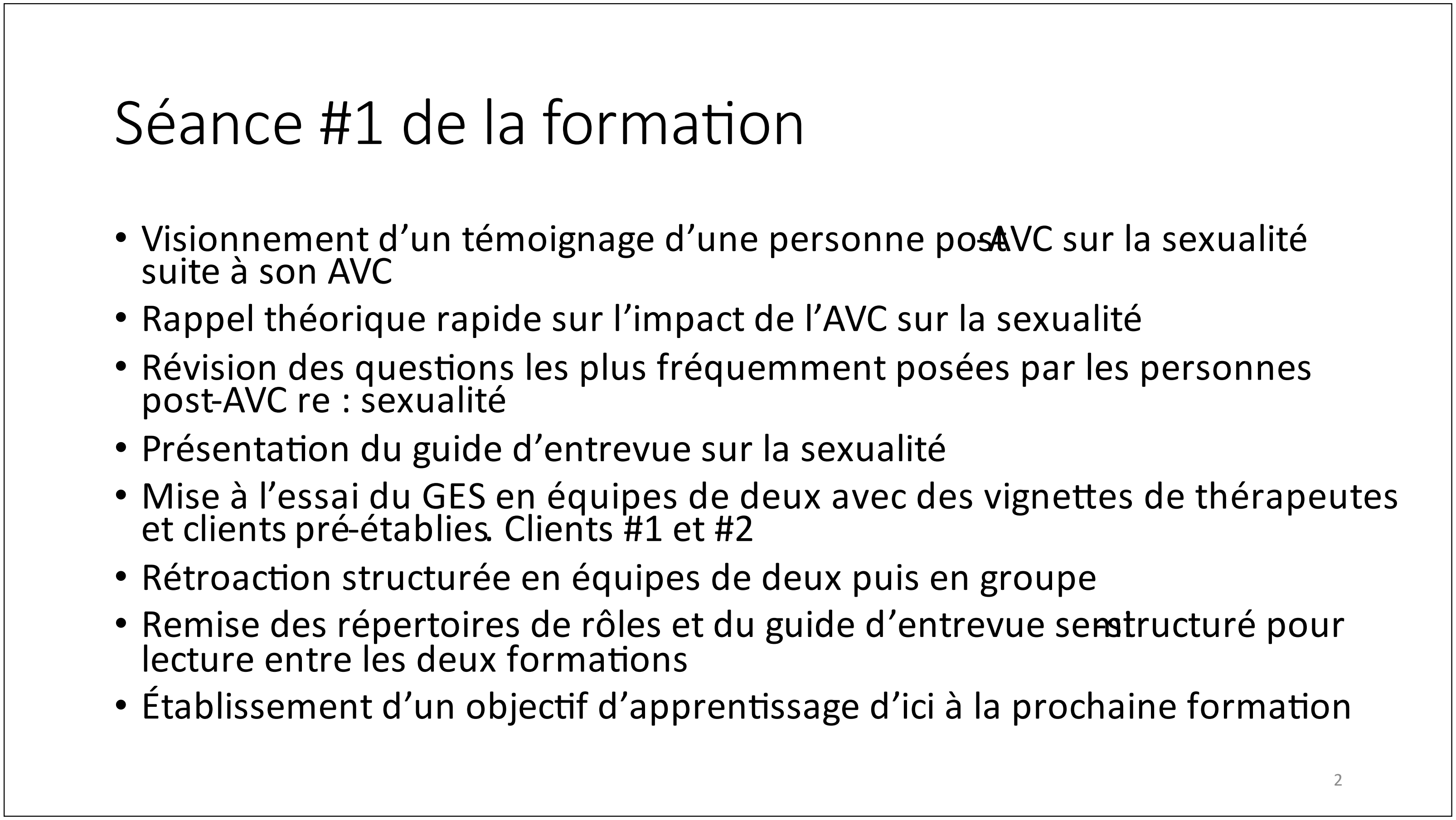
Annexe 11 – Plan de la formation interdisciplinaire sur la réadaptation sexuelle post-AVC



