BMJ Open

The Impact of Hypersexuality on Spousal Carers of Patients with Parkinson's Disease and Frontotemporal Dementia: A Qualitative Study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2024-090870
Article Type:	Original research
Date Submitted by the Author:	09-Jul-2024
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Keywords:	Caregivers, Parkinson-s disease < NEUROLOGY, Dementia < NEUROLOGY

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The Impact of Hypersexuality on Spousal Carers of Patients with Parkinson's Disease and Frontotemporal Dementia: A Qualitative Study

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Conflict of Interest
The authors declare that there are no conflicts of interest relevant to this work.

Funding Sources
This study received no specific grants from funding agencies in the public, commercial, or not-for-profit sectors. JNP is supported in part by funding from the United Kingdom's Department

of Health NIHR University College London Hospitals Biomedical Research Centres funding scheme.

Keywords:
hypersexuality, spousal carers, Parkinson's disease, frontotemporal dementia

Word Count: 4327

Abstract

Background:
Hypersexuality involves an inability to control intense, recurring sexual impulses, resulting in repetitive sexual behaviors. It frequently manifests as a disorder in patients with neurodegenerative disorders such as Parkinson's disease (PD) and dementia.

Aims:
Using a qualitative approach, the current study aims to explore the impact of hypersexuality on spousal carers of patients with PD and dementia.

Method:
Using the Carer Assessment Interview, a custom-developed semi-structured interview, eight carers (five PD, three dementia) participated in this study.

Results:
Thematic analysis identified twelve themes: manifestations, sexual practices, impact, control, emotional formulations, beliefs in causes of hypersexuality and attributions, relationship with the partner, dealing with hypersexuality, coping with hypersexuality, self-image, stigma, and professional help-seeking. Hypersexuality altered patients' sexual cognitions and behaviors, causing distress and strain on carers' mental health and their marital life. Carers struggled to cope with their partners' hypersexuality, facing emotional burden and barriers to seeking professional help.

Conclusions:
Hypersexuality significantly impacts spousal carers of patients with PD and dementia, affecting their emotional well-being and relationships. Healthcare professionals should recognize and address hypersexuality's psychological and relational implications. Psychoeducation, support groups, and tailored interventions for patients and carers are recommended to mitigate emotional distress. Future research should explore the broader familial impact of hypersexuality and develop effective management strategies.

Keywords:
hypersexuality, spousal carers, Parkinson's disease, frontotemporal dementia

Introduction

Hypersexuality, classified under compulsive sexual behavior disorder in the International Classification of Diseases 11th Revision (ICD-11), involves an inability to control intense, recurring sexual impulses, resulting in repetitive sexual behaviors, which can lead to distress and impairment in personal, social, or occupational functioning (WHO, 2019). Hypersexuality frequently manifests as a disorder in patients with neurodegenerative disorders such as Parkinson's disease (PD) and dementia (Latella et al., 2021). It typically arises as a side effect of dopamine replacement therapy (DRT) in PD (Zhang et al., 2021) and as a result of frontal lesions in dementia (R. De Giorgi & H. Series, 2016). The management of hypersexuality often involves the reduction or cessation of the behavior-inducing drug in PD and a switch to alternative medications like levodopa, catechol-O-methyltransferase (COMT) inhibitors, or monoamine oxidase B (MAO-B) inhibitors (Batla et al., 2016; Samuel et al., 2015).

As patients get older, they tend to become increasingly dependent on family members for support (Schulz et al., 2020). Accumulating responsibilities on the carer can lead to caregiver burden, which encompasses a range of negative responses such as a decrease in quality of life and physical and psychological deterioration (Liu et al., 2020). For example, spouses and female carers of patients with frontotemporal dementia (FTD) tend to experience distress, increased rates of depression, and poor sleep (Caceres et al., 2016). Hypersexuality can worsen caregiver burden and be detrimental to the patients' and their partners' quality of life (Chapman et al., 2020; Soares et al., 2023). Accounts of spousal carers of patients with neurological disorders suffering from hypersexuality are lacking in the literature. Therefore, using a qualitative approach, the current study aims to explore the impact of hypersexuality on spousal carers of patients with PD and dementia.

Methods

Ethics

This study (ethics application ID: 15/LO/0557) was approved by the London-Hampstead National Research Ethics Committee (NREC).

Study Design

This study employed a phenomenological qualitative approach. This approach was deemed most appropriate for the present study since the intention of this study is to understand the spousal carers' personal experiences of the phenomenon of hypersexuality and how they view and interpret their experiences.

Eligibility criteria

Carers were included in the study if they are spouses or partners of patients with clinically diagnosed PD according to the UK Brain Bank Criteria or clinically diagnosed FTD, indicated hypersexuality either in the past or present since developing PD or dementia, and having the ability to provide informed consent.

Carers were excluded from the study if they are spouses or partners of patients with hypersexuality predating the onset of PD or FTD, having co-existing neurological disorders as determined by clinical history, or difficulty understanding/speaking English.

Measure

Carer Assessment Interview. The interview is a semi-structured thirty-four item interview, developed by NT. During the interviews, the participants were asked to reflect on, describe, and/or recount their experience with hypersexuality and its impact on their lives to the best of their abilities considering the sensitive nature of the topic.

Procedure

Spouses of patients with PD who indicated hypersexuality as being an issue during patients' clinical appointments and who were prepared to discuss it in further detail with a researcher were contacted by NT. These carers as well as the carers who contacted the researchers after reading information leaflets about the study circulated by Parkinson's UK were further informed about the study's aims, methods, potential risks and benefits, and confidentiality over the phone.

Carers of patients with FTD or Alzheimer's disease (AD) were informed about the study by the clinical staff at the Dementia Research Centre (DRC), through either the newsletter that was sent out periodically which contained blurbs about the study and the contact details of the members of the research team, or through the carer leaflets passed out at the Frontotemporal Dementia Support Group (FTDSG) March 5th, 2016 Seminar, which took place at 33 Queen Square. These carers were further informed about the study's aims, methods, potential risks and benefits, and confidentiality over the phone.

Interested carers were then asked to come into the Department of Uroneurology at the National Hospital for Neurology and Neurosurgery (NHNN) where any of the available rooms on the scheduled dates was used to provide the participants with written information about the study, obtain written consent, and consequently complete assessment.

A total of twelve carers indicated hypersexuality as having been or still being an issue, eight of whom were carers of patients with PD, four of whom were carers of patients with FTD, and none of whom were carers of patients with AD. Eight carers were successfully recruited into the study. Five PD carers were recruited from the Movement Disorders Centre (MDC) at the NHNN, Edgware Community Hospital (ECH), as well as from Parkinson's UK. Three FTD carers were recruited from the DRC at the NHNN. **Figure 1** presents a summary of recruitment results for PD and dementia carers.

Insert Figure 1.

The interviews ranged from two hours to nearly four hours in duration with as many breaks as required by the participants.

Patient and Public Involvement

It was not appropriate or possible to involve patients or the public in the design, or conduct, or reporting, or dissemination plans of our research.

Data Analysis

Virginia Braun and Victoria Clarke's (2006) thematic analysis approach was used to analyze the qualitative data for this study (Braun & Clarke, 2006). We adhered to the thematic analysis process, which included becoming familiar with the data, organizing the data, generating initial codes, producing the report, naming and defining themes, generating themes, and determining the quality of analysis. Finally, the thematic analysis was checked against a 15-point checklist of criteria for good thematic analysis, which was produced by Braun and Clarke (2006; p. 96).

Results

Characteristics of the sample

A total of N = 8 carers (PD: n = 5 and FTD: n = 3) decided to participate in this study. **Table 1** summarizes the descriptive characteristics of the carer sample.

Insert Table 1.

Qualitative thematic analysis

Twelve themes emerged from the interview data of PD and FTD carers and are as follows: manifestations, sexual practices, impact, control, emotional formulations, beliefs in causes of hypersexuality and attributions, relationship with the partner, dealing with hypersexuality, coping with hypersexuality, self-image, stigma, and professional help-seeking. Quotes under each theme are presented in **Table S1**.

Theme 1: Manifestations

This theme outlines the carer-perceived manifestations of hypersexuality in their partners, encompassing five identified subthemes.

1.1. Indicators

The carers provided accounts of how they became cognizant of the hypersexuality. These instances, termed 'indicators', fell broadly into three categories: (1) their partners told them directly about their hypersexuality, (2) they found out based on changes in their partners' sexual behaviors towards them, or (3) they discovered their partners' clandestine behaviors (Carer 1).

1.2. Desires

Increased desire following the onset of hypersexuality was evident in carers' accounts. The predominant response involved partners exhibiting heightened desire in sexual activity within and outside the relationship, as well as engaging in self-pleasure through masturbation and the use of pornographic material (Carer 7).

1.3. Behaviors

Furthermore, the hypersexuality apparently caused changes in pre-existing behavior or the development of new behaviors. These changes fell broadly into two categories: (1) the adoption of pornographic materials or new sexual behaviors involving others and (2) an increase in the levels or forms of sexual behaviors towards partners or the intensification of old sexual behaviors (Carer 4).

1.4. Preoccupation

One of the main manifestations of hypersexuality was preoccupation with sexual thoughts (Carer 3).

1.5. Compulsivity

Carers perceived that their partners' preoccupation with sexual thoughts translated into compulsive behavior, another main manifestation of hypersexuality. Reported compulsive behaviors varied and encompassed frequent or intense consumption of pornographic materials, visiting prostitutes, and generally indulging in sexual behaviors throughout the day (Carer 3).

Theme 2: Sexual practices

This theme outlines the carer-perceived impacts of hypersexuality on their partners' sexual practices, encompassing four identified subthemes.

2.1. Practices with the partner

Sexual practices with the partner underwent changes in both the frequency and nature of sexual acts. Certain carers reported that their partners, upon developing hypersexuality, expressed an increased demand for sexual activity with them (Carer 7).

Additionally, a majority of carers noted changes in the nature of their partners' sexual demands or behaviors, often describing them as being out of character with the person they were before developing hypersexuality. These changes included, for instance, more aggressive sexual tendencies, demands for role play, and a shift towards more adventurous sexual practices, such as oral or anal sex, which deviated from their previous patterns (Carer 4).

Moreover, certain carers reported a decrease in sexual activity with their partner – in some cases because they started to resist their frequent or inappropriate advances. In other cases, the decline in marital sexual activity seemingly occurred as the partner sought gratification from alternative sources.

2.2. Practices with themselves

The majority of carers reported that their partners also indulged in masturbation and use of pornographic material.

2.3. Practices with others

Sexual practices with others included anonymous sexual encounters, paying for sex, and developing sexual interest in individuals other than the spouse.

2.4. Deviant sexual behavior

Lastly, desires did not appear to translate into paraphilic deviant practices as only one carer reported this (Carer 8).

Theme 3: Impact

This theme outlines the carer-perceived impacts of hypersexuality on their partners' different areas of daily living, encompassing three identified subthemes.

3.1. Marital life

Nearly all carers conveyed that hypersexuality had adverse effects on their marital lives, resulting in diminished intimacy, increased emotional distance between themselves and their partner, and a spectrum of negative emotions on their part. These included feelings of anger, betrayal, despair, disapproval, embarrassment, reduced self-confidence, sadness, and self-blame. Primarily, the impersonal or mechanical nature of their partners' increased demand for sexual activity had generated feelings of disgust or resentment on the part of their spouses. Additionally, these demands altered the nature of their sexual relationship in ways that were unwelcome to the spouses (Carer 1).

Furthermore, certain responses indicated a significant transformation in the nature of the marital relationship. This shift was characterized by a growing lack of respect for the partner and, in some instances, a perceived need to exert control over them in an effort to preserve the marriage (Carer 8).

Many carers emphasized that their partners had become markedly less affectionate and loving towards them in general since the onset of hypersexuality (Carer 1).

3.2. Family, social life and daily activities

Half of the carers reported that hypersexuality had a detrimental impact on their family lives, noting effects on their children that ranged from fathers being absent much of the time to children experiencing trauma or stress due to their father's hypersexuality (Carer 1).

Moreover, hypersexuality had a negative impact on the partners' finances, particularly for those whose hypersexual behaviors involved visits to sex shops for purchases or spending time with prostitutes (Carer 1).

3.3. Health and well-being

Half of the carers reported that their partners experienced sleep disturbances, mood deterioration, and overall poor mental health, as a result of hypersexuality (Carer 8).

Concerning the impact of hypersexuality on their partners' self-confidence, the findings were not clear-cut, with some participants noting a positive and some a negative impact, while others were unsure whether their partner's self-confidence had been affected at all (Carer 4).

Regarding the impact of hypersexuality on their partners' quality of life, the findings were similarly mixed. Four carers mentioned a negative impact, with one providing an explanation. This carer specified that her husband felt he now had a wife who did not love him as much as before, leading to a general sense of deflation.

Theme 4: Control

This theme outlines the carers' perceptions regarding how much control they believed their partners had over their hypersexuality. We identified three subthemes:

4.1. Loss of control

All carers believed their partners lacked control over their sexual behavior, but the extent of this loss varied across individuals (Carer 1).

Carers of patients with dementia characterized them as "*disinhibited*" (Carer 8).

4.2. Attempt to reduce/stop

Half of the carers reported that their partners attempted to reduce or stop their hypersexuality, with varying degrees of success reported among them (Carer 2).

4.3. Desire to overcome

More than half of the carers noted that their partners expressed a desire to overcome their hypersexuality. This was either conveyed through direct verbalization to the carers or others, or inferred from observable efforts to control their behaviors, such as reduced requests for sex (Carer 1).

Theme 5: Emotional formulations

This theme outlines the emotional formulations that the carers had around their partners and/or around the hypersexuality itself.

5.1. Around hypersexuality

At least half of the carers found hypersexuality to be a perplexing phenomenon, leading to a negative emotional formulation marked by shock, confusion, and horror, as they grappled with the profound changes in their long-term partners' feelings and behaviors (Carer 8).

Other carers expressed more positive emotional formulations around the hypersexuality. For instance, one carer conveyed emotions like amusement and interest in response to his wife's newly developed lustful approach (Carer 4).

5.2. Around partner

With the exception of one carer, all carers developed negative emotional formulations around their partners due to hypersexuality. These negative emotions encompassed annoyance,

betrayal, despair, embarrassment, hurt, irritation, pity, and repulsion. These emotions often evolved and changed over time in tandem with the partner's shifting behaviors (Carer 8).

It is noteworthy that carers found it challenging to separate their emotional formulations around their partners from those around the hypersexuality in itself. This may be indicative that the effects of the hypersexuality are overwhelming enough to cause the carers to regard them as being one and the same.

Theme 6: Beliefs in the causes of hypersexuality and attributions

This theme outlines the carers' opinions about the perceived reasons for the onset and progression of the hypersexuality. We identified three subthemes:

6.1. Self-blame
Certain carers attributed the onset of the hypersexuality to themselves (Carer 5).

6.2. Blame on neurological disease and/or its management
Attribution of the hypersexuality to the neurological disease and/or its management was the main reason given by carers for the development of their partner's hypersexuality. All five carers of the PD patients attributed the hypersexuality to the PD and its management (pharmacological and surgical) (Carer 5).

The three carers of the FTD patients, on the other hand, attributed the hypersexuality to the FTD as there had been no sign of it before its onset (Carer 6).

6.3 Blame on partners and their past experiences
Half of the carers attributed at least some aspects of the hypersexuality to their partner' past experiences (Carer 1).

Carer 6 suggested that her husband's hypersexuality might stem from two previous experiences. First, he had been sexually abused as a seven-year-old child by the headmaster of his school. Second, he had an ex-girlfriend of Indian descent during his twenties who died in a car accident. She indicated that both prostitutes her husband had been involved with were dark-skinned and considered that there might be a link between this and the evolution of his hypersexuality (Carer 6).

Theme 7: Relationship with the partner

This theme outlines the carer-perceived impacts of hypersexuality on the carers' relationships with their partners, encompassing three identified subthemes.

7.1. Impact on marriage
Certain carers highlighted changes in the nature of marital sexual activity, a decrease in affection between partners, and a shift in the overall balance of the relationship (Carer 7).

7.2. Image of partner

Some carers stressed that their image of their partners had changed due to their hypersexual behaviors. It seemed that these carers no longer regarded their partners as the same individuals they were before developing hypersexuality, indicating a difficulty in distinguishing between their partners as individuals and the hypersexuality itself (Carer 1).

7.3. Aggression

Evidently, certain carers, experiencing stress and frustration from dealing with their partners and their hypersexuality, expressed either a desire or an actual instance of having an aggressive response to their partners' hypersexuality (Carer 2).

Theme 8: Dealing with hypersexuality

This theme outlines the various ways in which the carers dealt with their partners' hypersexuality, encompassing three identified subthemes.

8.1. Attempt to limit hypersexuality

Carers attempted to limit hypersexuality by placing blocks on the computer, for instance, so that their partner could no longer access any pornography (Carer 8).

8.2. Attempt to uncover facts about hypersexuality

Half of the carers reported actively attempting to investigate their partner's hypersexual behaviors. This included actions such as searching for hidden pornographic materials, checking computers or phones for evidence of visits to sex sites, and examining phones for messages from other individuals that they might be involved with sexually (Carer 1).

