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Establishing dimensionality of sexual behaviours in patients with regional brain dysfunction

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Abstract

Objective: To develop a validated, caregiver-based measurement scale to assess sexual changes across several domains in a sample of 86 patients with penetrating traumatic brain injury (TBI) and 65 patients with neurodegeneration due to frontotemporal dementia and corticobasal syndrome.

Methods: A new measure, the Sexual Symptoms in Neurological Illness and Injury Questionnaire (SNIQ), was constructed. Dimensionality, monotonicity, item discrimination power, and scalability were evaluated using nonparametric Mokken item response theory (IRT) methodology.

Results: Three primary domains were established. The domains presented with sufficient reliability (ρ .70 to .80), while meeting the Mokken IRT criteria of medium scalability. The domains were labeled 'Prosocial sexual behaviour' ($H=.42$), 'Sexual interest' ($H=.50$), and

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‘Inappropriate sexual behaviour’ ($H=.41$). A fourth dimension emerged, ‘Detachment’ ($H=.47$), but with very few items.

Conclusions: Construct validity was established for groups of items pertaining to three unique aspects of sexuality. These findings support further use of the SNIQ in assessing and researching sexual behaviours in patients with dementia and brain injury.

Keywords

inhibition; sexuality; construct validity; brain injury; dementia

Introduction

Changes in sexual behaviour following the onset of neurodegenerative disease or traumatic brain injury (TBI) have been reported and described in several studies (1–4). These changes encompass a broad scope of behaviours, including personal changes in arousal, frequency of intercourse and ability to climax (3, 5–7), inappropriate sexual behaviours such as public masturbation or exposure (8–11), and changes in intimacy within relationships (12). These changes may be bidirectional; for example, Mendez and Shapira (2013) reported that 13% of the participants they examined with frontotemporal dementia (FTD) showed increased sexual drive and inappropriate behaviours (4), while Ahmed et al. (2015) found increased hyposexuality, such as decreased initiation of sexual relations, in the majority of participants with FTD (13). Similarly, Downing et al. (2013) found that although the majority of participants with TBI showed decreased sexual functioning and relationship quality, 16% showed an increase in these domains (3). Sexual dysfunction due to neural injury is diverse, as challenging to manage as other behavioural disturbances, and significantly affects the lives of both patient and caregiver (14). In the current study, we pooled data from patients with dementia and brain injury to validate the Sexual Symptoms in Neurological Illness and Injury Scale (SNIQ), a caregiver-based scale that measures sexual changes associated with regional brain dysfunction.

While most scales used in patients with TBI and dementia focus on problematic, clinically relevant behaviours, the purpose of the SNIQ was to assess changes in sexual behaviour in preparation to investigate the neuroanatomical bases of these symptoms. Thus, the SNIQ was designed to assess symptoms broadly (i.e. assessing behavioural changes whether or not they are clinically relevant), bidirectionally (i.e. assessing the emergence of new behaviours as well as the stopping of previously performed behaviours), and in reference to baseline behavior (15).

To our knowledge, three prominent scales have been used to measure sexual symptoms in patients with neurological illness and injury. The St Andrews Sexual Behaviour Assessment (SASBA), was designed to assess patients in an institutional setting through clinical staff observation (16). This scale is most sensitive to the extreme inappropriate sexual behaviour exhibited in institutional settings. Because it is completed by clinical staff, there are no items covering personal sexual dysfunction or changes from premorbid sexual behaviour.

The second commonly used measure is the Brain Injury Questionnaire of Sexuality (BIQS) (3, 5–7). This questionnaire focuses primarily on physiological sexual function, excepting three items that address relationship quality. It does not capture any of the disinhibition or inappropriate sexual behaviours that often occur in patients with TBI or neurodegenerative disease.

The third scale is the Sexual Behaviour and Intimacy Questionnaire (SIQ) (13). This scale was designed to capture pre- and post-morbid sexual behaviours in patients with dementia, using caregiver report. The SIQ covers a broad range of symptom types, captures base rates, and is administered to spouses. The scale focuses primarily on interpersonal relations, with the exception of some items on aberrant sexual behavior, and it does not include questions on physiological function, such as ability to maintain arousal or orgasm. The SIQ is a brief scale, comprised of 13 items. To our knowledge, its reliability and validity have not yet been evaluated.

The goal in developing the SNIQ was to create and validate a questionnaire that combines facets of these three scales, capturing sexual symptoms pertaining to inappropriate sexual behaviours, physical function, and interpersonal relationships and intimacy.

One challenge in developing an accurate scale is the unreliability of self-report in people suffering from neurological injury. Both dementia and TBI can result in a marked lack of insight (17, 18). Patients often minimize their behavioural symptoms due to anosognosia, a common symptom of dementia and brain injury that can influence self-report. For this reason, it is prudent for scales to incorporate reports from a spouse, partner, or caregiver. Partners can provide base rates of premorbid behaviours--essential for measuring change, as normal sexual behaviours vary in non-clinical populations (19). In addition, partners contribute valuable information about changes in patients' intimacy within their relationships. For these reasons, the SNIQ is designed to be completed by caregivers.