La formation

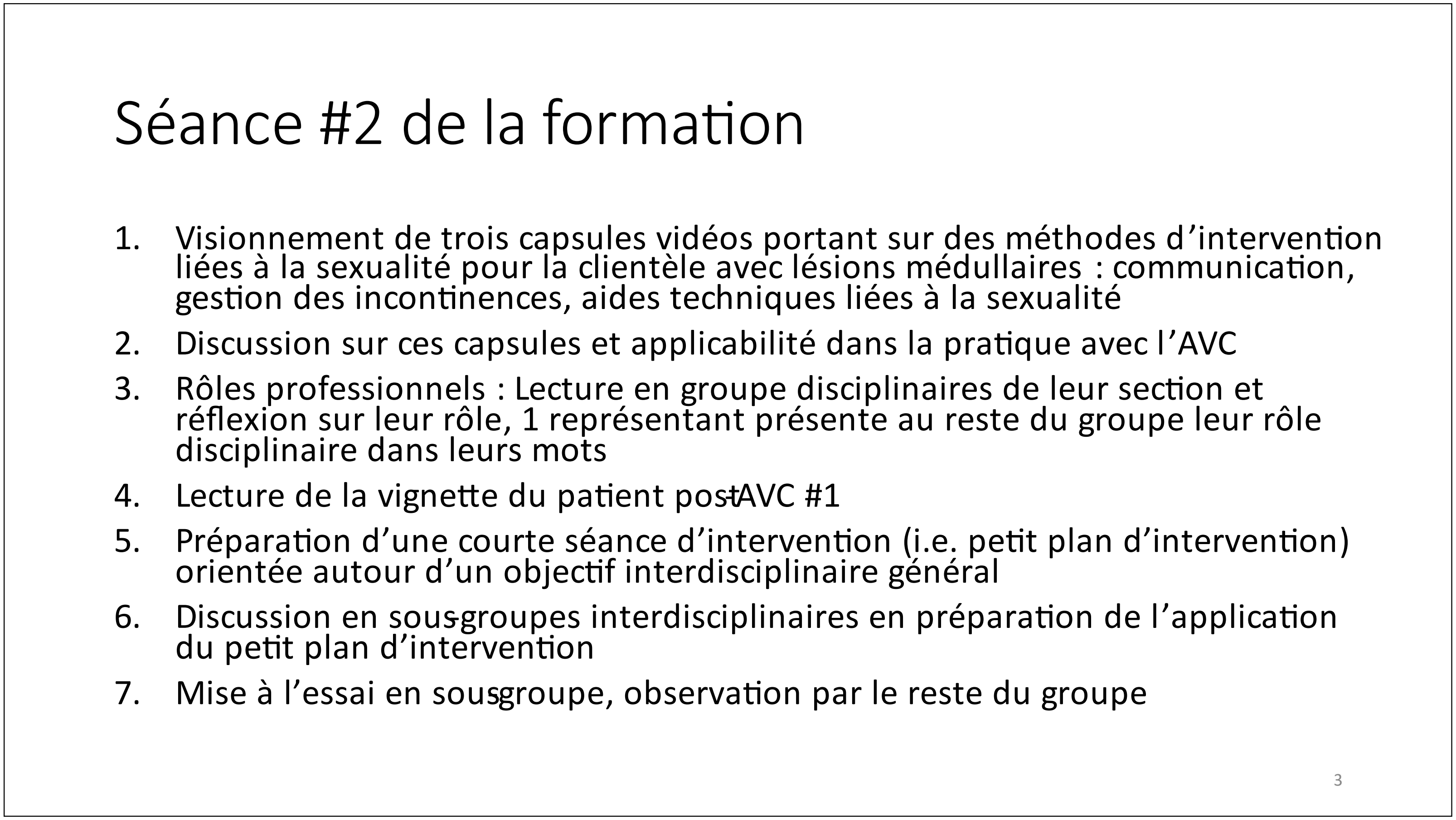
Prototype prévu :

- 2 périodes de 3h, séparées d’au moins 4 semaines
  - Les participants ont demandé d’avoir du temps pour assimiler le contenu
- En présentiel
- Formation interdisciplinaire
- En quelques mots : **concret, applicable, représentatif de la réalité**
- Les participants seront exposés aux outils du programme et auront à «jouer avec» dans des situations cliniques concrètes
- Nombre de participants -15 à 20, interdisciplinarité