8.3. Giving in to hypersexuality

Approximately half of the carers acknowledged their partner's hypersexual behaviors, albeit with dissatisfaction. For a small number, this acceptance extended to a greater degree of understanding and even support in helping their partner to indulge their hypersexual desires outside of the marital relationship (Carer 1).

Theme 9: Coping with hypersexuality

This theme outlines the various ways in which the carers coped with their partners' hypersexuality, encompassing three identified subthemes.

9.1. Responsibility/guilt

Except for one carer, all indicated no responsibility for their partners' hypersexuality. This lack of perceived responsibility may aid in maintaining necessary psychological and emotional distance to cope with the situation's stress and pressure (Carer 8).

9.2. Understanding the hypersexuality

All carers recognized the neurological origin of hypersexuality, yet this understanding did not uniformly translate into effective coping. Certain carers exhibited a more nuanced comprehension of the condition and its manifestations (Carer 7).

9.3. Forgiveness

Certain carers could forgive their partners for their hypersexuality, while others saw no need for forgiveness. Those considering forgiveness found it challenging and could only be achieved sometime in the future. Carer 1, for example, reported that she was "*on the road to forgiveness*".

9.4. Difficulties with coping

Coping with hypersexuality is challenging, with around half of carers facing difficulties, and for a few, leading to a desire to no longer exist (Carer 8).

Theme 10: Self-image

This theme outlines the carer-perceived effects of hypersexuality on the carers' self-image, encompassing three identified subthemes.

10.1. Feeling unloved

Half of the carers felt unloved by their husbands, especially when the sexual relationship became mechanical and non-affectionate due to hypersexuality. This evoked sadness and nostalgia for the previous loving relationships, highlighting shifts in relationship roles (Carer 5).

10.2. Feeling used

The same four carers felt not only unloved but also "*used*" by their husbands for sexual gratification. This signaled to them a shift from a normal loving sexual relationship to one primarily focused on satisfying their husbands' hypersexual needs (Carer 1).

10.3. Self-confidence

Three of the carers who expressed feeling unloved and used by their partners also asserted that hypersexuality and their husbands' consequent demeanor had adversely affected their self-confidence (Carer 8).

Theme 11: Stigma

This theme outlines the two carer-perceived forms of stigma associated with hypersexuality: personal stigma and social stigma.

One carer's reference to the older age group implies a stereotype that older people are less sexual, which may be used to reinforce the belief that hypersexuality is unnatural (Carer 5).

Three carers expressed concerns about the social stigma associated with hypersexuality, fearing that others discovering their partner's condition would reflect negatively on themselves and their families (Carer 1).

During interviews, carers often hesitated, laughed nervously, and apologized when asked sexually-specific questions or prompted to discuss their partners' sexual experiences. This may be attributed to the embarrassment of discussing sex, concerns about crossing social boundaries, and fear of being perceived as inappropriate (Carer 3).

Theme 12: Professional help-seeking

This theme outlines the professional help-seeking barriers regarding hypersexuality, as well as certain aspirations with regards to professional help.

12.1. Barriers

Issues with seeking professional help encompassed communication barriers, lack of understanding, insufficient education, neglect by health professionals, stigma related to hypersexuality, and challenges in discussing sex. All eight carers experienced difficulty obtaining adequate information and assistance for their partners' newly developed hypersexuality, expressing frustration, sadness, and anger over the unavailability of help. A key concern raised is that patients are not adequately informed about the likelihood and implications of hypersexuality when taking drugs for PD (Carer 1).

Certain carers noted a key issue: medical professionals lack knowledge about hypersexuality and show an apparent reluctance to investigate further or take patients' and carers' concerns seriously (Carer 5).

12.2. Aspirations

Due to these barriers, certain carers expressed specific aspirations for professional help for individuals with hypersexuality and their carers. Over half of the carers expressed a desire for health professionals to be educated about hypersexuality and its consequences. This education is seen as a means to enable professionals to educate patients and carers about the condition, with the ultimate goals of alleviating the patient and carer burden of living with hypersexuality and facilitating more effective help-seeking behavior (Carer 8).

Discussion

Using a qualitative approach, the current study aimed to explore the impact of hypersexuality on spousal carers of patients with PD and dementia. This study captured twelve themes illustrated in **Figure 2**.

Insert Figure 2.

In terms of clinical phenomenology, hypersexuality manifested through changes in patients' sexual cognitions and behaviors. These changes can be summarised using the categories presented in **Figure 3**.

Insert Figure 3.

These findings resonate with existing literature on hypersexuality in neurological disorders, particularly PD and dementia. Similar sexual changes have been documented in systematic reviews, aligning with our observations (Codling et al., 2015). Notably, patients with PD and hypersexuality often exhibit sexual compulsivity and impulsivity (Codling et al., 2015; Evans et al., 2009; Isaias et al., 2007; Krueger, 2016), while those with dementia may show sexual disinhibition and inappropriateness (R. De Giorgi & H. Series, 2016). Our study partially supports this distinction, with caregivers of patients with FTD describing behaviors as "*disinhibited*," although overlap with sexual preoccupation and compulsivity was evident. A larger sample size might clarify these distinctions further.

Contrary to expectations, despite increased sexual urges, patients often engaged less frequently in sexual activities with partners post-onset of hypersexuality, often due to partner discontent. Patients sought gratification through masturbation, pornography, prostitution, promiscuity, or affairs, influenced by partner satisfaction or absence. This association between heightened desires and actual sexual practices underscores the role of external factors, echoing literature on marital dynamics where dissatisfaction can lead to extramarital pursuits (Knox & Schacht, 2016).

Psychologically, caregivers reported disturbed moods and diminished mental health in patients, consistent with anxiety often coexisting with PD (Chen & Marsh, 2014). The emotional toll on caregivers was profound, reflecting themes of burden and distress documented in caregiver literature (Calne et al., 2008; Leroi et al., 2011; Leroi et al., 2012).

While all carers attributed their partners' hypersexuality to their neurological diseases, some believed its development is linked to the patients' past experiences. For example, Carer 1 indicated that her husband had a homosexual experience at the age of fifteen with a school friend. She claimed that her husband "*might have been a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him… allowing him… stimulating him to pursue the homosexuality as he had never done*" before. Carer 6 indicated that her husband had an ex-girlfriend of Indian descent during his twenties who died in a car accident. She indicated that both prostitutes her husband had been involved with, and one of whom he fell in love with, were dark-skinned and considered that there might be a link between this and the evolution of his hypersexuality. Two potential reasons for this link can be considered. First, it is possible that past behaviors had never disappeared but rather their partners had been successful in suppressing them. These behaviors resurfaced due to neurological disorders affecting inhibitions. Second, the biological and molecular effects of medications used to manage neurological disorders, like PD, may trigger latent tendencies, although this area remains unexplored within the scope of this research.

The study revealed that hypersexuality profoundly affected carers and strained their relationships with their partners. Some carers, overwhelmed by frustration and despair in

dealing with their partners' hypersexuality, reported experiencing desires or actual instances of aggressive reactions towards their partners.

Despite efforts to cope, caregivers struggled with responsibility, guilt, and at times, aggressive feelings toward their partners, mirroring the challenges seen in sex addiction research (Lerman et al., 2012; Ostrowski & Mietkiewicz, 2015; Praver, 2011; Wadleigh, 2017) (Praver, 2011; Wadleigh, 2017). Extended discussions during assessments, with one lasting over 3.5 hours instead of the anticipated two hours, indicate significant distress among carers. This underscores the urgent need for support and avenues for emotional expression and sharing experiences.

The stigma surrounding hypersexuality emerged as a significant concern for caregivers, influencing disclosure and help-seeking behaviors. Fear of stigma led some caregivers to conceal hypersexuality, decline study participation, or avoid healthcare appointments, reflecting broader societal discomfort with sexual topics (Czyz et al., 2013; Hinchcliff et al., 2005). The barriers to seeking professional help include inadequate communication and education among healthcare providers, exacerbating caregiver distress and prolonging their silence on the issue.

Implications

This study highlights the critical need for healthcare professionals to educate patients and caregivers about potential ICDs associated with PD and dementia, including hypersexuality, and to provide ongoing support and monitoring (R. De Giorgi & H. Series, 2016; Weintraub et al., 2009). Psychoeducation and support groups could benefit caregivers coping with the emotional and practical challenges of hypersexuality.

Limitations

While this study focused on spousal caregivers, hypersexuality's impact extends to other family members, warranting broader investigation. The small sample size restricted our ability to perform thorough quantitative analyses or extend findings beyond our specific study group. A larger sample would enable more rigorous exploration of relationships between factors like disease severity, medication effects, and hypersexuality. This would enhance the applicability of results across different patient demographics and clinical settings, offering stronger evidence for clinical practices and interventions.

Future directions

Future research should employ mixed methods to mitigate underreporting and explore comprehensive management strategies for hypersexuality in PD and dementia. Addressing stigma through public education and improving healthcare providers' readiness to discuss sexual health are crucial steps in supporting caregivers and patients alike.

Conclusion

In conclusion, hypersexuality in neurological disorders profoundly affects patients and caregivers, demanding tailored interventions and support mechanisms to alleviate its emotional and psychological toll.

Author Roles

1. Research project: A. Conception, B. Organization, C. Execution;
2. Qualitative Analysis: A. Design, B. Execution, C. Review and Critique;
3. Manuscript Preparation: A. Writing of the first draft, B. Review and Critique;

NT: 1A, 1B, 1C, 2A, 2B, 3A
JNP: 1A, 1B, 1C, 3B
JF: 2A, 2B, 2C, 3B
CS: 2A, 2B, 2C, 3B
WGES: 3A, 3B

Disclosures

- **Funding Sources and Conflict of Interest**

This study received no specific grants from funding agencies in the public, commercial, or not-for-profit sectors. JNP is supported in part by funding from the United Kingdom's Department of Health NIHR University College London Hospitals Biomedical Research Centres funding scheme.

The authors declare that there are no conflicts of interest relevant to this work.

- **Financial Disclosures for the previous 12 months**

The authors declare that there are no additional disclosures to report.

Ethical Compliance Statement

This study (ethics application ID: 15/LO/0557) was approved by the London-Hampstead National Research Ethics Committee (NREC).

Declaration of patient consent – Interested carers were asked to come into the Department of Uroneurology at the NHNN where any of the available rooms on the scheduled dates was used to provide the participants with written information about the study, obtain written consent, and consequently complete assessment.

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Table 1. Carer sample descriptives.

Variable	Carer 1	Carer 2	Carer 3	Carer 4	Carer 5	Carer 6	Carer 7	Carer 8
Neurological disorder	PD	PD	PD	PD	PD	FTD	FTD	FTD
Medications at the time of hypersexuality*+	Stalevo Rasagiline Clonazepam Fludrocortisone Movicol Atropine	Ropinirole Amantadine Selegiline Madopar Stalevo	Ropinirole Madopar Citalopram	Ropinirole Rasagiline Entacapone Amantadine	Ropinirole Madopar Stalevo	-	-	-
Implicating medications*+	Stalevo	Ropinirole	Unsure (Ropinirole)	Rasagiline	Ropinirole	-	-	-
Implicating medication reduced or discontinued*+	Yes discontinued	Yes discontinued	Yes discontinued	Yes discontinued	No	-	-	-
Still hypersexual+	Deceased	Yes	Yes	No	Yes	Deceased	Yes	Yes
DBS*	No	Yes	No	No	No	-	-	-
Type	-	Bilateral STN	-	-	-	-	-	-
Associated symptoms								
Sexual behavior	Preoccupation with sex Increased desire for sex generally Change in sexual orientation Uncontrollable masturbation Pornography Sex phone lines Sex channels	Preoccupation with sex Increased desire for sex with wife and generally Having sex more frequently Increased masturbation Pornography Fetishism	Preoccupation with sex Increased desire for sex with husband and generally Having sex more frequently Insatiable desire for masturbation	Increased desire for sex with husband Having sex more frequently Sexual attraction for therapist Having sex on stairs Hint of S&M Pornography	Preoccupation with sex Increased desire for sex with wife and generally Increased masturbation Pornography Sex phone line Dating sites	Preoccupation with sex Increased desire for sex generally Pornography Sex phone lines Dating sites Massage parlors Prostitutes	Preoccupation with sex Increased desire for sex with wife and generally Having sex more frequently Increased masturbation	Preoccupation with sex Increased desire for sex generally Increased masturbation Pornography Deviant interests Fantasies of dressing in women's underwear

	Visiting sex shops							
Other impulse control disorders	None	Compulsive eating Compulsive buying	None	Compulsive eating	None	Compulsive buying	Compulsive eating	Compulsive eating Compulsive buying
Other compulsive behaviors	None	None	None	Desire to move	None	None	None	Clock-watching Writing down electricity and water readings

DBS: deep brain stimulation; FTD: frontotemporal dementia; PD: Parkinson's disease; STN: subthalamic nucleus
*. There is no data available for the respective variables for Carers 5, 6, and 7 criteria only applicable to PD patients.
+. Information obtained from patient's clinical notes.

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Figure 1. Flowchart summarizing the recruitment results for Parkinson's disease and dementia carers.
AD: Alzheimer's disease; FTD: Frontotemporal dementia; HS: hypersexuality; PD: Parkinson's disease

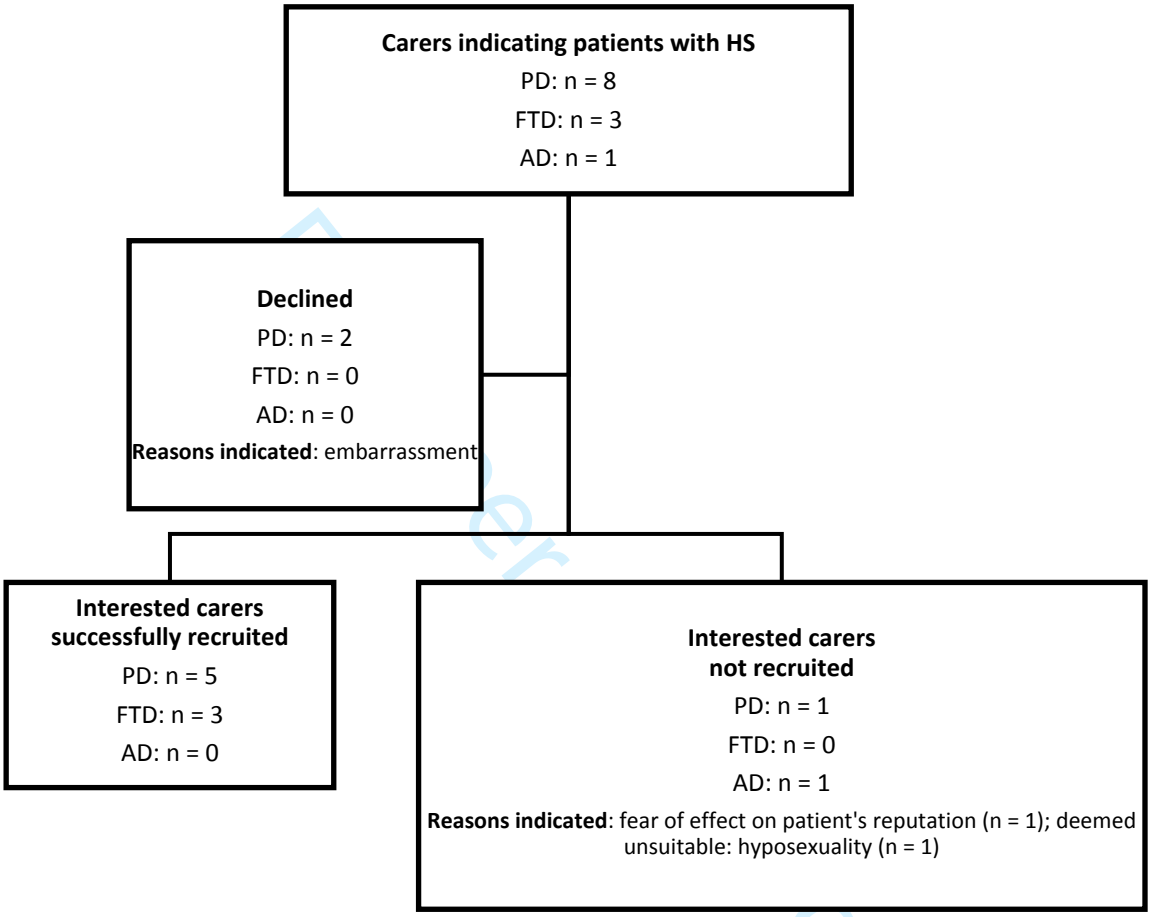
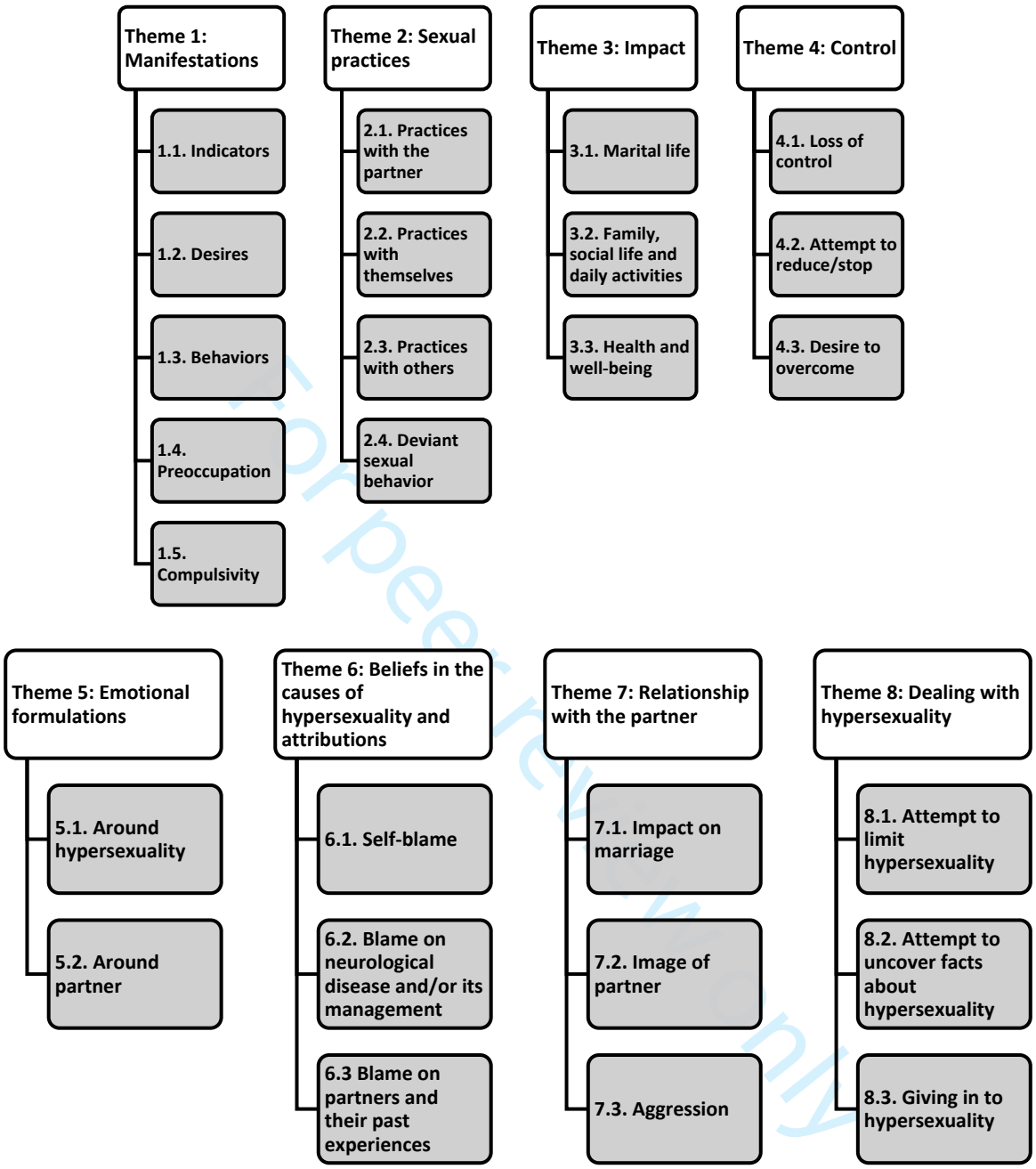