Another challenge in creating a scale is that existing research on sexual dysfunction tends to over-emphasize behaviours that violate social rules, such as disinhibited sexual behaviours, because they are most problematic for caregivers. Conversely, more passive changes such as decreased sexual drive (hyposexuality) may be considered less problematic and therefore be reported less often. This overemphasis on disruptive behaviours limits an understanding of the range of sexual changes that can arise from neurological injury. For example, some conceptualize hyposexuality as the converse of disinhibited sexual behaviour, but others (Lawrie, 2004; Ahmed et al, 2015) assert that hyposexuality can be concurrent with impulsivity and inappropriate sexual behaviours. To better understand how these symptoms co-occur, we included items addressing both increased and decreased sexual interest in the SNIQ.

A final problem in creating an effective research scale is that scales are often disease-specific and geared toward clinical application. From a neurological research perspective, this is limiting, as a variety of neurodegenerative diseases and brain injuries can have similar neurological effects and present with overlapping symptoms. While they are not often studied together, both acquired neural injury (e.g. trauma from a head wound) and atrophy

due to a neurodegenerative disease cause regional brain dysfunction. There are important distinctions between the diagnoses: for example, neurodegenerative disease is progressive and thus its symptoms are more likely to change over time than symptoms due to a traumatic injury. However, our interest was in how regional brain dysfunction affects sexual behaviour, not in the particular etiology of the dysfunction. For this reason, we chose to validate the SNIQ in a sample of patients with both penetrating (open head) TBI and neurodegenerative disease (FTD and corticobasal syndrome, CBS). We hoped that in this diverse sample, we would capture a wider range of symptoms.

The goal of the present study was to examine the construct validity of a new measure, the Sexual Symptoms in Neurological Illness and Injury Questionnaire (SNIQ), a caregiver-based measurement scale designed to assess a broad scope of sexual behaviours in a sample of patients with regional brain dysfunction. The items capture behaviours across the entire hypo-hypersexual spectrum. Its design was modeled on the Frontal System Behavioural Inventory (FrSBe) to include both premorbid and postmorbid behaviours (20). We sought to enhance construct validity by examining dimensionality, item discriminatory power and monotonicity.

Method

Participants

A total of 151 participants took place in the present study. Participants fell into one of two groups: Vietnam veterans with head injuries studied in the Vietnam Head Injury Study (VHIS) and people with neurodegenerative disorders studied in an ongoing research study on non-Alzheimer's dementia at the National Institute of Neurological Disorders and Stroke (NINDS) in the Cognitive Neuroscience Section of the NIH, Bethesda, MD. Demographic characteristics for the participants are represented in Table 1.

Participants were comparable in age and years of education. All Vietnam veterans with TBI were male. Participants with TBI had much earlier onsets of injury than those with dementia, as their injuries were sustained during the Vietnam War. Participants in the dementia groups showed clear cognitive impairment, falling in the bottom quartile of performance on the Mattis Dementia Rating Scale (21). Participants in the TBI group were within normal limits in measures of intelligence (the Wechsler Adult Intelligence Scale (22)) and cognitive impairment (the Mini Mental State Exam (23)). Both groups showed behavioural symptoms as evidenced by the Neuropsychiatric Inventory (24) and the Neurobehavioral Rating Scale (25), but these were more severe in the dementia groups. These descriptives imply that the neural damage in participants with dementia was more widespread than in participants with TBI.

The Vietnam veterans with head injuries were seen as part of the longitudinal W.F. Caveness Vietnam Head Injury Study (VHIS). This study had several phases of evaluation. The data for the current study were taken from Phase IV, conducted from 2009 to 2013 at the National Naval Medical Center in Bethesda, MD. During Phase IV, participants received extensive neuropsychological testing, including the sexual symptoms questionnaire and a CT scan of

the brain [see (26) for description of the VHIS]. All participants gave informed consent and all procedures were approved by the appropriate IRB.

Participants with neurodegenerative illness were either self-referred or referred by a neurologist to the study conducted in the intramural programme at NINDS. Participants were referred with diagnoses of FTD or CBS, but the diagnosis was re-evaluated at NIH based on published criteria (27, 28). The participants received MRI and FDG-PET scans and extensive neuropsychological testing at NINDS. All participants were required to have an assigned power of attorney suitable for research. The power of attorneys gave written informed consent while the participants gave assent for the study. All aspects of the study were approved by NINDS Institutional Review Board.