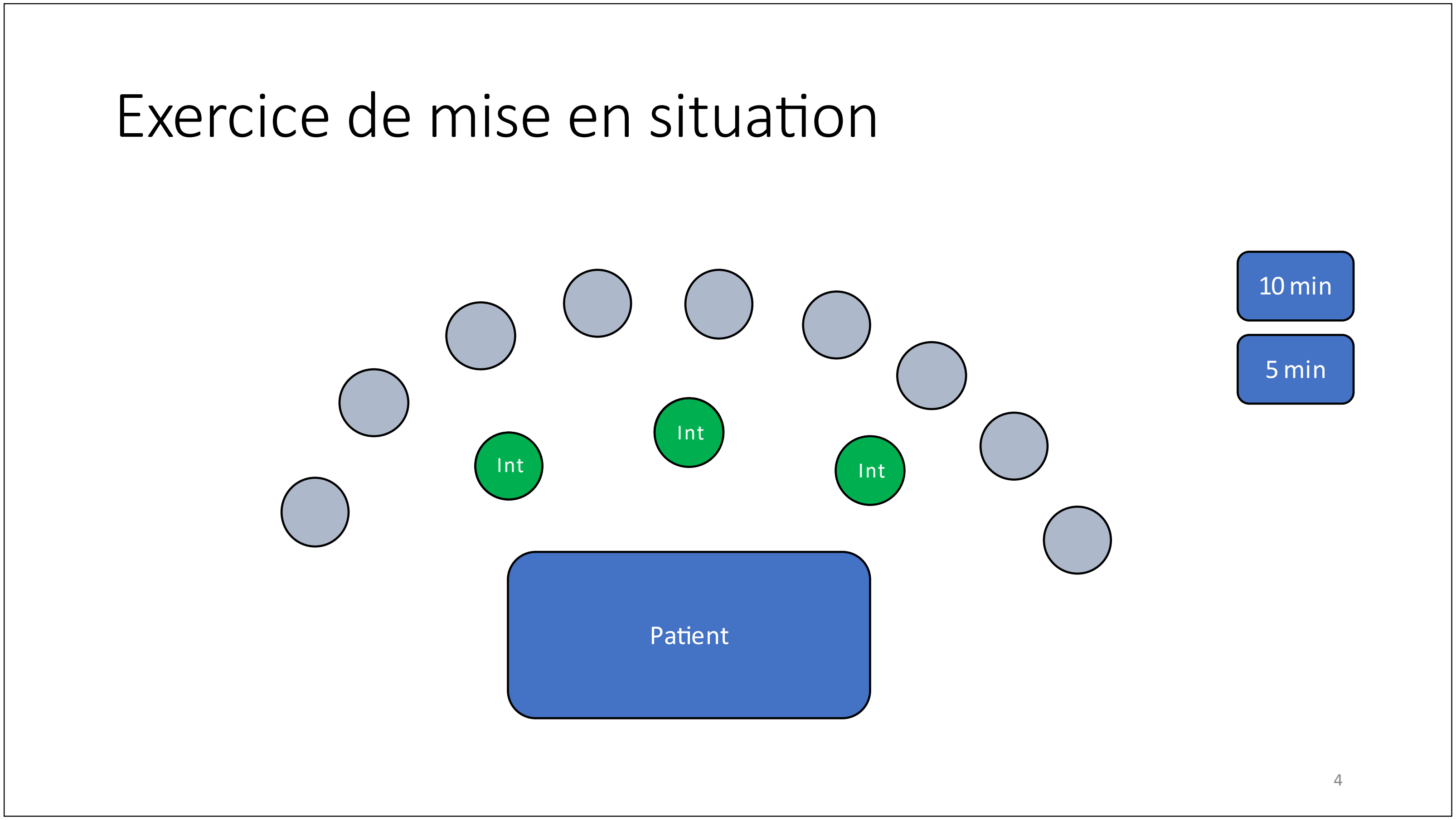
Séance #1 de la formation

- Visionnement d'un témoignage d'une personne post-AVC sur la sexualité suite à son AVC
- Rappel théorique rapide sur l'impact de l'AVC sur la sexualité
- Révision des questions les plus fréquemment posées par les personnes post-AVC re : sexualité
- Présentation du guide d'entrevue sur la sexualité
- Mise à l'essai du GES en équipes de deux avec des vignettes de thérapeutes et clients pré-établies. Clients #1 et #2
- Rétroaction structurée en équipes de deux puis en groupe
- Remise des répertoires de rôles et du guide d'entrevue semi-structuré pour lecture entre les deux formations
- Établissement d'un objectif d'apprentissage d'ici à la prochaine formation



Séance #2 de la formation

1. Visionnement de trois capsules vidéos portant sur des méthodes d’intervention liées à la sexualité pour la clientèle avec lésions médullaires : communication, gestion des incontinences, aides techniques liées à la sexualité
2. Discussion sur ces capsules et applicabilité dans la pratique avec l’AVC
3. Rôles professionnels : Lecture en groupe disciplinaires de leur section et réflexion sur leur rôle, 1 représentant présente au reste du groupe leur rôle disciplinaire dans leurs mots
4. Lecture de la vignette du patient post-AVC #1
5. Préparation d’une courte séance d’intervention (i.e. petit plan d’intervention) orientée autour d’un objectif interdisciplinaire général
6. Discussion en sous-groupes interdisciplinaires en préparation de l’application du petit plan d’intervention
7. Mise à l’essai en sous-groupe, observation par le reste du groupe



Exercice de mise en situation

10 min

5 min

Int

Int

Int

Patient