Figure 2. Themes and subthemes identified in the interviews.



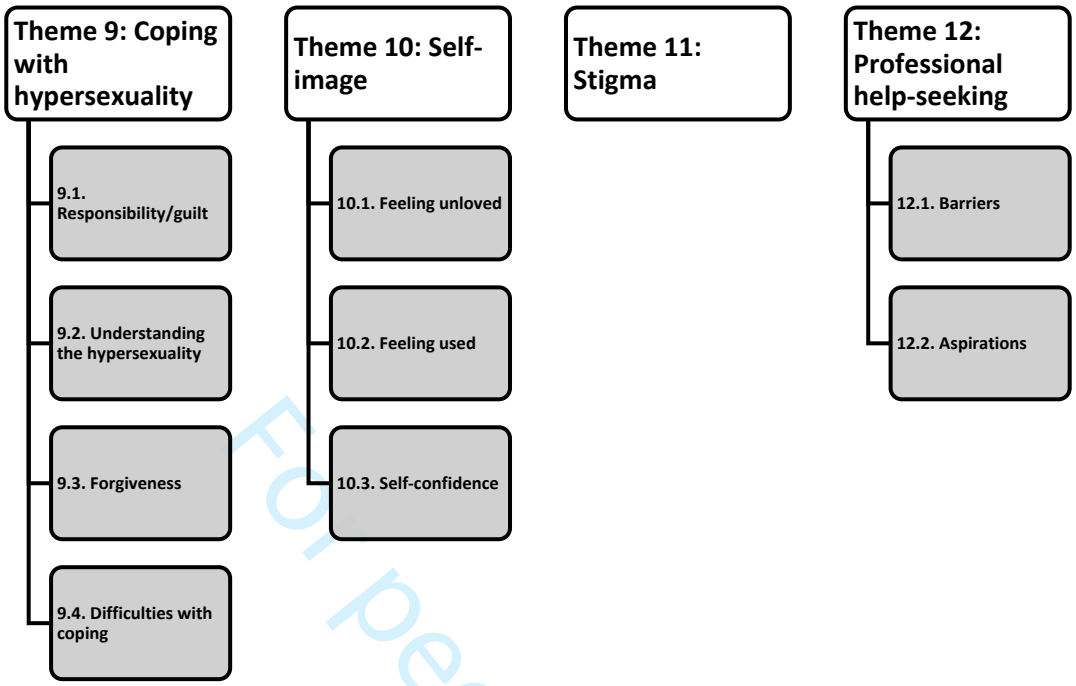


Figure 3. Summary of categories for clinical phenomenology of hypersexuality in Parkinson's disease and dementia.

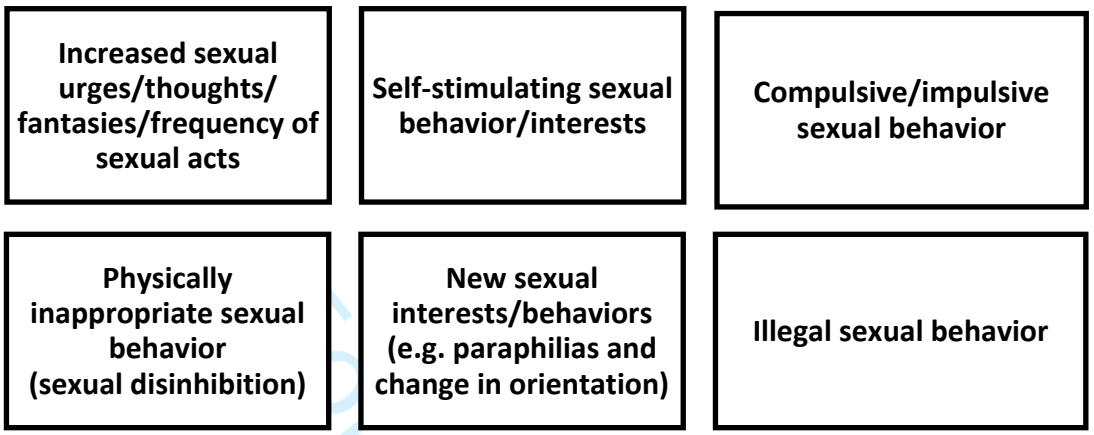


Table S1. Emergent themes, subthemes, and quotes analyzed for Parkinson's disease/frontotemporal dementia carers.

Themes	Subthemes	Quotes
Theme 1: Manifestations	**1.1. Indicators**	"I found a till receipt for a gay magazine… I sat on the knowledge for a couple of weeks but first of all I went straight up to WH Smith and bought a copy of the magazine thinking that either it wasn't what I thought it was… it was Gay Times… or this had been bought by mistake… I got a copy… I sat there outside and read it and realised it was highly unlikely that it had been bought by mistake…" (Carer 1)
	1.2. Desires	"That's the only thing he's interested in … to have sex." (Carer 7)
		"I don't know where desire's gone because it is practically... it is non-existent… they happened about the same time I think... I think it must be... it must be a good five or six years as far as he's concerned... and I honestly think that things changed for me around sixty..." (Carer 5)
	1.3. Behaviors	"Normally she likes tenderness and sweetness and it was sort of a bit more lust… go for it… behavior was extreme if you like because she's a reserved person … who has other high standards of good behavior… so this was her nature in the raw really…" (Carer 4).
	1.4. Preoccupation	"her thoughts are uncontrollable and come so much of the time…" (Carer 3)
	1.5. Compulsivity	"Hypersexuality is present all throughout the day and during the night while I am asleep…" (Carer 3)
Theme 2: Sexual practices	**2.1. Practices with the partner**	"And now [he was asking for sex] every morning… every evening… sometimes he's asking during the day…" (Carer 7)
		"She didn't ask for Fifty Shades of Grey no… but still … a little hint of S&M which really wasn't part of our repertoire…" (Carer 4)
		"Things like going outside the door and knocking on the door and coming in or something… you know… I'm somebody he's picked up outside or something and who knocks on his door and slips in with exotic underwear on or something… never had all this before… it's just weird… like he was sort of switched off… he's actually thinking he's with a prostitute or something I don't know…" (Carer 5)
	2.2. Practices with themselves	
	2.3. Practices with others	
	2.4. Deviant sexual behavior	"It needs to be more upfront that it's not just about a decrease in sex or an increase in sex… it could be a decrease in a normal sexual relationship and a… a subverted or a hidden cover increase in some kind of deviant sexual behavior which had been what was going on for twenty years and I didn't know about…" (Carer 8)

Theme 3: Impact	**3.1. Marital life**	"It was dreadful… devastating … I couldn't make head and the tail of it… it just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)
		"It's awful really because he's not the same person… apart from everything else that's going on… I feel like I'm sort of living a double life and sort of have to live his life as well and double check everything … life's so difficult so it's not surprising that I'm tired…" (Carer 5)
		"I've always thought of it very old fashioned as making love… sex for sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex..." (Carer 1)
		"It's kind of became more of ritual… more of a… I mean he would say things like 'I need a fuck'… like every morning and every evening, I have felt really pursued… that's the only thing he's interested in… is to have sex" (Carer 7)
		"It's difficult to separate if it's the dementia or more the sexual aspect of it… it's kind of loss of companionship in all areas so it has affected the relationship…" (Carer 7)
		"I'm competing with the women on television… sometimes I'm thinking… does he think that he's making love to me or does he think he's making love to somebody off the television…" (Carer 5)
		"I've lost respect for him… how can you respect someone that gets off of watching little boys being humiliated… I've said to him I won't collude or condone with anything he's done… and I won't accept those things either… and that whilst he lives in the house with me he behaves in a way I would want him to behave legally..." (Carer 8)
	3.2. Family, social life and daily activities	"My kids were shocked, so mentally and emotionally distanced themselves…" (Carer 1)
		"The children just could not understand it… he never denied it… both the children were irritable… they couldn't understand it you know because [of] the way he'd been brought up and how he'd brought them up…" (Carer 6)
		"I decided that if he agreed… and he did agree… that I would take his credit and debit cards off him… hide any money I'd got in the house… I left him… I think we agreed on fifteen pounds which would be enough for taxi and whatever so he couldn't do that… I hid the cheque books and hid any money I'd got in the house so he didn't have any access to cash… and that worked well for a couple of months and then he remembered that he had an account that I'd forgotten about…" (Carer 1)
	3.3. Health and well-being	"He couldn't sleep because I was working so hard and he was messing around… he said he cried most nights…" (Carer 6)

		“He was anxious and depressed… worried about everything…” (Carer 1)
		“He was more stressed because he just couldn’t understand what he was doing…” (Carer 6)
		“He seemed very withdrawn… he was completely locked into this mad behavior… there was no happiness… there was no joy… he never smiled… he was apathetic… he was almost irritable… he was quite angry… he doesn’t get irritable… he doesn’t show it… if he is and this is what frightens me about him. I feel it’s like watching a pressure cooker and there’s going to be a time when it pops.” (Carer 8)
		“Probably more confident… I mean she was writing all the time… that’s her identity… she’s a writer…” (Carer 4)
		“When I asked him when he stopped loving me … he said he didn’t know and he eventually said ‘I think I’m narcissistic and I’m in love with myself…” (Carer 8)
		“I think that as with the madness of love or something… it raises you up but it also is a madness so it is a sickness… it is a sickness we all enjoy.” (Carer 4)
		“I knew he was dating again… he’d go out looking quite handsome in something that I’d suggested to upgrade his wardrobe… go out looking attractive…” (Carer 6)
Theme 4: Control	**4.1. Loss of control**	“He couldn’t resist it… it was hopeless… he couldn’t stop it…” (Carer 1)
		“It’s become like a bit of a habit… like something he asks for… it’s a bit like asking for a bit more wine…” (Carer 7)
		“There is a difference… the impulse to do something and the ability to know right from wrong… he knows what’s right and what’s wrong but he chose to take a risk and his risk-taking has increased… he is the one with his hand on his penis…” (Carer 8)
		“I think she probably hadn’t got [control]… I think she probably felt a bit out of control… but she didn’t seem distressed…” (Carer 4)
	4.2. Attempt to reduce/stop	“I think he’s doing a good job in trying to keep a lid on it… it’s still there but more controlled…” (Carer 2)
	4.3. Desire to overcome	“[He] desperately wanted to stop it… he just couldn’t work out what had hit him…” (Carer 1)
		“[It] absolutely drives her mad and does not make her happy… if clitoris removal existed she would have gone for it…” (Carer 3)
		“I don’t think that he admits that he’s hypersexual… because whenever it’s come up like now or even when the neuropsychologist was there… it’s not something that he’d actually readily say ‘Yes I have got a problem’… I don’t think he thinks he’s got a problem…” (Carer 5)
		“I don’t think he understands actually…” (Carer 7)

Theme 5: Emotional formulations	**5.1. Around hypersexuality**	"I just didn't know what had happened ... it's like waking up on the other side of the mirror like Alice in... Through the Looking Glass... it was just so abnormal... he was cold towards me…" (Carer 8)
		"I was shocked... I couldn't make head and the tail of it... it just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 7)
		"Normally she likes tenderness and sweetness and this was sort of a bit more lust... go for it... [laughing]... and in a way that was fresh and amusing... again one took that as a positive thing... for a while anyway…" (Carer 4)
	5.2. Around partner	"I just felt really sorry for him… the only pleasure he has in life is to have sex so I didn't find it difficult for me to… you know… have sex with him… because I felt sorry for him… it was fine for me as well…" (Carer 7)
		"I was so angry… it wasn't just emotion… there was anger… I felt very angry about what he'd done … I wouldn't want him to touch me because I don't know who he is… he was doing things that are completely unacceptable… sad… I was very sad… I felt rejected… I felt confused… I feel such a fool… let down…" (Carer 8)
		"I was a bit unquestioned maybe looking back… it wasn't that extreme you know… it was extreme if you like because she's a reserved person who you know… who has other high standards of good behavior you know… so this was like nature in the raw really… which didn't in the least turn me off…" (Carer 4)
Theme 6: Beliefs in the causes of hypersexuality and attributions	**6.1. Self-blame**	"The longer he's not having sex the worse it's making him… so basically that might be my fault…" (Carer 5)
	6.2. Blame on neurological disease and/or its management	"I suppose now I can point to Ropinirole and say it's Ropinirole's fault…" (Carer 5)
		"He was already on this medication then so you know… and we tried to work out which it was... I thought it was when the entacapone had been added…" (Carer 4)
		"Part of the pain in the neck of the disease… awfulness of package that's changed our lives…" (Carer 3)
		"I think it just came with the disease… right before he passed I said to him 'You couldn't help it… it wasn't you… it wasn't what you were like… it was a disease and you've got two of them and they're both serious'…" (Carer 6)
		"I recognised that it isn't his fault… it doesn't make it any easier to bare…" (Carer 8)
	6.3 Blame on partners and their past experiences	"[Husband's] parents were away… he was allowed… for a night… and he was allowed to ask his friend from his school to stay overnight which he did… and then some sort of homosexual activity occurred… I mean the implication has always been that he was a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him... allowing him... whatever... stimulating him to pursue the homosexuality as he never had done as far as I know…" (Carer 1)