Participants in this study were accompanied by caregivers. All caregiver informants were heterosexual spouses and partners of the patients, with the exception of one informant of a patient with TBI and four informants of patients with dementia. These informants (an ex-girlfriend, a friend, a sister, two daughters, and one uncharacterized) were asked to estimate any changes in sexual behaviour related to the injury based on reports from other family members and friends. All informants for patients with dementia knew the patients before and after the onset of illness. Informants for the Vietnam War veterans had been in relationships with the participants for an average of 27.5 years (SD 11.83), however many did not know their partners prior to injury, due to injuries having occurred in the 1960s. For this reason, we only performed analyses on current patient symptomatology.

SNIQ Questionnaire

Caregivers rated the frequency of 39 specific behaviours before and after the onset of illness or injury on a 5 point Likert scale (1=Never, 2=Sometimes, 3=Frequently, 4=Very often, 5=All of the time or almost all of the time). We chose this model of questionnaire because it provides information on pre-morbid behaviours, and because it uses frequency measures to record behaviours that are otherwise difficult to quantify. In addition, the SNIQ includes four items rated on individualized 5-point likert scales and four numeric or open-response items (See Table 2).

Individual items were developed from a series of non-structured clinical interviews with approximately 20 patients with neurodegenerative disease and their spouses about sexual changes that had arisen since the onset of the disease. The interviews covered a range of sexual domains (functioning, intimacy, behaviours, hypo/hyper-sexuality) and included discussion of premorbid sexuality. All interviews took place at the National Institute of Neurological Disorders and Stroke. From the interviews, initial items were developed based on observed trends and specific reported symptoms. A committee of experts in relevant areas (including a psychiatrist, neuropsychologists, neurologists, and a sexologist who had experience with sexual disorders) met to review the initial items, adding to and changing them based on clinical experience and discussion. The SNIQ was then piloted with several more neurodegenerative disease patients and their spouses, and was further updated. While the SNIQ was developed in patients with neurodegenerative disease, based on overlap with reported symptoms in patients with TBI (7, 29), we predicted that it would translate to

patients with TBI and possibly to other diagnostic groups in the future. The final set of items is presented in Table 2.

Ten of the items proved exceptionally difficult for caregivers to respond to, with an average of 25% of participants failing to report on each item. These items included questions pertaining to masturbation, difficulties with erection or vaginal dryness, pain during sex, difficulty reaching orgasm, and quality of life. Excluding participants who did not respond to these items would have substantially reduced the sample size. For this reason, we chose to exclude these items from the analysis. We will discuss these items in the future directions section of this manuscript. The total number of items included in the analysis was 35. The initial coding of the items was polytomous, with five frequency response categories (1= 'Never' to 5= 'All of the time or almost all of the time'). However, because most participants experienced only a small number of the wide range of potential symptoms, responses were not normally distributed across the 5 categories for all questions. Consequentially, we collapsed and dichotomized responses to a yes/no option. Responses of 'Never' were coded as 'no,' and responses of 'Sometimes', 'Often', 'Very often', and 'All of the time or almost all of the time' were coded as 'yes'. Empty cells were directly related to the limited sample size in terms of item response theory methodology.

Data analysis

Item response theory (IRT) is a psychometric technique used in the development, evaluation, improvement, and scoring of multi-item scales (30). IRT comprises a host of statistical models employed to define the relationship between an individual's unobserved continuous trait or latent construct (e.g., fatigue, perceived self-efficacy, sexual proclivities) and item characteristics (e.g., ease of endorsing an item that reflects prosocial sexual behaviour) to predict the probability of endorsing an item on a scale (31, 32). Mokken scaling is a non-parametric IRT model used to assess whether a number of items measure the same underlying construct or trait, and in ways may be considered analogous to factor analysis (33). Mokken scaling orders items within a particular domain hierarchically, such that if a person responds yes to a more 'difficult' question (i.e. a question denoting greater dysfunction), he or she has a high probability of also responding yes to the less 'difficult' questions within the same domain, i.e. questions that denote less dysfunction (34). The Mokken model specifies the relationship between the item and latent trait in terms of an item characteristic curve (or ICC). This curve represents the probability of a positive response on an item, given the respondent's latent trait in a particular domain (35).

Construct validity can be defined in several ways, e.g., reference to an external network (nomological) of variables that relate to the construct under investigation (based on well-established theories), or the way in which item responses depend on theta/latent construct (36). Though the conception of construct validity has shifted over time, Rosenbaum's 1989 model (37) is currently well regarded in the field of psychometrics. Rosenbaum uses the term criterion-related construct validity, which is established based on four criteria: unidimensionality, monotonicity, local independence, and the absence of differential item functioning (i.e., item bias based on group membership). Mokken scaling addresses the first three criteria within in the Monotone Homogeneity Model (MHM) framework.