Theme 7: Relationship with the partner	**7.1. Impact on marriage**	"It's not like an intimate loving relationship… it's more mechanical and ritual-like…" (Carer 7)
		"Hypersexuality is his way of being masculine… not for sexual gratification but rather for me to enjoy it as well… but he doesn't understand that I don't…" (Carer 2)
		"It's not making love to me or me making love to him in the way that I used to know… it's not that anymore…" (Carer 5)
		"I stopped being a wife and became a housekeeper and a carer…" (Carer 1)
		"I'm just there to put food on the table… to clean the house… and he's polite to me because that's how he's been brought up… to be polite… but it's not a marriage…" (Carer 8)
		"I actually feel now that I'm… it's a role reversal… I don't think he's looking after me… I think I'm looking after him…" (Carer 5)
		"I half felt amused in a way because I don't really feel insecure … you know… it's a good relationship…" (Carer 4)
	7.2. Image of partner	"It just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)
		"I'm losing the husband that I had… he's just not the same anymore…" (Carer 5)
		"The man I married was intelligent… vibrant… really really fun to be with… very very loving… I'm now living with not just the fact that I lost my husband but that my husband was never who I thought he was… I don't know who this person is and in fact I got him to move out of our bedroom the night I found out about the pornography… and I lay in bed that night on my own… he was in the other room… and I had the duvet and my arms underneath and I thought 'Put your arms on top' and then I thought 'Why did I think that?' and I thought 'Because he might come in… I'm frightened' then I got up and I locked my bedroom door… because I was so frightened of who this person was because he was not the man I married and I now had proof he was not the man I married… this is a man who was having to imagine he was wearing women's clothes before he could get an erection with me… who is this man and did I ever know? It made me question everything…" (Carer 5)
	7.3. Aggression	"I think the worst thing was that on one occasion I actually momentarily considered violence towards him… he'd had one of his trips to the sex shop… he got stuff… I'd been out in the garden… and I'd seen him through the window of his office… obviously he was busy looking at some stuff… and it was lunch time and I came in to give him his lunch… and I stood behind him and I really can't believe it now but I've got to tell you… it's the truth… I stood behind him with this big hammer in my hand… and I thought quite clearly 'A couple of blows to your skull with this and this would all be over'… and then I put the hammer away and served his lunch…" (Carer 2)

		"Even after I'd found out, I couldn't get him to talk to me about it and I remember going to his workshop one day like this and I asked him and asked him and he just stood there like a defiant little boy… and I picked him up… I'm only five feet… he's five foot six… he's much bigger… I picked him up by his boiler suit and I walked him backwards to the wall… just lifted him off the floor, banged him against the wall and I said 'Talk to me' and he just stood there till I let go of him… nothing moves him… nothing moves him… my GP said 'Make sure you're not near the knife block when you do hit him… get out of the kitchen'… she said 'Don't put yourself in danger' and what she meant was danger of being arrested I think…" (Carer 8)
Theme 8: Dealing with hypersexuality	**8.1. Attempt to limit hypersexuality**	"If he did continue to do something and the police were… I would step aside… I would explain that he had a degenerative brain disease but I'm not going to protect him if he's doing something illegal which he was… I think there's a limit to how much protection I can afford someone who has done not to deserve protection…" (Carer 8)
		"I would switch the television off and take the [pornographic] DVD out… I think I became very controlling... and I'm not sure if that was the right thing or the wrong thing to do but I did… for a start because I found it offensive… very offensive…" (Carer 1)
		"I don't like going to bed first because I lay in bed trying to listen whether he's changing channels… whether it's really Match of the Day or something else… and he started going to the second living room a bit too… the guest accommodation next door… he goes in there occasionally and says it's because he wants to watch something different to what I'm watching and then she starts putting the DVD player on… and again it's probably all okay but I think maybe… has he got some funny DVD or something…" (Carer 5)
	8.2. Attempt to uncover facts about hypersexuality	"I certainly looked for materials he'd obtained and was using… when I realised that he had bought a gay magazine… because I found the receipt by chance… after it when I thought about it he just said he was just curious… when he was out I went and unlocked the case and found more magazines… so yes I did go looking for them… yes I did go and look in his case and see what he'd got…" (Carer 1)
		"Partly I snooped... when I saw two thousand pounds being taken out of... you don't just take that out... but partly I did a ring back... a 1471 and got connected to the sex line on our phone... I mean he didn't bother to disguise it because I don't think he could…" (Carer 6)

		"He goes into day care two days a week… I search the room… I look under the mattress… I look under the carpet… I look inside the pillowcases… it's turned me on to being hyper vigilant…" (Carer 8)
	8.3. Giving in to hypersexuality	"I thought 'God this poor man has been a repressed gay all his life… he's never indulged in it… I know he's ill… he hasn't got that many more years to live… if he wants to indulge in this why shouldn't he?' and so I said to him 'Look you can't drive now… if you want to go to gay bars and clubs I will take you there'… after you'd phoned me and said that there is some evidence that it does alter sexual orientation… I just sat and cried… I thought 'Poor man'… he must've been so confused with what's happening to him… utterly… and he couldn't resist it…(Carer 1)
		"Not like I feel it's a great suffering to me… it's… to me… about his needs… maybe more than mine…" (Carer 7)
Theme 9: Coping with hypersexuality	**9.1. Responsibility/guilt**	"I thought I had done something and I tried for twenty years to find out what it was and when I found out it had all been him I didn't feel responsible…" (Carer 8)
		"I sort of think well [laughing] maybe it is my fault… maybe it is my fault that you know I'm not... wanting to have sex every night or whatever... I don't know where desire's gone because it is practically... it is non-existent…" (Carer 5)
	9.2. Understanding the hypersexuality	"Kind of owning the fact that… that sex is not just with the other… it's your relationship with yourself as well as the other person so I'm able to separate how to be who I am and who he is so I don't actually feel exploited… like I'm able just to see that he has a greater need for sex than me and for our relationship to work I help him to meet that need and I'm having lots of other needs met in our relationship… it balances quite nicely…" (Carer 7)
		"I think I put it down to her transference and the peculiar relationship that is actually truly expected within... within a serious therapeutic relationship... I mean it is a relationship of huge power... and... I think in a way she was supposed to have this transference... I think that was part of the deal... he was meant to become her father and she felt a sort of way towards her father…" (Carer 4)
		"After you'd phoned me and said that there is some evidence that it does alter sexual orientation... I just sat and cried... I thought 'Poor man... he must've been so confused with what's happening to him... utterly... and he couldn't resist it…" (Carer 1)
		"She [GP] just let me cry and she said to me 'You know... you're always going to feel sad about this'… she didn't try and pretend it would go away… I said to her 'That's the most genuine response I've had so far'…" (Carer 8)
	9.3. Forgiveness	"on the road to forgiveness" (Carer 1)

		"some things can't be unsaid" (Carer 8)
	9.4. Difficulties with coping	"[I am] further back than I have ever been because I don't feel that safety and security that I feel I need to have" (Carer 2)
		"I just wished I didn't exist" (Carer 2)
		"[I] didn't want to commit suicide but I would like not to exist and there's a difference between not wanting to exist and wanting to be dead." (Carer 8)
Theme 10: Self-image	**10.1. Feeling unloved**	"I feel as if he is only interested in me sexually…" (Carer 2)
		"All the time it will end up in 'You don't know how much I love you and I wouldn't do anything to hurt you'… he used to always be telling me that he loved me and… I think that's what I miss a bit really… he isn't quite so affectionate… he used to say it on a daily basis how much he loved me and things and that was quite nice..." (Carer 5)
	10.2. Feeling used	"I've always thought of it very old fashioned as making love… sex of sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex… he was using me… like an animal really…" (Carer 1)
		"I feel… I'm competing with the women on the television or in his mind… I feel like he wants me to be one of them rather than… being me…" (Carer 5)
		"He has said he had had to imagine he was wearing women's clothes before he could get an erection with me and that makes me feel really creepy because I was in bed with someone who was going to imagine he was wearing women's clothes before he could touch me…" (Carer 8)
	10.3. Self-confidence	"On one occasion I said to my husband 'I don't understand how you can do this to me'… I've always stayed slim… I was always reasonably dressed… I was his official wife… had to go to functions and things with him… he always said how well dressed I looked… I could talk to people and do the proper job as a wife… that he had never been short of sex… so what was it?" (Carer 1)
		"At the time I felt completely worthless… completely and utterly worthless… I just felt so ugly and old…" (Carer 8)
		"[My] counselling training has helped me to be more confident in who I am so it doesn't rattle me as much as it might other people…" (Carer 7)
Theme 11: Stigma		"We're in our sixties so it's quite obvious that we're not going to feel how we did when we first met in our thirties… but he seems to be still back in that era and wants it in the same way…" (Carer 5)
		"I suppose the thing that bothered me most was the thought that other people would find out and laugh at me because I'd always... pride always comes before a fall... I'd always been proud of my happy marriage... we'd worked at it and the thought that

		my husband was gay and might be discovered to be gay are... yeah... that did worry me...” (Carer 1)
		“I can’t really spread the word because... I would... but because of the children and the embarrassment of you know having a father do that which is difficult …. Someone such as myself who has been through it... I’m actually quite free to talk about it away from home and I’m quite happy to talk about it away from home…” (Carer 6)
		“[laughing] she’d go straight to the… not too much foreplay… not too much… normally she likes tenderness and sweetness and this was sort of a bit more lust… go for it [laughing]…” (Carer 3)
		“I mean the change was there in just the amount of sex we were having and the sort of… you know… on the stairs as it were you know… which wasn’t something we’d done for many years not since our young days… sorry…” (Carer 3)
		“I’m being horribly honest here… is this alright?” (Carer 1)
Theme 12: Professional help-seeking	**12.1. Barriers**	“If somebody had said… well warning you that this might happen when he went on these drugs… I mean it says in the leaflets… it talks about hypersexuality… I looked at it and read the sheets through and I said ‘Oh hypersexual… he’ll be a bit frisky and that’ll be alright’… you know… the horrors of what were to come never occurred to me… if nobody speaks out then this will go on and other marriages will be ruined like mine was ruined… at least had we’ve been told it wouldn’t have been such a terrible shock…” (Carer 1)
		“I have tried to broach this a few times with my husband’s neurologist… I do a bit more than hint at the problems now and again but he never sort of takes it and runs with it… we’ve been seeing him for ten years and not once has he asked about hypersexuality… or hinted… that it could be a problem… he would spend more time talking about gambling…” (Carer 5)
		“No one cares enough … you just don’t feel listened to… the overwhelming feeling is of not being believed … even neurologist, even psychoneurologists… don’t know enough about it” (Carer 6)
	12.2. Aspirations	“necessity of full disclosure” (Carer 4)
		“[hypersexuality] has to become a specialty… I wish that they wouldn’t say to go to marriage guidance and counselling because… they are not equipped to handle [it]” (Carer 6)
		“[I need help] with managing the anger that I feel in a way that is useful… not in a way where somebody just sits there and tell me that my mantra should be that my husband can’t help it… I want somebody who can help me understand why I’m angry and who can help me resolve these angry feelings before my husband dies” (Carer 8)

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Carer Assessment Interview
Chief Investigator:
Patient Identification Number:
Date:

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

Carer Assessment Interview

Semi-structured interview schedule

Please note that not all carers are necessarily partners; therefore, there are some interview questions that can only apply to partners. Questions that only apply to partners are under a separate heading.

Interview length: 35-60 minutes

*About the patient (*to be extracted from patient notes)

Age of patient:

Neurological disorder of the patient:

Age of onset of neurological disorder:

Date:

Time:

INTRODUCTION

Thank you for agreeing to take part in an interview for this project.

This interview will be audio recorded. The main reason for this is to have an accurate set of data on this topic. This will help researchers analyze the data as the project develops. Rest assured that you would remain completely anonymous. All data collected is confidential. No records of the interview will be kept with your name or the name of the patient on it.

The following sections include questions about increased sexual behavior that has happened since the patient has developed (insert name of neurological disorder). This is called hypersexuality. Please remember that sexual acts involving physical harm to others or child abuse is against the law. For this reason, please do not answer any questions that show that the patient's sexual behavior has been a threat to others or that the patient has had sexual relationships with minors.

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Carer Assessment Interview

Chief Investigator:
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I understand how sensitive this topic is. If any questions make you uncomfortable, you are completely free not to answer, but we would be grateful if you can answer all questions. Also, if any questions are not understandable, please ask and they will be explained.

GENERAL BACKGROUND

1. **Question:** How old was the patient when they first became hypersexual?

2. **Question:** What is your relationship to the patient?

   Probe 1: How long have you been in this relationship?

   Probe 2: (if applicable) When did the relationship end?

   Probe 3: Was the hypersexuality a reason for the end of your relationship?

3. **Question**: Did the patient have any behavioral or cognitive disorders before the (insert name of neurological condition)?

   Example of behavioral disorder is obsessive-compulsive disorder.

   Example of cognitive disorder is perception and memory disorders.

   Probe: Can you tell me what they are?

4. **Question:** Does the patient have any previous addictions, such as drugs or alcohol?

   Probe: What addictions?

5. **Question:** Did/does the patient have any other impulse control disorders such as increased gambling behavior, increased eating behavior, or increased buying behavior?

   Probe 1: Which ones?

   Probe 2: When did they start?

   Probe 3: How severe were/are these behaviors?

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6. **Question:** Did/do you notice any other changes in the patient's behavior apart from these and the hypersexuality?

   Probe 1: What are they?

   Probe 2: When did these changes start?

7. **Question:** Did you notice that the hypersexuality developed after use of any medications?

   Probe: What medications?

SPECIFIC

8. **Question:** When did you first notice this increased sexual behavior?

   Probe 1: When you first noticed this behavior, how did you feel?

   Probe 2: Is the patient still showing this behavior?

9. **Question:** Do you believe the patient developed hypersexuality because of (insert name of neurological disorder)?

   Probe: Why do you think so?

10. **Question:** Since the patient's (insert name of neurological disorder) started, did/do you feel the patient has lost interest in sex in general?

    Probe: What makes you think so?

11. **Question:** Since the hypersexuality started, do you believe the patient has new sexual interests that were not there before the (insert name of neurological disorder)?

    Probe 1: What are the new interests?

    Probe 2: How did you notice them?

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12. **Question**: How much time do you think the patient spent/spends on their new sexual interests?

13. **Question:** Since the hypersexuality started, do you believe that your physical relationship with the patient has changed?
Probe: Can you tell me how?

14. **Question:** Since the hypersexuality started, has the patient become more interested in sex with you?
Probe: What is your reaction?

15. **Question:** Since the hypersexual behavior started, do you think the patient had/has no control over their hypersexuality?
Probe: What makes you think so?

16. **Question:** Since the hypersexual behavior started, do you feel like the only thing the patient could/can think about is sex?
Probe: What makes you think so?

17. **Question:** Does the patient's hypersexuality cause problems in your relationship?
Probe 1: Can you please give elaborate? What kind of problems?
Probe 2: How does this make you feel?
Probe 3: How do you think this makes the patient feel?

18. **Question:** Do you believe the patient was/is more tempted to engage in sexual behavior when they have certain feelings, such as sadness or anxiety?
Probe: What feelings?

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19. **Question:** Which of the following has your partner tried since developing hypersexuality? I will list them and you are required to just say yes or no to each.

    Internet porn?

    Pornographic novels?

    Uncontrollable masturbation?

    Prostitution?

    Voyeurism: getting sexual satisfaction from spying on sexual objects or acts?

    Exhibitionism: the act of showing your genitals to strangers?

    Affairs?

    Anonymous sexual encounters?

    One-night stands?

    Bath houses: communal bath places?

    Massage parlors?

    Strip clubs?

    Sexual encounters with gender not typically interested in?

    Sexual misconduct in the workplace?

    Being aggressive with sexual partner?

    Asking for sexual partner to be aggressive?

    Bestiality: sexual encounters with animals?

    Any others that I haven't listed?

1. **Question:** Do you think the hypersexuality has negatively affected the patient's life?

   Probe: Has it affected their

   Marital life? How so?

   Family life? How so?

   Social life? How so?

   Work? How so?

   Finances? How so?

   Health? How so?

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Mood? How so?

Sleep? How so?

Self-confidence? How so?

Quality of life? How so?

20. **Question:** To your knowledge, has the patient tried to control their sexual behavior or stop it altogether?

    Probe 1: Has it been successful?

    Probe 2: How does this make the patient feel?

21. **Question:** To your knowledge, does the patient want to overcome their hypersexuality?

    Probe: How can you tell?

22. **Question:** Did the patient ever seek advice for their sexual behavior?

    Probe: What was the result of that?

23. **Question:** How did/does the patient's hypersexuality make you feel?

    Probe 1: Do you think the patient knows this?

    Probe 2: Have you tried to make them aware?

    Probe 3: What has been the patient's reaction?

24. **Question:** Do you believe the hypersexual behavior was/is out of the patient's control?

    Probe 1: Did/do you discuss this issue with the patient?

    Probe 2: What has resulted from those conversations?

PARTNER QUESTIONS

25. **Question:** Since the hypersexual behavior started, did/do you feel there was/is less intimacy and confidence between you and your partner when you have sex?

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Probe: Why do you think this has happened?

26. **Question:** Since the hypersexual behavior started, did/do you feel your partner was/is not sexually interested in you anymore?

    Probe 1: How does this make you feel?

    Probe 2: Have you talked to your partner about this?

    Probe 3: What did they reply?

27. **Question:** Before the patient's (insert name of neurological condition) started, how often did you and your partner have sex?

28. **Question:** In the period between the start of the patient's (insert name of neurological condition) but before the start of hypersexuality, how often did you and your partner have sex?

29. **Question:** Since the hypersexuality started, how often do you and your partner have sex?

30. **Question**: Did/do you find your partner repulsive?

31. **Question**: Did/do you feel you lost respect for him?

32. **Question**: Do you think you will ever be able to forgive him?

33. **Question:** Do you ever blame yourself for the patient's hypersexuality?

CLOSURE

We have reached the end of our interview. I would like to thank you for being so patient. However, do you believe there is anything we have missed out that you would like to add?

Do you have any other comments about what we have discussed, or about the research as a whole?

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Carer Assessment Interview

Chief Investigator:
Patient Identification Number:
Date:

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

We will send you a summary of the research findings when it becomes available.

Thank you so much for your participation.

BMJ Open

The Impact of Hypersexuality on Spousal Carers of Patients with Parkinson's Disease and Frontotemporal Dementia: A Qualitative Study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2024-090870.R1
Article Type:	Original research
Date Submitted by the Author:	01-Mar-2025
Complete List of Authors:	Tayim, Natalie; Doha Institute for Graduate Studies, Psychology Panicker, Jalesh; University College London Hospitals NHS Foundation Trust, Department of Uro-Neurology; University College London, Department of Brain Repair and Rehabilitation Foley, Jennifer; University College London Hospitals NHS Foundation Trust National Hospital for Neurology and Neurosurgery, Neuropsychology Selai, Caroline; University College London Hospitals NHS Foundation Trust, Department of Uro-Neurology; University College London, Department of Clinical and Movement Neurosciences El Sheikh, Walaa; American University of Beirut, Faculty of Medicine
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Qualitative research
Keywords:	Caregivers, Parkinson-s disease < NEUROLOGY, Dementia < NEUROLOGY

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The Impact of Hypersexuality on Spousal Carers of Patients with Parkinson's Disease and Frontotemporal Dementia: A Qualitative Study

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Conflict of Interest
The authors declare that there are no conflicts of interest relevant to this work.

Funding Sources
This study received no specific grants from funding agencies in the public, commercial, or not-for-profit sectors. JNP is supported in part by funding from the United Kingdom's Department

of Health NIHR University College London Hospitals Biomedical Research Centres funding scheme.

Keywords:
hypersexuality, spousal carers, Parkinson's disease, frontotemporal dementia

Word Count: 7189

Abstract

Objectives:

Hypersexuality involves an inability to control intense, recurring sexual impulses, resulting in repetitive sexual behaviors. It frequently manifests as a disorder in patients with neurodegenerative disorders such as Parkinson's disease (PD) and dementia. Using a qualitative approach, the current study aims to explore the impact of hypersexuality on spousal carers of patients with PD and dementia.

Methods:

Using the Carer Assessment Interview, a custom-developed semi-structured interview, eight carers (five PD, three dementia) participated in this study.

Results:

Thematic analysis identified twelve themes: manifestations, sexual practices, impact, control, emotional formulations, beliefs in causes of hypersexuality and attributions, relationship with the partner, dealing with hypersexuality, coping with hypersexuality, self-image, stigma, and professional help-seeking. Hypersexuality altered patients' sexual cognitions and behaviors, causing distress and strain on carers' mental health and their marital life. Carers struggled to cope with their partners' hypersexuality, facing emotional burden and barriers to seeking professional help.

Conclusions:

Hypersexuality significantly impacts spousal carers of patients with PD and dementia, affecting their emotional well-being and relationships. Healthcare professionals should recognize and address hypersexuality's psychological and relational implications. Psychoeducation, support groups, and tailored interventions for patients and carers are recommended to mitigate emotional distress. Future research should explore the broader familial impact of hypersexuality and develop effective management strategies.

Keywords:

hypersexuality, spousal carers, Parkinson's disease, frontotemporal dementia

Strengths and limitations of this study:

1. This study provides qualitative insights into the experiences of spousal carers managing hypersexuality in PD and dementia.
2. The use of semi-structured interviews allows for an in-depth exploration of carer perspectives.
3. Potential underreporting of hypersexuality due to stigma may have influenced the data.
4. The study focuses solely on spousal carers, excluding experiences of other family members or care professionals.

Introduction

Hypersexuality, classified under compulsive sexual behavior disorder in the International Classification of Diseases 11th Revision (ICD-11), involves an inability to control intense, recurring sexual impulses, resulting in repetitive sexual behaviors, which can lead to distress and impairment in personal, social, or occupational functioning [1]. Hypersexuality frequently manifests as a disorder in patients with neurodegenerative disorders such as Parkinson's disease (PD) and dementia [2]. It typically arises as a side effect of dopamine replacement therapy (DRT) in PD [3] and as a result of frontal lesions in dementia [4]. The management of hypersexuality often involves the reduction or cessation of the behavior-inducing drug in PD and a switch to alternative medications like levodopa, catechol-O-methyltransferase (COMT) inhibitors, or monoamine oxidase B (MAO-B) inhibitors [5, 6].

As patients get older, they tend to become increasingly dependent on family members for support [7]. Accumulating responsibilities on the carer can lead to carer burden, which encompasses a range of negative responses such as a decrease in quality of life and physical and psychological deterioration [8]. For example, spouses and female carers of patients with frontotemporal dementia (FTD) tend to experience distress, increased rates of depression, and poor sleep [9]. Hypersexuality can worsen carer burden and be detrimental to the patients' and their partners' quality of life [10, 11]. Accounts of spousal carers of patients with neurological disorders suffering from hypersexuality are lacking in the literature. Therefore, using a qualitative approach, the current study aims to explore the impact of hypersexuality on spousal carers of patients with PD and dementia.

Methods

Ethics

This study (ethics application ID: 15/LO/0557) was approved by the London-Hampstead National Research Ethics Committee (NREC).

Study Design

This study employed a phenomenological qualitative approach. This approach was deemed most appropriate for the present study since the intention of this study is to understand the spousal carers' personal experiences of the phenomenon of hypersexuality and how they view and interpret their experiences.

This study was conducted from April 2015 to August 2017. It was part of a broader UCL project examining hypersexuality in neurological disorders, which includes a recently published systematic review [12] and a qualitative study exploring the clinical phenomenology and impact of hypersexuality in patients with Parkinson's Disease [13].

Eligibility Criteria

Carers were included in the study if they are spouses or partners of patients with clinically diagnosed PD according to the UK Brain Bank Criteria or clinically diagnosed FTD, indicated hypersexuality either in the past or present since developing PD or dementia, and having the ability to provide informed consent.

Carers were excluded from the study if they are spouses or partners of patients with hypersexuality predating the onset of PD or FTD, having co-existing neurological disorders as determined by clinical history, or difficulty understanding/speaking English.

Measure

Carer Assessment Interview (Supplementary Appendix 2). The interview is a semi-structured thirty-four item interview, developed by NT. During the interviews, the participants were asked to reflect on, describe, and/or recount their experience with hypersexuality and its impact on their lives to the best of their abilities considering the sensitive nature of the topic.

Procedure

Spouses of patients with PD who indicated hypersexuality as being an issue during patients' clinical appointments and who were prepared to discuss it in further detail with a researcher were contacted by NT. These carers as well as the carers who contacted the researchers after reading information leaflets about the study circulated by Parkinson's UK were further informed about the study's aims, methods, potential risks and benefits, and confidentiality over the phone.

Carers of patients with FTD or Alzheimer's disease (AD) were informed about the study by the clinical staff at the Dementia Research Centre (DRC), through either the newsletter that was sent out periodically which contained blurbs about the study and the contact details of the members of the research team, or through the carer leaflets passed out at the Frontotemporal Dementia Support Group (FTDSG) March 5th, 2016 Seminar, which took place at 33 Queen Square. These carers were further informed about the study's aims, methods, potential risks and benefits, and confidentiality over the phone, as well as that the interview portion of the study was going to be audio-recorded using a Dictaphone and that the recorded material was only to be used in writing up the transcripts, which was completed almost immediately after assessment. Participants were assured that the recorded material would not be passed on and that it would be deleted at the end of transcription. Participants, however, who did not consent to the use of the Dictaphone were informed that they were still eligible to take part in the study.

Interested carers were then asked to come into the Department of Uroneurology at the National Hospital for Neurology and Neurosurgery (NHNN) where any of the available rooms on the scheduled dates was used to provide the participants with written information about the study, obtain written consent, and consequently complete assessment.

A total of twelve carers indicated hypersexuality as having been or still being an issue, eight of whom were carers of patients with PD, four of whom were carers of patients with FTD, and none of whom were carers of patients with AD. Eight carers were successfully recruited into the study. Five PD carers were recruited from the Movement Disorders Centre (MDC) at the NHNN, Edgware Community Hospital (ECH), as well as from Parkinson's UK. Three FTD carers were recruited from the DRC at the NHNN. **Figure 1** presents a summary of recruitment results for PD and dementia carers.

Insert Figure 1.

The interviews were conducted by NT, a PhD candidate at the time of the research. As part of her doctoral thesis, she drew on her undergraduate background in psychology to inform her approach to qualitative data collection. NT had no prior relationship with the study participants before the research commenced. Participants were informed about the study's purpose through a leaflet, which explained the association between neurological disorders and changes in sexual desire, as well as the study's aims to understand these changes and their impact. The leaflet also provided details about the study's collaboration between the DRC and the Department of Uroneurology at Queen Square, emphasizing the potential benefits of the research in improving care and developing psychological interventions. Additional details regarding the interviewer's background and role were available in the study materials provided to participants. The interviews ranged from two hours to nearly four hours in duration with as many breaks as required by the participants.

Sample Size

The sample size for this qualitative study was eight carers, which is considered adequate for exploratory research in qualitative methodologies. In qualitative research, the focus is on in-depth understanding rather than statistical generalizability. The concept of "saturation" was used as a guide, defined as the point where additional data no longer contribute new insights to the research questions [14, 15]. According to qualitative research standards, a sample size of eight can be sufficient for generating meaningful insights, especially in studies involving sensitive topics like hypersexuality in PD. This number allows for a thorough exploration of individual experiences and contributes to theory development within the constraints of qualitative research.

Patient and Public Involvement

It was not appropriate or possible to involve patients or the public in the design, or conduct, or reporting, or dissemination plans of our research.

Data Analysis

Virginia Braun and Victoria Clarke's (2006) thematic analysis approach was used to analyze the qualitative data for this study [16]. We adhered to the thematic analysis process, which included becoming familiar with the data, organizing the data, generating initial codes, generating themes, naming and defining themes, producing the report, and determining the quality of analysis.

Initially, interview transcripts were reviewed and organized into an Excel chart to facilitate data accessibility and ensure comprehensive analysis. This systematic arrangement allowed researchers to examine participant responses to each interview question without repeatedly referring to full transcripts. Following data familiarization, key extracts were identified through annotation and highlighting, capturing recurring words, ideas, and patterns. These extracts were systematically grouped into codes by NT and study supervsiors. Researchers then compared and refined codes through discussion, establishing coherent relationships and categorizing them into preliminary themes. Themes were subsequently reviewed for coherence, consistency, and distinctiveness. Based on this evaluation, themes

were retained, modified, or removed as necessary. Subthemes were identified where applicable, representing distinct yet interconnected elements within overarching themes.

Finally, the thematic analysis was checked against a 15-point checklist of criteria for good thematic analysis, which was produced by Braun and Clarke (2006; p. 96).

Rigor and Reflexivity

To ensure methodological rigor, we adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) [17]. Strategies to enhance trustworthiness included investigator triangulation, whereby multiple researchers participated in coding, theme generation, and data interpretation to minimize individual biases. Member checking was conducted informally, allowing participants to clarify or expand on their responses during interviews, ensuring the authenticity of the data. Reflexivity was maintained throughout the research process, with researchers critically examining their own preconceptions and potential influences on data collection and analysis. Regular discussions within the research team facilitated awareness of positionality and its impact on interpretation, thereby strengthening the credibility and dependability of the findings.

Results

Characteristics of the sample

A total of N = 8 carers (PD: n = 5 and FTD: n = 3) decided to participate in this study. **Table 1** summarizes the descriptive characteristics of the carer sample.

Insert Table 1.

Qualitative thematic analysis

Twelve themes emerged from the interview data of PD and FTD carers and are as follows: manifestations, sexual practices, impact, control, emotional formulations, beliefs in causes of hypersexuality and attributions, relationship with the partner, dealing with hypersexuality, coping with hypersexuality, self-image, stigma, and professional help-seeking (**Figure 2**).

Insert Figure 2.

Quotes under each theme are presented in **Table S1**.

Theme 1: Manifestations

This theme outlines the carer-perceived manifestations of hypersexuality in their partners, encompassing five identified subthemes.

1.1. Indicators

The carers provided accounts of how they became cognizant of the hypersexuality. These instances, termed 'indicators', fell broadly into three categories: (1) their partners told them

directly about their hypersexuality, (2) they found out based on changes in their partners' sexual behaviors towards them, or (3) they discovered their partners' clandestine behaviors (Carer 1).

> *"I found a till receipt for a gay magazine… I sat on the knowledge for a couple of weeks but first of all I went straight up to WH Smith and bought a copy of the magazine thinking that either it wasn't what I thought it was… it was Gay Times… or this had been bought by mistake… I got a copy… I sat there outside and read it and realised it was highly unlikely that it had been bought by mistake…" (Carer 1)*

1.2. Desires

Increased desire following the onset of hypersexuality was evident in carers' accounts. The predominant response involved partners exhibiting heightened desire in sexual activity within and outside the relationship, as well as engaging in self-pleasure through masturbation and the use of pornographic material (Carer 7).

> *"That's the only thing he's interested in … to have sex…" (Carer 7)*

1.3. Behaviors

Furthermore, the hypersexuality apparently caused changes in pre-existing behavior or the development of new behaviors. These changes fell broadly into two categories: (1) the adoption of pornographic materials or new sexual behaviors involving others and (2) an increase in the levels or forms of sexual behaviors towards partners or the intensification of old sexual behaviors (Carer 4).

> *"Normally she likes tenderness and sweetness and this was sort of a bit more lust… go for it… behavior was extreme if you like because she's a reserved person … who has other high standards of good behavior… so this was like nature in the raw really…" (Carer 4).*

1.4. Preoccupation

One of the main manifestations of hypersexuality was preoccupation with sexual thoughts (Carer 3).

> *"her thoughts are uncontrollable and come so much of the time…" (Carer 3)*

1.5. Compulsivity

Carers perceived that their partners' preoccupation with sexual thoughts translated into compulsive behavior, another main manifestation of hypersexuality. Reported compulsive behaviors varied and encompassed frequent or intense consumption of pornographic materials, visiting prostitutes, and generally indulging in sexual behaviors throughout the day (Carer 3).

> *"Hypersexuality is present all throughout the day and during the night while I am asleep…" (Carer 3)*

Theme 2: Sexual practices

This theme outlines the carer-perceived impacts of hypersexuality on their partners' sexual practices, encompassing four identified subthemes.

2.1. Practices with the partner

Sexual practices with the partner underwent changes in both the frequency and nature of sexual acts. Certain carers reported that their partners, upon developing hypersexuality, expressed an increased demand for sexual activity with them (Carer 7).

> *"And now [he was asking for sex] every morning… every evening… sometimes he's asking during the day…" (Carer 7)*

Additionally, a majority of carers noted changes in the nature of their partners' sexual demands or behaviors, often describing them as being out of character with the person they were before developing hypersexuality. These changes included, for instance, more aggressive sexual tendencies, demands for role play, and a shift towards more adventurous sexual practices, such as oral or anal sex, which deviated from their previous patterns (Carer 4).

> *"She didn't ask for Fifty Shades of Grey no… but still … a little hint of S&M which really wasn't part of our repertoire…" (Carer 4)*

Moreover, certain carers reported a decrease in sexual activity with their partner – in some cases because they started to resist their frequent or inappropriate advances. In other cases, the decline in marital sexual activity seemingly occurred as the partner sought gratification from alternative sources.

2.2. Practices with themselves

The majority of carers reported that their partners also indulged in masturbation and use of pornographic material.

2.3. Practices with others

Sexual practices with others included anonymous sexual encounters, paying for sex, and developing sexual interest in individuals other than the spouse.

2.4. Deviant sexual behavior

Lastly, desires did not appear to translate into paraphilic deviant practices as only one carer reported this (Carer 8).

> *"It needs to be more upfront that it's not just about a decrease in sex or an increase in sex… it could be a decrease in a normal sexual relationship and a… a subverted or a hidden cover increase in some kind of deviant sexual behavior which had been what was going on for twenty years and I didn't know about…" (Carer 8)*

Themes 1 and **2** illustrate the clinical phenomenology of hypersexuality. These changes can be summarised using the categories presented in **Figure 3**.

Insert Figure 3.

Theme 3: Impact

This theme outlines the carer-perceived impacts of hypersexuality on their partners' different areas of daily living, encompassing three identified subthemes.

3.1. Marital life

Nearly all carers conveyed that hypersexuality had adverse effects on their marital lives, resulting in diminished intimacy, increased emotional distance between themselves and their partner, and a spectrum of negative emotions on their part. These included feelings of anger, betrayal, despair, disapproval, embarrassment, reduced self-confidence, sadness, and self-blame. Primarily, the impersonal or mechanical nature of their partners' increased demand for sexual activity had generated feelings of disgust or resentment on the part of their spouses. Additionally, these demands altered the nature of their sexual relationship in ways that were unwelcome to the spouses (Carer 1).

> *"It was dreadful… devastating … I couldn't make head and the tail of it… it just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)*

Furthermore, certain responses indicated a significant transformation in the nature of the marital relationship. This shift was characterized by a growing lack of respect for the partner and, in some instances, a perceived need to exert control over them in an effort to preserve the marriage (Carer 8).