Dimensionality determines whether one, two, or three total scores are needed for proper interpretation of a participant's psychological state. Local independence indicates that, given their level of the construct, individuals' answers to the items are independent. The monotonicity feature assures that the probability of endorsing an item is a non-decreasing function of the latent trait or construct. When all of these assumptions are met, a set of items fits within the MHM. This means that for all items, as the score on the latent trait increases, the score on the items in the scale should also increase. Individuals can thus be ordered in terms of their latent trait (θ)/'ability' by the sum of their item scores (38, 39).

The Mokken Scaling Procedure (version 5.0 for Windows (40)) was used to examine the items of the SNIQ pertaining to current symptomatology. The model produces a 'scalability' diagnostic (Loevinger's H coefficient) to assess these MHM assumptions (41). The primary function of the Mokken scalability component is to assess the degree to which patients can be ordered on the latent trait by means of their summary score (42). Several statistics based on the Loevinger's H coefficient are produced to confirm that the MHM holds. Less discriminating items have response probabilities that are less responsive to changes in trait level (43). From the item H values, Mokken produces a weighted sum, referred to as the Total H or scale H . When interpreting H , the following guidelines are common: 0.3–0.4 = weak scale, 0.4–0.5 = medium scale, and > 0.5 = strong scale (44). Finally, for the nonparametric Mokken scaling, Rho is used to define scale reliability and is an internal consistency coefficient comparable to Cronbach's alpha (45).

The most popular method for assigning individual items to each construct is the automated item selection procedure--ASIP (automated item selection procedure). The purpose of such procedures is to select as many items as possible from the total pool into unidimensional subscales based on meeting specified criteria for discriminability. Murray, McKenzie (46) provides an outline of the early staging:

1. The item pair with the highest positive H_{ij} (item i & item j) value is selected. Mokken Scale Analysis (MSA) produces several H coefficients: Mokken scale analysis uses three types of scalability coefficients to assess the quality of (a) pairs of items, (b) individual items, and (c) an entire scale. MSA seeks to establish the MHM based on the assumptions of unidimensionality, local independence, and monotonicity of the item response function (IRF; a respondents probability of endorsing an item; fundamental unit in IRT).
2. From the pool of the remaining items, the item is selected that
 - a. covaries positively with the items selected in Step 1 (Scale Condition 1); the procedure deems item pairs with negative inter-item covariances as unacceptable for the chosen domain, thus, for any set of items comprising a scale, the interitem covariances must be nonnegative (47).
 - b. has an H_i value with respect to the already selected items that is significantly larger than zero and is equal or larger than the predefined lowerbound c (Scale Condition 2), with the lowerbound default set to .30.

- c. maximizes the total H , considering the items already selected.

Step 2 is repeated until there are no items left that fulfill the conditions for being selected. From the items left over, if any, a new scale is formed, proceeding along the same steps noted above. New scales will continue to be formed until there are no items left that meet the guidelines 2a through 2c. Any possible remaining items are denoted as being unscalable (44, 48).

Results

Means and H coefficients for each item, reliability statistics, and H coefficients for all subscales are presented in Table 3. A phi coefficient matrix is presented in Table 4. All subscales reflected medium scalability strength. In terms of the total scalability coefficient, the best performing domain was 'Sexual interest,' with a total H coefficient of .50. The best performing items for this domain were 'Spend money on sexual pursuits' (item $H=.64$) and 'View pornographic magazines' (item $H=.63$). These high H values suggest that the item characteristic curves are relatively steep, and likely to be quite responsive to changes in the latent trait (i.e. Sexual interest). For the domain 'Prosocial sexual behaviour', the items 'Express love for partner' and 'Physical affection outside of sex' presented with the highest discriminatory power, both at .50. The most divergent item in this scale was the 'Satisfied with sex life currently', perhaps suggesting that satisfaction with sex may share some sexual prosocial features, but that this question taps into another construct. The best performing item (i.e. the item most responsive to changes in the overall construct) from the 'Inappropriate sexual behaviour' domain was 'Talk about sex in inappropriate situations' (item $H=.47$), followed by 'Make sexual jokes in inappropriate situations' (.45). The 'Detachment' domain presented with one dominant item, 'Emotionally disconnected from partner' (item $H=.80$), with which the remaining two items appear to share a relatively small variance; that is, the 'Desire to end the relationship' and 'Contacting old partners' require the individual to be somewhat detached, but perhaps while retaining some emotional availability. Eight items were not endorsed by any caregiver, and so were not included in any of the four emergent domains.

For the nonparametric Mokken scaling, Rho is used to define scale reliability, and is an internal consistency coefficient comparable to Cronbach's alpha (45). The 'Prosocial sexual behaviour' domain proved to be the most reliable, with a Rho coefficient of .80, followed by the 'Sexual interest' scale (Rho = .74), and finally the 'Inappropriate sexual behaviour' scale (Rho = .71). Most theorists agree that a Rho over .80 is desirable, and a Rho over .70 is a minimum requirement(49). The 'Detachment' domain did not meet the proposed reliability standard of .70.

Discussion

From the SNIQ's relatively large item pool of sexuality questions, drawn from a sample of patients with dementia and traumatic brain injury (TBI), we derived four domains of sexuality. Three of the four domains were of sufficient length and met psychometric standards of reliability. Those three domains were 'Prosocial sexual behaviour', 'Inappropriate sexual behaviour' and 'Sexual interest'. Prior to the application of Mokken

scaling IRT methodology, the interpretation of the SNIQ would have been limited to a severity score based on all the items endorsed. However, the application of Mokken scaling allowed for increased interpretive power. We were able to define three domains with monotone homogeneity properties that allow us to be reasonably confident that the item sum scores represent the underlying sexuality construct. Further, we were able to establish item quality or discrimination power.

Deriving the sexuality domains has several important ramifications for clinical practice and research. Each domain may present with a unique pattern of risk or progression of sexual dysfunction related to neurodegenerative disease or traumatic brain injury. Because each scale meets the Mokken monotone homogeneity requirements, changes in sexual dysfunction can be tracked with greater accuracy. Calculating item discriminatory values (item H coefficients) allows for the identification of high quality items, that is, items that are most sensitive to changes in the latent trait. For instance, using the original polytomous item response format (with five frequency response categories), changes in the high discriminatory item options may precede significant changes in total scores.

The components of changes in sexual behaviour we derived have face validity in that they for the most part agree with previous research on the topic. Past researchers have noted dissociations between sexual interest, inappropriate sexual behaviours, and prosocial sexual behaviours in patients with brain dysfunction. For example, patients with FTD can have inappropriate sexual behaviours with both increased and decreased sexual interest (4, 50). De Medeiros and colleagues' (2008) two-factor model splits changes in sexual behaviour into 'intimacy', analogous to the prosocial sexual behaviours we found, and 'disinhibition', analogous to the inappropriate sexual behaviours we found (11). Notable differences between these previous conceptions of change in sexual behaviour and those in the present study is that the SNIQ incorporated more domains and the components of our model of change have been validated with the necessary psychometric analyses. The SNIQ is thus well-suited to achieve our desired goal of investigating the neuroanatomy of sexual symptoms due to regional brain dysfunction. Future research could analyse the correlations between the SNIQ subscales and existing measures and correlates of these domains.

It is worth pointing out that there is some overlap between the 'Sexual interest' and 'Inappropriate sexual behaviour' domains. In some respects, inappropriate sexual behaviours can be viewed as sexual interest in an inappropriate context, or taken to an extreme such that it becomes inappropriate. In general, the two criterion we used to distinguish between the two were **extremity** of behaviour (i.e. 'makes sexual jokes' and 'views internet pornography' fall under interest, but 'makes sexual jokes in inappropriate situations' and 'contact people via internet for sex' fall under inappropriate behaviours) and **legality** (i.e. the distinction between 'acts in a sexually aggressive way toward partner' and 'acts in a sexually aggressive way with people other than partner' or 'acts aggressive in a non-sexual way'). We acknowledge that these distinctions can be murky and can vary depending on interpretation. For example, 'expresses interest in sex with people other than partner,' if the interest was expressed to or in front of a current partner, could be interpreted as an inappropriate behaviour or lack of social cognition. Given the nuance, we would argue that the two

domains do retain face validity in their attempts to piece apart these subtle distinctions. In the future, further analyses could be performed to distinguish between the domains.

Limitations

The sample size proved to be a prominent limitation for this study. Due to an abundance of empty cells, it was necessary to collapse the polytomous item response into a simple dichotomous yes/no response. This resulted in a reduction of information, which is likely to have adversely affected the reliability coefficients. The small sample size also resulted in fewer participants endorsing ‘unpopular’ items (i.e. that their spouses have telephone sex with other people). It is common for psychometricians employing item response theory to exclude items that are endorsed with frequencies $\geq 2\%$ (51). We chose to retain items endorsed with frequencies as low as 1%. This proved troublesome for estimating H coefficients for two items in particular -- ‘Contact via the internet for sex’ from the ‘Inappropriate sexual behaviours’ domain and ‘Attempt to have sex with people other than partner’ from the ‘Sexual interest’ domain. However, despite the lack of data points, these aforementioned items were thought to be clinically relevant to their respective domains (primarily based on face validity). We would like these items to be retained for future studies in which larger sample sizes with more data points can confirm or refute their utility.

The ‘medical’ approach has been criticized [symptom measurement] as placing unwanted faith in various clinical criteria. Conversely, psychometrically sound tests may provide reliable and valid data, but may not yield rich clinical information, and the ways in which patients differ from one to another. In the early development of hard to define constructs, a compromise should be struck (52).