> *"I've lost respect for him… how can you respect someone that gets off of watching little boys being humiliated… I've said to him I won't collude or condone with anything he's done… and I won't accept those things either… and that whilst he lives in the house with me he behaves in a way I would want him to behave legally..." (Carer 8)*

Many carers emphasized that their partners had become markedly less affectionate and loving towards them in general since the onset of hypersexuality (Carer 1).

> *"I've always thought of it very old fashioned as making love… sex for sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex..." (Carer 1)*

3.2. Family, social life and daily activities

Half of the carers reported that hypersexuality had a detrimental impact on their family lives, noting effects on their children that ranged from fathers being absent much of the time to children experiencing trauma or stress due to their father's hypersexuality (Carer 1).

> *"My kids were shocked, so mentally and emotionally distanced themselves…" (Carer 1)*

Moreover, hypersexuality had a negative impact on the partners' finances, particularly for those whose hypersexual behaviors involved visits to sex shops for purchases or spending time with prostitutes (Carer 1).

> *"I decided that if he agreed… and he did agree… that I would take his credit and debit cards off him… hide any money I'd got in the house… I left him… I think we agreed on fifteen pounds which would be enough for taxi and whatever so he couldn't do that… I hid the cheque books and hid any money I'd got in the house so he didn't have any access to cash… and that worked well for a couple of months and then he remembered that he had an account that I'd forgotten about…" (Carer 1)*

3.3. Health and well-being

Half of the carers reported that their partners experienced sleep disturbances, mood deterioration, and overall poor mental health, as a result of hypersexuality (Carer 8).

> *"He seemed very withdrawn… he was completely locked into this mad behavior… there was no happiness… there was no joy… he never smiled… he was apathetic… he was almost irritable… he was quite angry… he doesn't get irritable… he doesn't show it… if he is and this is what frightens me about him… I feel it's like watching a pressure cooker and there's going to be a time when it pops…" (Carer 8)*

Concerning the impact of hypersexuality on their partners' self-confidence, the findings were not clear-cut, with some participants noting a positive and some a negative impact, while others were unsure whether their partner's self-confidence had been affected at all (Carer 4).

> *"Probably more confident… I mean she was writing at the time… that's her identity… she's a writer…" (Carer 4)*

Regarding the impact of hypersexuality on their partners' quality of life, the findings were similarly mixed. Four carers mentioned a negative impact, with one providing an explanation. This carer specified that her husband felt he now had a wife who did not love him as much as before, leading to a general sense of deflation.

Theme 4: Control

This theme outlines the carers' perceptions regarding how much control they believed their partners had over their hypersexuality. We identified three subthemes:

4.1. Loss of control

All carers believed their partners lacked control over their sexual behavior, but the extent of this loss varied across individuals (Carer 1).

> *"He couldn't resist it… it was hopeless… he couldn't stop it…" (Carer 1)*

Carers of patients with dementia characterized them as "*disinhibited*" (Carer 8).

> *"There is a difference… the impulse to do something and the ability to know right from wrong… he knows what's right and what's wrong but he chose to take a risk and his risk-taking has increased… he is the one with his hand on his penis…" (Carer 8)*

4.2. Attempt to reduce/stop

Half of the carers reported that their partners attempted to reduce or stop their hypersexuality, with varying degrees of success reported among them (Carer 2).

> *"I think he's doing a good job in trying to keep a lid on it… it's still there but more controlled…" (Carer 2)*

4.3. Desire to overcome

More than half of the carers noted that their partners expressed a desire to overcome their hypersexuality. This was either conveyed through direct verbalization to the carers or others, or inferred from observable efforts to control their behaviors, such as reduced requests for sex (Carer 1).

> *"[He] desperately wanted to stop it… he just couldn't work out what had hit him…" (Carer 1)*

Theme 5: Emotional formulations

This theme outlines the emotional formulations that the carers had around their partners and/or around the hypersexuality itself.

5.1. Around hypersexuality

At least half of the carers found hypersexuality to be a perplexing phenomenon, leading to a negative emotional formulation marked by shock, confusion, and horror, as they grappled with the profound changes in their long-term partners' feelings and behaviors (Carer 8).

> *"I just didn't know what had happened ... it's like waking up on the other side of the mirror like Alice in... Through the Looking Glass... it was just so abnormal... he was cold towards me…" (Carer 8)*

Other carers expressed more positive emotional formulations around the hypersexuality. For instance, one carer conveyed emotions like amusement and interest in response to his wife's newly developed lustful approach (Carer 4).

> *"Normally she likes tenderness and sweetness and this was sort of a bit more lust... go for it... [laughing]... and in a way that was fresh and amusing... again one took that as a positive thing... for a while anyway…" (Carer 4)*

5.2. Around partner

With the exception of one carer, all carers developed negative emotional formulations around their partners due to hypersexuality. These negative emotions encompassed annoyance, betrayal, despair, embarrassment, hurt, irritation, pity, and repulsion. These emotions often evolved and changed over time in tandem with the partner's shifting behaviors (Carer 8).

> *"I was so angry… it wasn't just emotion… there was anger… I felt very angry about what he'd done … I wouldn't want him to touch me because I don't know who he is… he was doing things that are completely unacceptable… sad… I was very sad… I felt rejected… I felt confused… I feel such a fool… let down…" (Carer 8)*

It is noteworthy that carers found it challenging to separate their emotional formulations around their partners from those around the hypersexuality in itself. This may be indicative that the effects of the hypersexuality are overwhelming enough to cause the carers to regard them as being one and the same.

Theme 6: Beliefs in the causes of hypersexuality and attributions

This theme outlines the carers' opinions about the perceived reasons for the onset and progression of the hypersexuality. We identified three subthemes:

6.1. Self-blame

Certain carers attributed the onset of the hypersexuality to themselves (Carer 5).

> *"The longer he's not having sex the worse it's making him… so basically that might be my fault…" (Carer 5)*

6.2. Blame on neurological disease and/or its management

Attribution of the hypersexuality to the neurological disease and/or its management was the main reason given by carers for the development of their partner's hypersexuality. All five carers of the PD patients attributed the hypersexuality to the PD and its management (pharmacological and surgical) (Carer 5).

> *"I suppose now I can point to Ropinirole and say it's Ropinirole's fault…" (Carer 5)*

The three carers of the FTD patients, on the other hand, attributed the hypersexuality to the FTD as there had been no sign of it before its onset (Carer 6).

> *"I think it just came with the disease… right before he passed I said to him 'You couldn't help it… it wasn't you… it wasn't what you were like… it was a disease and you've got two of them and they're both serious'…" (Carer 6)*

6.3 Blame on partners and their past experiences

Half of the carers attributed at least some aspects of the hypersexuality to their partner' past experiences (Carer 1).

> *"[Husband's] parents were away… he was allowed… for a night… and he was allowed to ask his friend from his school to stay overnight which he did… and then some sort of homosexual activity occurred… I mean the implication has always been that he was a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him... allowing him... whatever... stimulating him to pursue the homosexuality as he never had done as far as I know..." (Carer 1)*

Carer 6 suggested that her husband's hypersexuality might stem from two previous experiences. First, he had been sexually abused as a seven-year-old child by the headmaster of his school. Second, he had an ex-girlfriend of Indian descent during his twenties who died in a car accident. She indicated that both prostitutes her husband had been involved with were dark-skinned and considered that there might be a link between this and the evolution of his hypersexuality (Carer 6).

Theme 7: Relationship with the partner

This theme outlines the carer-perceived impacts of hypersexuality on the carers' relationships with their partners, encompassing three identified subthemes.

7.1. Impact on marriage

Certain carers highlighted changes in the nature of marital sexual activity, a decrease in affection between partners, and a shift in the overall balance of the relationship (Carer 7).

> *"It's not like an intimate loving relationship… it's more mechanical and ritual-like…" (Carer 7)*

7.2. Image of partner

Some carers stressed that their image of their partners had changed due to their hypersexual behaviors. It seemed that these carers no longer regarded their partners as the same individuals they were before developing hypersexuality, indicating a difficulty in distinguishing between their partners as individuals and the hypersexuality itself (Carer 1).

> *"It just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)*

7.3. Aggression

Evidently, certain carers, experiencing stress and frustration from dealing with their partners and their hypersexuality, expressed either a desire or an actual instance of having an aggressive response to their partners' hypersexuality (Carer 2).

> *"I think the worst thing was that on one occasion I actually momentarily considered violence towards him… he'd had one of his trips to the sex shop… he got stuff… I'd been out in the garden… and I'd seen him through the window of his office… obviously he was busy looking at some stuff… and it was lunch time and I came in to give him his lunch… and I stood behind him and I really can't believe it now but I've got to tell you… it's the truth… I stood behind him with this big hammer in my hand… and I thought quite clearly 'A couple of blows to your skull with this and this would all be over'… and then I put the hammer away and served his lunch…" (Carer 2)*

Theme 8: Dealing with hypersexuality

This theme outlines the various ways in which the carers dealt with their partners' hypersexuality, encompassing three identified subthemes.

8.1. Attempt to limit hypersexuality

Carers attempted to limit hypersexuality by placing blocks on the computer, for instance, so that their partner could no longer access any pornography (Carer 8).

> *"If he did continue to do something and the police came… I would step aside… I would explain that he had a degenerative brain disease but I'm not going to protect him if he's doing something illegal which he was… I think there's a limit to how much protection I can afford someone who has done nothing to deserve protection…" (Carer 8)*

8.2. Attempt to uncover facts about hypersexuality

Half of the carers reported actively attempting to investigate their partner's hypersexual behaviors. This included actions such as searching for hidden pornographic materials, checking computers or phones for evidence of visits to sex sites, and examining phones for messages from other individuals that they might be involved with sexually (Carer 1).

> *"I certainly looked for materials he'd obtained and was using… when I realised that he had bought a gay magazine… because I found the receipt by chance… after it when I thought about it he just said he was just curious… when he was out I went and unlocked the case and found more magazines… so yes I did go looking for them… yes I did go and look in his case and see what he'd got…" (Carer 1)*

8.3. Giving in to hypersexuality

Approximately half of the carers acknowledged their partner's hypersexual behaviors, albeit with dissatisfaction. For a small number, this acceptance extended to a greater degree of

understanding and even support in helping their partner to indulge their hypersexual desires outside of the marital relationship (Carer 1).

> *"I thought 'God this poor man has been a repressed gay all his life… he's never indulged in it… I know he's ill… he hasn't got that many more years to live… if he wants to indulge in this why shouldn't he?' and so I said to him 'Look you can't drive now… if you want to go to gay bars and clubs I will take you there'… after you'd phoned me and said that there is some evidence that it does alter sexual orientation… I just sat and cried… I thought 'Poor man'… he must've been so confused with what's happening to him… utterly… and he couldn't resist it…" (Carer 1)*

Theme 9: Coping with hypersexuality

This theme outlines the various ways in which the carers coped with their partners' hypersexuality, encompassing three identified subthemes.

9.1. Responsibility/guilt

Except for one carer, all indicated no responsibility for their partners' hypersexuality. This lack of perceived responsibility may aid in maintaining necessary psychological and emotional distance to cope with the situation's stress and pressure (Carer 8).

> *"I thought I had done something and I tried for twenty years to find out what it was and when I found out it had all been him I didn't feel responsible…" (Carer 8)*

9.2. Understanding the hypersexuality

All carers recognized the neurological origin of hypersexuality, yet this understanding did not uniformly translate into effective coping. Certain carers exhibited a more nuanced comprehension of the condition and its manifestations (Carer 7).

> *"Kind of owning the fact that… that sex is not just with the other… it's your relationship with yourself as well as the other person so I'm able to separate how to be who I am and who he is so I don't actually feel exploited… like I'm able just to see that he has a greater need for sex than me and for our relationship to work I help him to meet that need and I'm having lots of other needs met in our relationship… it balances quite nicely…" (Carer 7)*

9.3. Forgiveness

Certain carers could forgive their partners for their hypersexuality, while others saw no need for forgiveness. Those considering forgiveness found it challenging and could only be achieved sometime in the future. Carer 1, for example, reported that she was "*on the road to forgiveness*".

9.4. Difficulties with coping

Coping with hypersexuality is challenging, with around half of carers facing difficulties, and for a few, leading to a desire to no longer exist (Carer 8).

> *"[I] didn't want to commit suicide but I would like not to exist and there's a difference between not wanting to exist and wanting to be dead…" (Carer 8)*

Theme 10: Self-image

This theme outlines the carer-perceived effects of hypersexuality on the carers' self-image, encompassing three identified subthemes.

10.1. Feeling unloved

Half of the carers felt unloved by their husbands, especially when the sexual relationship became mechanical and non-affectionate due to hypersexuality. This evoked sadness and nostalgia for the previous loving relationships, highlighting shifts in relationship roles (Carer 5).

> *"All the time it will end up in 'You don't know how much I love you and I wouldn't do anything to hurt you'… he used to always be telling me that he loved me and… I think that's what I miss a bit really… he isn't quite so affectionate… he used to say it on a daily basis how much he loved me and things and that was quite nice..." (Carer 5)*

10.2. Feeling used

The same four carers felt not only unloved but also "*used*" by their husbands for sexual gratification. This signaled to them a shift from a normal loving sexual relationship to one primarily focused on satisfying their husbands' hypersexual needs (Carer 1).

> *"I've always thought of it very old fashioned as making love… sex of sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex… he was using me… like an animal really…" (Carer 1)*

10.3. Self-confidence

Three of the carers who expressed feeling unloved and used by their partners also asserted that hypersexuality and their husbands' consequent demeanor had adversely affected their self-confidence (Carer 8).

> *"At the time I felt completely worthless… completely and utterly worthless… I just felt so ugly and old…" (Carer 8)*

Theme 11: Stigma

This theme outlines the two carer-perceived forms of stigma associated with hypersexuality: personal stigma and social stigma.

One carer's reference to the older age group implies a stereotype that older people are less sexual, which may be used to reinforce the belief that hypersexuality is unnatural (Carer 5).

> *"We're in our sixties so it's quite obvious that we're not going to feel how we did when we first met in our thirties… but he seems to be still back in that era and wants it in the same way…" (Carer 5)*

Three carers expressed concerns about the social stigma associated with hypersexuality, fearing that others discovering their partner's condition would reflect negatively on themselves and their families (Carer 1).

> *"I suppose the thing that bothered me most was the thought that other people would find out and laugh at me because I'd always... pride always comes before a fall... I'd always been proud of my happy marriage... we'd worked at it and the thought that my husband was gay and might be discovered to be gay are... yeah... that did worry me..." (Carer 1)*

During interviews, carers often hesitated, laughed nervously, and apologized when asked sexually-specific questions or prompted to discuss their partners' sexual experiences. This may be attributed to the embarrassment of discussing sex, concerns about crossing social boundaries, and fear of being perceived as inappropriate (Carer 3).

> *"[laughing] she'd go straight to the… not too much foreplay… not too much… normally she likes tenderness and sweetness and this was sort of a bit more lust… go for it [laughing]…" (Carer 3)*

Theme 12: Professional help-seeking

This theme outlines the professional help-seeking barriers regarding hypersexuality, as well as certain aspirations with regards to professional help.

12.1. Barriers

Issues with seeking professional help encompassed communication barriers, lack of understanding, insufficient education, neglect by health professionals, stigma related to hypersexuality, and challenges in discussing sex. All eight carers experienced difficulty obtaining adequate information and assistance for their partners' newly developed hypersexuality, expressing frustration, sadness, and anger over the unavailability of help. A key concern raised is that patients are not adequately informed about the likelihood and implications of hypersexuality when taking drugs for PD (Carer 1).

> *"If somebody had said… well warning you that this might happen when he went on these drugs… I mean it says in the leaflets… it talks about hypersexuality… I looked at it and read the sheets through and I said 'Oh hypersexual… he'll be a bit frisky and that'll be alright'… you know… the horrors of what were to come never occurred to me… if nobody*

speaks out then this will go on and other marriages will be ruined like mine was ruined… at least had we've been told it wouldn't have been such a terrible shock…" (Carer 1)

Certain carers noted a key issue: medical professionals lack knowledge about hypersexuality and show an apparent reluctance to investigate further or take patients' and carers' concerns seriously (Carer 5).

"I have tried to broach this a few times with my husband's neurologist… I do a bit more than hint at the problems now and again but he never sort of takes it and runs with it… we've been seeing him for ten years and not once has he asked about hypersexuality… or hinted… that it could be a problem… he would spend more time talking about gambling…" (Carer 5)

12.2. Aspirations

Due to these barriers, certain carers expressed specific aspirations for professional help for individuals with hypersexuality and their carers. Over half of the carers expressed a desire for health professionals to be educated about hypersexuality and its consequences. This education is seen as a means to enable professionals to educate patients and carers about the condition, with the ultimate goals of alleviating the patient and carer burden of living with hypersexuality and facilitating more effective help-seeking behavior (Carer 8).

"[I need help] with managing the anger that I feel in a way that is useful… not in a way where somebody just sits there and tell me that my mantra should be that my husband can't help it… I want somebody who can help me understand why I'm angry and who can help me resolve these angry feelings before my husband dies" (Carer 8)

Discussion

Using a qualitative approach, the current study aimed to explore the impact of hypersexuality on spousal carers of patients with PD and dementia. This study captured twelve themes illustrated in **Figure 2**.