Sample size may also have contributed to the lack of endorsement of eight items capturing more sexually deviant behaviours (e.g. ‘Has sex with someone contacted over the internet,’ ‘Has many sexual partners,’ ‘Views or attempts to view pornography with illegal content’), which were subsequently excluded from the final domains. However, it is also likely that these behaviours are very rare in patients with dementia and TBI, despite the characterization of certain patient groups as hypersexual.

Another limitation is that because our sample of patients with TBI sustained their injuries during the Vietnam War, their time between injury and testing was much greater than for patients with dementia. Because of this discrepancy within the sample, we only analysed current symptomatology of patients, thus not taking advantage of the SNIQ’s capacity to incorporate base rates. In future studies, it would be preferable to include only participants accompanied by caretakers who could answer questions about current *and* pre-illness/injury behaviours (ideally spouses or partners, who would be best equipped to answer more sensitive or private questions).

Limits to construct validity also affected our results, including the potential for confounding variables which are likely to result in item bias, e.g., gender. It was a challenge to develop a valid construct measure without a well-established knowledge base. That is, ‘One cannot show that a predictor of some form of psychopathology is valid, unless one can show that the predictor relates to an indicator of that form of psychopathology that is, itself, valid’ (53).

Further investigations should include item bias or differential item functioning, which will serve to enhance construct validity. Moreover, it would also be very informative to understand how a normal population responds to the scale items.

Future examination of the psychometric properties of the SNIQ will need to address participants' inability to respond to particular questions. Four of the items proved exceptionally difficult for partners to complete. These items included questions pertaining to masturbation, difficulties with erection or vaginal dryness, pain during sex, and difficulty reaching orgasm. The high frequency of missing responses to these items for proxy reporting by partners is likely due to the partner not having knowledge of these experiences or perhaps to their taboo-type aspects. Either way, these items may need special emphasis placed on them by the clinician who gathers the information. We hope that in future studies, sufficient data can be collected on these items to analyse them as a possible fifth 'Sexual function' domain, as prior research clearly shows the prevalence of symptoms in these areas following neurological injury (5). For this reason, we think these items should remain included the scale in future studies. A final limitation of our study is that because our participants with TBI were a part of a Vietnam veteran study, they were all male. In the future, gender-balanced participant groups should be used. Similarly, our sample included exclusively heterosexual partners; preferably future samples would include same-sex couples. Finally, because of the particular disease groups we focused on, our sample is comprised of older adults; future use of the SNIQ could broaden to younger patient groups as well.

In conclusion, the data-driven analysis we performed demonstrates construct validity and provides separable, psychometrically-supported components of change in sexual behaviour derived from patient groups with a high incidence of sexual symptoms. Three domains had properties that allowed us to be reasonably confident that they measured constructs underlying changes in sexual behaviour: 'Prosocial sexual behaviour', 'Inappropriate sexual behaviour', and 'Sexual interest'. These domains hold validity across multiple diagnoses, and thus we anticipate that the SNIQ will be beneficial for research that is not diagnosis-specific. We hope that future research will investigate whether these domains have separable neuroanatomical associations. Further, we hypothesize that neurodegenerative disorders that affect specific neuroanatomical areas (e.g. FTD vs. AD) will have distinct patterns of dysfunction in the components of change in sexual behaviour we identified. These issues will be clarified by further research on this topic.

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Table 1.

Participant demographics.

	<u>TBI</u> [*]	<u>FTD</u> ^{**}	<u>CBS</u>	<u>Other Dementia</u>
N	86	30	20	15
Age	63.4 (3.0)	60.4 (9.0)	62.7 (5.9)	61.3 (8.0)
Gender (M/F)	86/0	18/12	10/10	14/1
Education	14.9 (2.1)	15.6 (2.9)	15.0 (2.5)	16.5 (2.8)
Years since Injury/Onset	41.82 (1.2)	4.8 (3.2)	4.3 (2.1)	5.4 (2.9)
MMSE total	28.8 (1.5)	-	-	-
MDRS AEMSS	-	2.5 (2.8)	2.7 (2.5)	5.7 (4.4)
WAIS full scale	111.0 (23.2)	-	-	-
WAIS performance	105.9 (13.3)	-	-	-
WAIS verbal	105.4 (13.2)	-	-	-
Neuropsychiatric Inventory total	-	33.4 (15.2)	10.8 (11.1)	27.5 (20.6)
Neurobehavioral Rating Scale total	36.0 (13.7)	60.2 (14.0)	56.9 (17.9)	46.1 (20.5)

^{*} Frontal: n=33; Posterior: n=30; Basal Ganglia: n=6; Anterior Temporal: n=4; Uncharacterized/Multiple: n=13

^{**} bvFTD: n=24; PPA: n=3; SD: n=1; FTD-ALS: n=2

MMSE: Mini mental state exam

MDRS AEMSS: Mattis Dementia Rating Scale Age- and Education-Corrected MOANS (Mayo Clinic's Older Americans Normative Studies) Scaled Scores

WAIS: Wechsler Adult Intelligence Scale

Table 2.