In terms of clinical phenomenology, hypersexuality manifested through changes in patients' sexual cognitions and behaviors. These changes can be summarised using the categories presented in **Figure 3**.

These findings resonate with existing literature on hypersexuality in neurological disorders, particularly PD and dementia. Similar sexual changes have been documented in systematic reviews, aligning with our observations [18]. Notably, patients with PD and hypersexuality often exhibit sexual compulsivity and impulsivity [18-21], while those with dementia may show sexual disinhibition and inappropriateness [22]. Our study partially supports this distinction, with carers of patients with FTD describing behaviors as "*disinhibited*," although overlap with sexual preoccupation and compulsivity was evident. A larger sample size might clarify these distinctions further.

Contrary to expectations, despite increased sexual urges, patients often engaged less frequently in sexual activities with partners post-onset of hypersexuality, often due to partner

discontent. Patients sought gratification through masturbation, pornography, prostitution, promiscuity, or affairs, influenced by partner satisfaction or absence. This association between heightened desires and actual sexual practices underscores the role of external factors, echoing literature on marital dynamics where dissatisfaction can lead to extramarital pursuits [23].

Psychologically, carers reported disturbed moods and diminished mental health in patients, consistent with anxiety often coexisting with PD [24]. The emotional toll on carers was profound, reflecting themes of burden and distress documented in carer literature [25-27].

While all carers attributed their partners' hypersexuality to their neurological diseases, some believed its development is linked to the patients' past experiences. For example, Carer 1 indicated that her husband had a homosexual experience at the age of fifteen with a school friend. She claimed that her husband "*might have been a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him… allowing him… stimulating him to pursue the homosexuality as he had never done*" before. Carer 6 indicated that her husband had an ex-girlfriend of Indian descent during his twenties who died in a car accident. She indicated that both prostitutes her husband had been involved with, and one of whom he fell in love with, were dark-skinned and considered that there might be a link between this and the evolution of his hypersexuality. Two potential reasons for this link can be considered. First, it is possible that past behaviors had never disappeared but rather their partners had been successful in suppressing them. These behaviors resurfaced due to neurological disorders affecting inhibitions. Second, the biological and molecular effects of medications used to manage neurological disorders, like PD, may trigger latent tendencies, although this area remains unexplored within the scope of this research.

The study revealed that hypersexuality profoundly affected carers and strained their relationships with their partners. Some carers, overwhelmed by frustration and despair in dealing with their partners' hypersexuality, reported experiencing desires or actual instances of aggressive reactions towards their partners.

Despite efforts to cope, carers struggled with responsibility, guilt, and at times, aggressive feelings toward their partners, mirroring the challenges seen in sex addiction research [28-31] [30, 31]. Extended discussions during assessments, with one lasting over 3.5 hours instead of the anticipated two hours, indicate significant distress among carers. This underscores the urgent need for support and avenues for emotional expression and sharing experiences.

The stigma surrounding hypersexuality emerged as a significant concern for carers, influencing disclosure and help-seeking behaviors. Fear of stigma led some carers to conceal hypersexuality, decline study participation, or avoid healthcare appointments, reflecting broader societal discomfort with sexual topics [32, 33]. The barriers to seeking professional help include inadequate communication and education among healthcare providers, exacerbating carer distress and prolonging their silence on the issue.

Implications

This study highlights the critical need for healthcare professionals to educate patients and carers about ICDs associated with PD and dementia, including hypersexuality, and to provide ongoing support and monitoring [22, 34]. Targeted psychological and behavioral strategies could help carers manage distress and improve coping mechanisms. Acceptance and

commitment therapy (ACT) [35] may be particularly beneficial, as it encourages carers to accept the challenges of their partners' hypersexual behaviors while fostering psychological flexibility and values-based action. Group-based interventions, such as structured peer-support programs modeled after Al-Anon [36], could provide a shared space for carers to exchange experiences, reduce isolation, and develop practical coping strategies. Additionally, cognitive-behavioral therapy (CBT) tailored for carers could address maladaptive thought patterns and emotional distress related to managing hypersexual behaviors. Psychosocial interventions, including couple-based therapy and family counseling, may also facilitate communication and adaptive strategies.

Limitations

While this study focused on spousal carers, the impact of hypersexuality extends to other family members and professional carers, warranting broader investigation. The small sample size limited the generalizability of findings and restricted the ability to perform in-depth quantitative analyses. Future studies with larger and more diverse samples could better explore relationships between disease severity, medication effects, and hypersexuality, enhancing the applicability of results across different patient demographics and clinical settings.

Additionally, qualitative research is inherently subject to response biases, such as social desirability bias, where participants may have underreported or framed their experiences in a way they perceived as socially acceptable. The sensitive nature of hypersexuality may have further influenced participants' willingness to fully disclose their experiences. While we mitigated this by fostering a confidential and nonjudgmental interview environment, future research could incorporate anonymous surveys or mixed-method approaches to capture a broader range of perspectives.

Future directions

Future research should employ mixed methods to mitigate underreporting and explore comprehensive management strategies for hypersexuality in PD and dementia. Addressing stigma through public education and improving healthcare providers' readiness to discuss sexual health are crucial steps in supporting carers and patients alike.

Conclusion

In conclusion, hypersexuality in neurological disorders profoundly affects patients and carers, demanding tailored interventions and support mechanisms to alleviate its emotional and psychological toll.

Author Roles

1. Research project: A. Conception, B. Organization, C. Execution;
2. Qualitative Analysis: A. Design, B. Execution, C. Review and Critique;
3. Manuscript Preparation: A. Writing of the first draft, B. Review and Critique;

NT: 1A, 1B, 1C, 2A, 2B, 3A
JNP: 1A, 1B, 1C, 3B
JF: 2A, 2B, 2C, 3B

CS: 2A, 2B, 2C, 3B
WGES: 3A, 3B

Guarantor is Natalie Tayim / NT.

Disclosures

- **Funding Sources and Conflict of Interest**

This study received no specific grants from funding agencies in the public, commercial, or not-for-profit sectors. JNP is supported in part by funding from the United Kingdom's Department of Health NIHR University College London Hospitals Biomedical Research Centres funding scheme.

The authors declare that there are no conflicts of interest relevant to this work.

- **Financial Disclosures for the previous 12 months**

The authors declare that there are no additional disclosures to report.

Ethical Compliance Statement

This study (ethics application ID: 15/LO/0557) was approved by the London-Hampstead National Research Ethics Committee (NREC).

Declaration of patient consent – Interested carers were asked to come into the Department of Uroneurology at the NHNN where any of the available rooms on the scheduled dates was used to provide the participants with written information about the study, obtain written consent, and consequently complete assessment.

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Figure Legends

Figure 1. Flowchart summarizing the recruitment results for Parkinson's disease and dementia carers.
AD: Alzheimer's disease; FTD: Frontotemporal dementia; HS: hypersexuality; PD: Parkinson's disease

Figure 2. Themes and subthemes identified in the interviews.

Figure 3. Summary of categories for clinical phenomenology of hypersexuality in Parkinson's disease and dementia.

Table 1. Carer sample descriptives.

Variable	Carer 1	Carer 2	Carer 3	Carer 4	Carer 5	Carer 6	Carer 7	Carer 8
Neurological disorder	PD	PD	PD	PD	PD	FTD	FTD	FTD
Medications at the time of hypersexuality*+	Stalevo Rasagiline Clonazepam Fludrocortisone Movicol Atropine	Ropinirole Amantadine Selegiline Madopar Stalevo	Ropinirole Madopar Citalopram	Ropinirole Rasagiline Entacapone Amantadine	Ropinirole Madopar Stalevo	-	-	-
Implicating medications*+	Stalevo	Ropinirole	Unsure (Ropinirole)	Rasagiline	Ropinirole	-	-	-
Implicating medication reduced or discontinued*+	Yes discontinued	Yes discontinued	Yes discontinued	Yes discontinued	No	-	-	-
Still hypersexual+	Deceased	Yes	Yes	No	Yes	Deceased	Yes	Yes
DBS*	No	Yes	No	No	No	-	-	-
Type	-	Bilateral STN	-	-	-	-	-	-
Associated symptoms								
Sexual behavior	Preoccupation with sex Increased desire for sex generally Change in sexual orientation Uncontrollable masturbation Pornography Sex phone lines Sex channels	Preoccupation with sex Increased desire for sex with wife and generally Having sex more frequently Increased masturbation Pornography Fetishism	Preoccupation with sex Increased desire for sex with husband and generally Having sex more frequently Insatiable desire for masturbation	Increased desire for sex with husband Having sex more frequently Sexual attraction for therapist Having sex on stairs Hint of S&M Pornography	Preoccupation with sex Increased desire for sex with wife and generally Increased masturbation Pornography Sex phone line Dating sites	Preoccupation with sex Increased desire for sex generally Pornography Sex phone lines Dating sites Massage parlors Prostitutes	Preoccupation with sex Increased desire for sex with wife and generally Having sex more frequently Increased masturbation	Preoccupation with sex Increased desire for sex generally Increased masturbation Pornography Deviant interests Fantasies of dressing in women's underwear

	Visiting sex shops							
Other impulse control disorders	None	Compulsive eating Compulsive buying	None	Compulsive eating	None	Compulsive buying	Compulsive eating	Compulsive eating Compulsive buying
Other compulsive behaviors	None	None	None	Desire to move	None	None	None	Clock-watching Writing down electricity and water readings

DBS: deep brain stimulation; FTD: frontotemporal dementia; PD: Parkinson's disease; STN: subthalamic nucleus
*. There is no data available for the respective variables for Carers 5, 6, and 7 criteria only applicable to PD patients.
+. Information obtained from patient's clinical notes.

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Figure 1. Flowchart summarizing the recruitment results for Parkinson's disease and dementia carers.
AD: Alzheimer's disease; FTD: Frontotemporal dementia; HS: hypersexuality; PD: Parkinson's disease

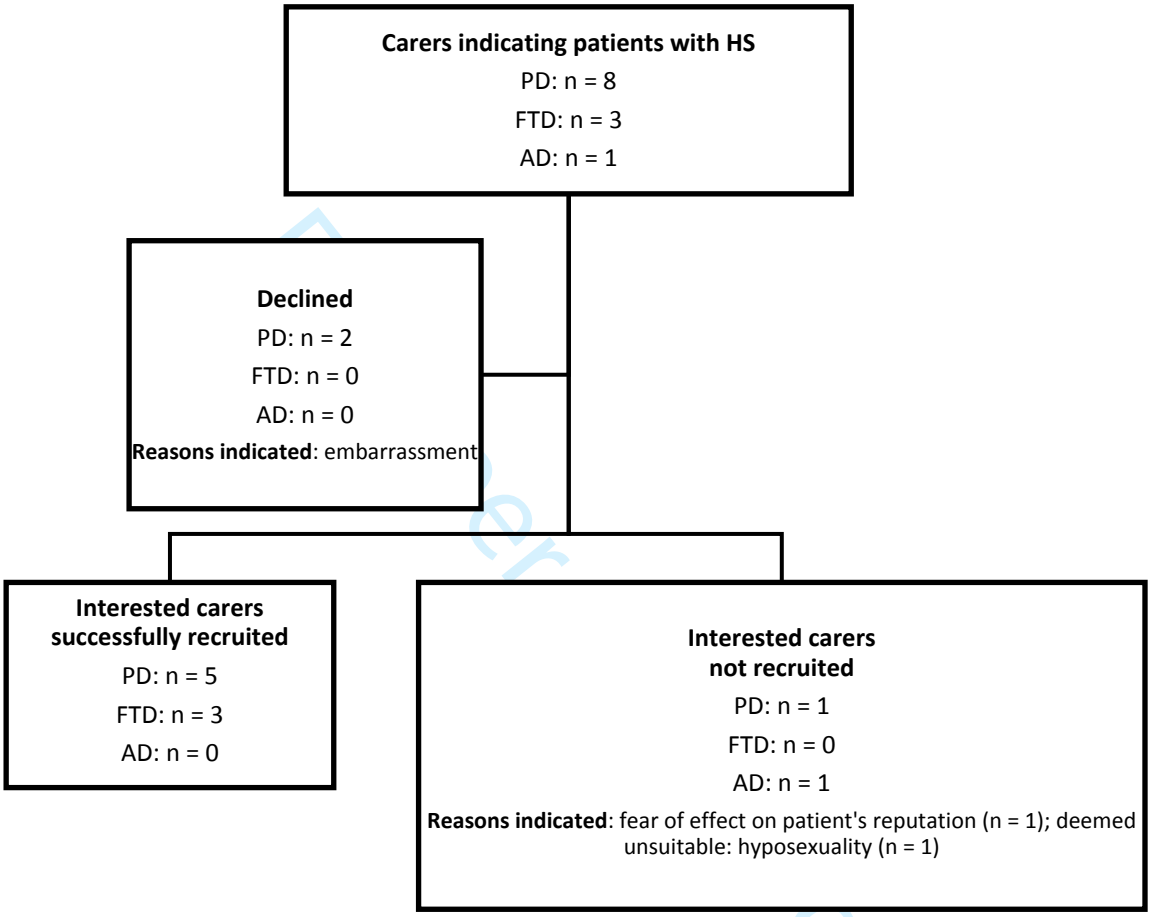
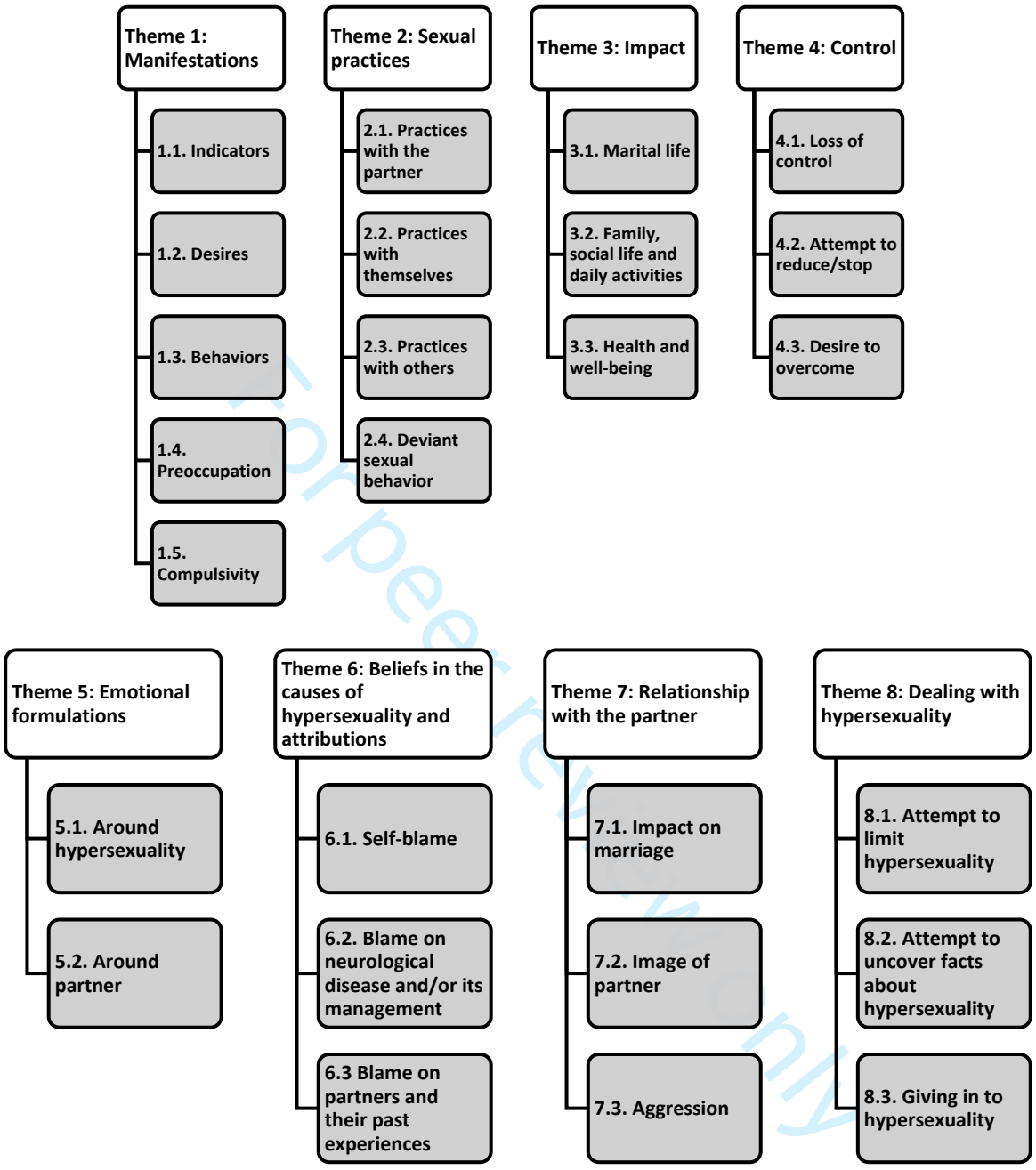


Figure 2. Themes and subthemes identified in the interviews.