Original SNIQ Item Set

Talks about sex	25. Has telephone sex with people other than partner
Talks about sex in inappropriate situations or in an inappropriate way	26. Has sexually explicit text conversations over the internet with people other than partner
Asks strangers to have sex	27. Has sex with people contacted through internet
Exposes self inappropriately in public	28. Views pornographic magazines
Makes sexual jokes	29. Views pornographic films/DVDs
Makes sexual jokes in inappropriate situations	30. Views internet pornography
Expresses interest in having sex with partner	31. Views or attempts to view pornography with illegal content
Performs sexually childish behaviour (e.g., making childish jokes)	32. Goes to strip clubs
Acts in a sexually aggressive way (e.g., attempts to have sex when partner is unwilling)	33. Has sex with prostitutes
Acts in a sexually aggressive way with people other than partner (e.g., attempts to touch strangers)	34. Spends money on sexual pursuits (e.g., pornography, telephone sex)
Acts aggressively in a non-sexual way (e.g., yelling, pushing, or hitting)	*35. Masturbates
Expresses love for partner	*36. Masturbates in inappropriate situations
Performs 'romantic' actions (e.g., buying partner gifts, taking partner out to dinner)	*37. Has difficulties relating to maintaining an erection or vaginal dryness
Displays affection in ways such as helping around the house	*38. Has pain with sex
Is emotionally disconnected from partner	*39. Has difficulty having an orgasm
Displays physical affection before and/or after sex	*40. How many times per month does the patient initiate sex with partner?
Displays physical affection outside of sex	*41. How many times per month does the patient masturbate?
Expresses desire to end relationship with partner	42. (If patient is your spouse or partner): How satisfied are you with your sex life? (1. Very unsatisfied – 5. Very satisfied)
Expresses interest in sex with people other than partner	*43. (If patient is your spouse or partner): How much have sexual symptoms affected your relationship? (1. Not at all – 5. Severely)
Attempts to have sex with people other than partner	*44. How much have these sexual symptoms affected your quality of life? (1. Not at all – 5. Severely)
21. Has sex with people other than partner since being in a relationship with partner	*45. How bothersome are these sexual symptoms in comparison to other symptoms of illness or injury? (1. Not at all – 5. Worst symptoms)
22. Has many sexual partners or changes partners frequently	*46. Has there been any change in the people or objects the patient finds sexually arousing since he or she became ill?
23. Contact people over the internet for sexual purposes	*47. Have there been any other changes in sexual interest or behaviour since illness onset?
24. Contacts old boyfriends or girlfriends	

Note: Items 1–39 are preceded by the prompt 'Please indicate how often your partner...' Study partners then rate the frequency of the behaviour 'Before illness or injury' and 'At the present time' on a scale from 1–5.

* = item was not included in analyses

Table 3.

Mokken scalability of SNIQ subdomains.

<u>prosocial Sexual Behaviour</u>	<u>Mean</u>	<u>Item H</u>	<u>RR</u>	<u>Sexual Interest</u>	<u>Mean</u>	<u>Item H</u>	<u>RR</u>
Expresses love for partner *	0.09	0.50	96	Attempts to have sex with people other than partner	0.01	--	97
Physical affection outside of sex *	0.13	0.50	97	Has sex with others while in a relationship with partner	0.01	0.36	97
Displays affection in ways such as helping around the house *	0.19	0.39	97	Acts in a sexually aggressive way toward partner	0.02	0.43	100
Expresses interest in sex with partner *	0.20	0.47	96	Spends money on sexual pursuits	0.03	0.64	97
Displays physical affection before and after sex *	0.22	0.43	89	Views internet pornography	0.09	0.48	95
Partner's satisfaction with sex life currently *	0.25	0.32	89	Views pornographic films/DVDs	0.12	0.43	95
Performs romantic actions *	0.29	0.43	95	Views pornographic magazines	0.12	0.63	95
Talks about sex *	0.35	0.43	99	Makes sexual jokes	0.31	0.39	100
Total H: 0.42 Rho: 80				Total H: 0.50 Rho: 74			
<u>Inappropriate Sexual Behaviours</u>				<u>Detachment</u>			
Contact people via internet for sex	0.02	--	97	Contacts old partners	0.08	0.34	98
Expresses interest in sex with people other than partner	0.03	0.37	97	Desires to end relationship	0.13	0.32	95
Exposes self inappropriately in public	0.03	0.31	99	Emotionally disconnected from partner	0.55	0.80	95
Performs sexually childish behaviour	0.08	0.43	100	Total H: 0.47			
Acts in a sexually aggressive way with people other than partner	0.10	0.30	97				
Makes sexual jokes in inappropriate situations	0.13	0.45	99				
Acts aggressive in non-sexual way	0.21	0.35	100				
Talks about sex in inappropriate situations	0.26	0.49	99				
Total H: 0.41 Rho: 71							

Mean = mean response to item

Item H = Loevinger's *H* item scalability coefficient

RR = Response Rate (% of sample)

Total *H* = the scalability coefficient and reflects the weighted sum of the item *H* coefficients

Rho = scale reliability measure

* = reverse coded items, e.g., persons in the Prosocial Sexual Behaviour scale *not* 'Expressing love for partner'

Table 4.

Phi (ϕ) matrix SNIQ items

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
Talk about sex after (1)	–	–.39**	.21*	.11	–.36**	–.17	.38**	–.15	.01	.04	–.03	.24**	.40**	.20*	.15	.34**	.30**	.24*	–.13	.13	–.07	.02	–.10	–.15	–.09	–.10	–.01
Talk about sex, inappropriate (2)		–	–.06	.03	.29**	.53**	–.08	.36**	.15	.23*	.27**	.03	.04	.15	.20*	.10	.02	.08	.16	.16	–.06	.07	.23*	.04	–.03	.25*	.03
Caregiver satisfaction w/ sex life (3)			–	.29	–.06	.03	.31**	–.03	.08	.07	.13	.33**	.20*	.27**	.09	.22*	.28**	.22	.03	–.06	–.06	–.01	.08	–.02	–.09	–.04	.03
Expose inappropriately (4)				–	.01	.10	.21*	.15	.13	.39**	.20*	–.05	.26**	.35**	.04	.32**	.10	.10	.31**	–.02	–.02	–.05	.39**	–.06	–.06	–.06	–.03
Sex jokes (5)					–	.52**	–.13	.23*	.11	.21*	.36**	–.01	–.17	–.07	–.04	–.01	–.08	–.08	.01	.15	–.06	.19*	.21*	.31**	.18	.13	.01
Sex jokes Inappropriate (6)						–	.02	.28**	.23**	.18	.35**	.07	.06	.10	.13	.13	.10	.10	.10	.25*	–.04	.21*	.15	.11	.11	.07	.10
Sex interest w/ partner (7)							–	.02	–.09	–.07	.10	.24*	.41**	.31**	.12	.60**	.37**	.30**	–.09	–.05	–.05	–.06	–.07	–.19	–.19	–.16	–.10
Childish sex behavior (8)								–	.34**	.21*	.18	.02	.10	.11	.14	.17	–.02	–.02	.15	–.03	–.03	–.09	.46**	–.01	.20*	.13	–.05
Sexually aggressive, partner (9)									–	.18	.13	.10	.12	.07	–.01	–.10	–.04	.05	.32**	–.03	–.03	.02	.18	.06	.34**	–.01	–.06
Sexually aggressive other, <i>not</i> partner (10)										–	.27**	.19*	.22*	.29**	.13	.26**	.15	.15	.39**	.70**	–.01	.22*	.49**	.16	–.05	.19*	.39**
Act aggressive non-sexual (11)											–	.15	.23*	.35**	.14	.24*	.21*	.21*	.05	.19*	–.05	.03	.27**	.21	–.05	.15	.05
Express love partner (12)												–	.22*	.26**	.16	.30**	.54**	.26**	–.05	.30	–.03	.27**	–.05	.08	–.12	.01	.14
Romantic actions (13)													–	.49**	.21*	.27**	.30**	.24*	.02	.15	–.06	.05	.06	–.05	–.11	.01	.02
Display affection, e.g., help around house (14)														–	.25*	.33**	.31**	.31**	.06	.20*	–.05	.05	.11	.04	–.03	.09	.06
Feel emotionally disconnected (15)															–	.20*	.19	.24**	.04	.09	.09	.26**	.13	–.01	–.06	.03	.15
Affection before/after sex (16)																–	.40**	.33**	.05	.19	–.05	.02	.26**	–.06	–.20*	.07	.05

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
Affection outside sex (17)																		.18	-.07	.25	-.04	.21	-.05	.02	-.06	.07	.10
Desire to end relationship (18)																		–	.10	-.04	-.04	-.01	.15	-.06	-.15	-.03	-.07
Interest in sex others, not partner (19)																			–	-.02	.57	.17	.39	.11	.11	-.05	.31
Attempt sex others, not partner (20)																				–	-.01	.34	-.01	.26	-.04	.30	.57
Sex others, not partner (21)																					–	.34	-.14	.26	.26	-.03	.57
Contact <i>old</i> partners (22)																						–	-.04	.33	.11	.15	.38
Internet contact for sex (23)																							–	-.05	-.05	.19	-.02
Pornographic magazine (24)																								–	.56	.57	.46
Films/DVD pornography (25)																											
Internet pornography (26)																									–	.37	.28
Spend money, sex pursuits (27)																										–	.33
																											–

Note:

* Correlation is significant at the 0.05 level (2-tailed);

** Correlation is significant at the 0.01 level (2-tailed)