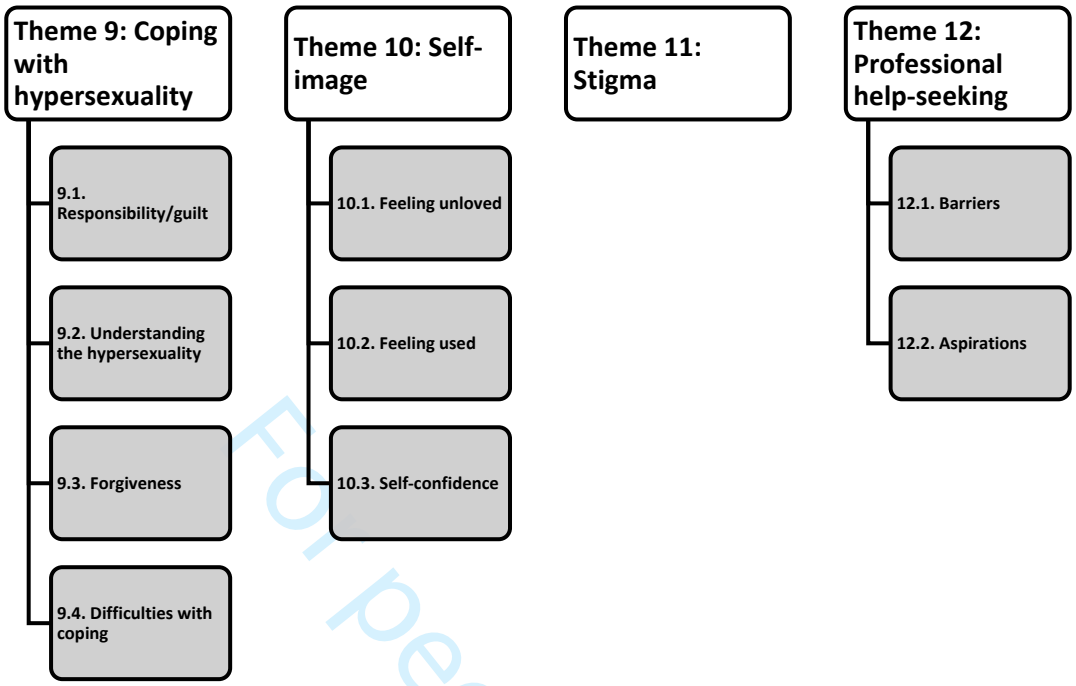


Figure 3. Summary of categories for clinical phenomenology of hypersexuality in Parkinson's disease and dementia.

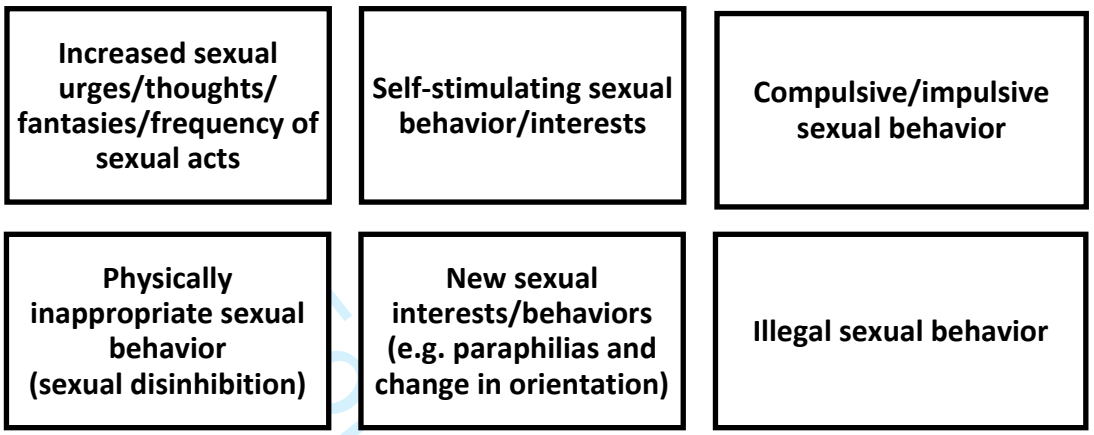


Table S1. Emergent themes, subthemes, and quotes analyzed for Parkinson's disease/frontotemporal dementia caregivers.

Themes	Subthemes	Quotes
Theme 1: Manifestations	**1.1. Indicators**	"I found a till receipt for a gay magazine… I sat on the knowledge for a couple of weeks but first of all I went straight up to WH Smith and bought a copy of the magazine thinking that either it wasn't what I thought it was… it was Gay Times… or this had been bought by mistake… I got a copy… I sat there outside and read it and realised it was highly unlikely that it had been bought by mistake…" (Carer 1)
	1.2. Desires	"That's the only thing he's interested in … to have sex." (Carer 7)
		"I don't know where desire's gone because it is practically... it is non-existent… they happened about the same time I think... I think it must be... it must be a good five or six years as far as he's concerned... and I honestly think that things changed for me around sixty..." (Carer 5)
	1.3. Behaviors	"Normally she likes tenderness and sweetness and it was sort of a bit more lust… go for it… behavior was extreme if you like because she's a reserved person … who has other high standards of good behavior… so this was her nature in the raw really…" (Carer 4).
	1.4. Preoccupation	"her thoughts are uncontrollable and come so much of the time…" (Carer 3)
	1.5. Compulsivity	"Hypersexuality is present all throughout the day and during the night while I am asleep…" (Carer 3)
Theme 2: Sexual practices	**2.1. Practices with the partner**	"And now [he was asking for sex] every morning… every evening… sometimes he's asking during the day…" (Carer 7)
		"She didn't ask for Fifty Shades of Grey no… but still … a little hint of S&M which really wasn't part of our repertoire…" (Carer 4)
		"Things like going outside the door and knocking on the door and coming in or something… you know… I'm somebody he's picked up outside or something and who knocks on his door and slips in with exotic underwear on or something… never had all this before… it's just weird… like he was sort of switched off… he's actually thinking he's with a prostitute or something I don't know…" (Carer 5)
	2.2. Practices with themselves	
	2.3. Practices with others	
	2.4. Deviant sexual behavior	"It needs to be more upfront that it's not just about a decrease in sex or an increase in sex… it could be a decrease in a normal sexual relationship and a… a subverted or a hidden cover increase in some kind of deviant sexual behavior which had been what was going on for twenty years and I didn't know about…" (Carer 8)

Theme 3: Impact	**3.1. Marital life**	"It was dreadful… devastating … I couldn't make head and the tail of it… it just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)
		"It's awful really because he's not the same person… apart from everything else that's going on… I feel like I'm sort of living a double life and sort of have to live his life as well and double check everything … life's so difficult so it's not surprising that I'm tired…" (Carer 5)
		"I've always thought of it very old fashioned as making love… sex for sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex..." (Carer 1)
		"It's kind of became more of ritual… more of a… I mean he would say things like 'I need a fuck'… like every morning and every evening, I have felt really pursued… that's the only thing he's interested in… is to have sex" (Carer 7)
		"It's difficult to separate if it's the dementia or more the sexual aspect of it… it's kind of loss of companionship in all areas so it has affected the relationship…" (Carer 7)
		"I'm competing with the women on television… sometimes I'm thinking… does he think that he's making love to me or does he think he's making love to somebody off the television…" (Carer 5)
		"I've lost respect for him… how can you respect someone that gets off of watching little boys being humiliated… I've said to him I won't collude or condone with anything he's done… and I won't accept those things either… and that whilst he lives in the house with me he behaves in a way I would want him to behave legally..." (Carer 8)
	3.2. Family, social life and daily activities	"My kids were shocked, so mentally and emotionally distanced themselves…" (Carer 1)
		"The children just could not understand it… he never denied it… both the children were irritable… they couldn't understand it you know because [of] the way he'd been brought up and how he'd brought them up…" (Carer 6)
		"I decided that if he agreed… and he did agree… that I would take his credit and debit cards off him… hide any money I'd got in the house… I left him… I think we agreed on fifteen pounds which would be enough for taxi and whatever so he couldn't do that… I hid the cheque books and hid any money I'd got in the house so he didn't have any access to cash… and that worked well for a couple of months and then he remembered that he had an account that I'd forgotten about…" (Carer 1)
	3.3. Health and well-being	"He couldn't sleep because I was working so hard and he was messing around… he said he cried most nights…" (Carer 6)

		"He was anxious and depressed… worried about everything…" (Carer 1)
		"He was more stressed because he just couldn't understand what he was doing…" (Carer 6)
		"He seemed very withdrawn… he was completely locked into this mad behavior… there was no happiness… there was no joy… he never smiled… he was apathetic… he was almost irritable… he was quite angry… he doesn't get irritable… he doesn't show it… if he is and this is what frightens me about him. I feel it's like watching a pressure cooker and there's going to be a time when it pops." (Carer 8)
		"Probably more confident… I mean she was writing all the time… that's her identity… she's a writer…" (Carer 4)
		"When I asked him when he stopped loving me … he said he didn't know and he eventually said 'I think I'm narcissistic and I'm in love with myself…" (Carer 8)
		"I think that as with the madness of love or something… it raises you up but it also is a madness so it is a sickness… it is a sickness we all enjoy." (Carer 4)
		"I knew he was dating again… he'd go out looking quite handsome in something that I'd suggested to upgrade his wardrobe… go out looking attractive…" (Carer 6)
Theme 4: Control	**4.1. Loss of control**	"He couldn't resist it… it was hopeless… he couldn't stop it…" (Carer 1)
		"It's become like a bit of a habit… like something he asks for… it's a bit like asking for a bit more wine…" (Carer 7)
		"There is a difference… the impulse to do something and the ability to know right from wrong… he knows what's right and what's wrong but he chose to take a risk and his risk-taking has increased… he is the one with his hand on his penis…" (Carer 8)
		"I think she probably hadn't got [control]… I think she probably felt a bit out of control… but she didn't seem distressed…" (Carer 4)
	4.2. Attempt to reduce/stop	"I think he's doing a good job in trying to keep a lid on it… it's still there but more controlled…" (Carer 2)
	4.3. Desire to overcome	"[He] desperately wanted to stop it… he just couldn't work out what had hit him…" (Carer 1)
		"[It] absolutely drives her mad and does not make her happy… if clitoris removal existed she would have gone for it…" (Carer 3)
		"I don't think that he admits that he's hypersexual… because whenever it's come up like now or even when the neuropsychologist was there… it's not something that he'd actually readily say 'Yes I have got a problem'… I don't think he thinks he's got a problem…" (Carer 5)
		"I don't think he understands actually…" (Carer 7)

Theme 5: Emotional formulations	**5.1. Around hypersexuality**	"I just didn't know what had happened ... it's like waking up on the other side of the mirror like Alice in... Through the Looking Glass... it was just so abnormal... he was cold towards me…" (Carer 8)
		"I was shocked... I couldn't make head and the tail of it... it just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 7)
		"Normally she likes tenderness and sweetness and this was sort of a bit more lust... go for it... [laughing]... and in a way that was fresh and amusing... again one took that as a positive thing... for a while anyway…" (Carer 4)
	5.2. Around partner	"I just felt really sorry for him… the only pleasure he has in life is to have sex so I didn't find it difficult for me to… you know… have sex with him… because I felt sorry for him… it was fine for me as well…" (Carer 7)
		"I was so angry… it wasn't just emotion… there was anger… I felt very angry about what he'd done … I wouldn't want him to touch me because I don't know who he is… he was doing things that are completely unacceptable… sad… I was very sad… I felt rejected… I felt confused… I feel such a fool… let down…" (Carer 8)
		"I was a bit unquestioned maybe looking back… it wasn't that extreme you know… it was extreme if you like because she's a reserved person who you know… who has other high standards of good behavior you know… so this was like nature in the raw really… which didn't in the least turn me off…" (Carer 4)
Theme 6: Beliefs in the causes of hypersexuality and attributions	**6.1. Self-blame**	"The longer he's not having sex the worse it's making him… so basically that might be my fault…" (Carer 5)
	6.2. Blame on neurological disease and/or its management	"I suppose now I can point to Ropinirole and say it's Ropinirole's fault…" (Carer 5)
		"He was already on this medication then so you know… and we tried to work out which it was... I thought it was when the entacapone had been added…" (Carer 4)
		"Part of the pain in the neck of the disease… awfulness of package that's changed our lives…" (Carer 3)
		"I think it just came with the disease… right before he passed I said to him 'You couldn't help it… it wasn't you… it wasn't what you were like… it was a disease and you've got two of them and they're both serious'…" (Carer 6)
		"I recognised that it isn't his fault… it doesn't make it any easier to bare…" (Carer 8)
	6.3 Blame on partners and their past experiences	"[Husband's] parents were away… he was allowed… for a night… and he was allowed to ask his friend from his school to stay overnight which he did… and then some sort of homosexual activity occurred… I mean the implication has always been that he was a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him... allowing him... whatever... stimulating him to pursue the homosexuality as he never had done as far as I know…" (Carer 1)

Theme 7: Relationship with the partner	**7.1. Impact on marriage**	"It's not like an intimate loving relationship… it's more mechanical and ritual-like…" (Carer 7)
		"Hypersexuality is his way of being masculine… not for sexual gratification but rather for me to enjoy it as well… but he doesn't understand that I don't…" (Carer 2)
		"It's not making love to me or me making love to him in the way that I used to know… it's not that anymore…" (Carer 5)
		"I stopped being a wife and became a housekeeper and a carer…" (Carer 1)
		"I'm just there to put food on the table… to clean the house… and he's polite to me because that's how he's been brought up… to be polite… but it's not a marriage…" (Carer 8)
		"I actually feel now that I'm… it's a role reversal… I don't think he's looking after me… I think I'm looking after him…" (Carer 5)
		"I half felt amused in a way because I don't really feel insecure … you know… it's a good relationship…" (Carer 4)
	7.2. Image of partner	"It just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)
		"I'm losing the husband that I had… he's just not there for me anymore…" (Carer 5)
		"The man I married was intelligent… vibrant… really, really fun to be with… very very loving… I'm now living with not just the fact that I lost my husband but that my husband was never who I thought he was… I don't know who this person is and in fact I got him to move out of our bedroom the night I found out about the pornography… and I lay in bed that night on my own… he was in the other room… and I had the duvet and my arms underneath and I thought 'Put your arms on top' and then I thought 'Why did I think that?' and I thought 'Because he might come in… I'm frightened' then I got up and I locked my bedroom door… because I was so frightened of who this person was because he was not the man I married and I now had proof he was not the man I married… this is a man who was having to imagine he was wearing women's clothes before he could get an erection with me… who is this man and did I ever know? It made me question everything…" (Carer 5)
	7.3. Aggression	"I think the worst thing was that on one occasion I actually momentarily considered violence towards him… he'd had one of his trips to the sex shop… he got stuff… I'd been out in the garden… and I'd seen him through the window of his office… obviously he was busy looking at some stuff… and it was lunch time and I came in to give him his lunch… and I stood behind him and I really can't believe it now but I've got to tell you… it's the truth… I stood behind him with this big hammer in my hand… and I thought quite clearly 'A couple of blows to your skull with this and this would all be over'… and then I put the hammer away and served his lunch…" (Carer 2)

		"Even after I'd found out, I couldn't get him to talk to me about it and I remember going to his workshop one day like this and I asked him and asked him and he just stood there like a defiant little boy… and I picked him up… I'm only five feet… he's five foot six… he's much bigger… I picked him up by his boiler suit and I walked him backwards to the wall… just lifted him off the floor, banged him against the wall and I said 'Talk to me' and he just stood there till I let go of him… nothing moves him… nothing moves him… my GP said 'Make sure you're not near the knife block when you do hit him… get out of the kitchen'… she said 'Don't put yourself in danger' and what she meant was danger of being arrested I think…" (Carer 8)
Theme 8: Dealing with hypersexuality	**8.1. Attempt to limit hypersexuality**	"If he did continue to do something and the police were… I would step aside… I would explain that he had a degenerative brain disease but I'm not going to protect him if he's doing something illegal which he was… I think there's a limit to how much protection I can afford someone who has done not to deserve protection…" (Carer 8)
		"I would switch the television off and take the [pornographic] DVD out… I think I became very controlling... and I'm not sure if that was the right thing or the wrong thing to do but I did… for a start because I found it offensive… very offensive…" (Carer 1)
		"I don't like going to bed first because I lay in bed trying to listen whether he's changing channels… whether it's really Match of the Day or something else… and he started going to the second living room a bit too… the guest accommodation next door… he goes in there occasionally and says it's because he wants to watch something different to what I'm watching and then she starts putting the DVD player on… and again it's probably all okay but I think maybe… has he got some funny DVD or something…" (Carer 5)
	8.2. Attempt to uncover facts about hypersexuality	"I certainly looked for materials he'd obtained and was using… when I realised that he had bought a gay magazine… because I found the receipt by chance… after it when I thought about it he just said he was just curious… when he was out I went and unlocked the case and found more magazines… so yes I did go looking for them… yes I did go and look in his case and see what he'd got…" (Carer 1)
		"Partly I snooped... when I saw two thousand pounds being taken out of... you don't just take that out... but partly I did a ring back... a 1471 and got connected to the sex line on our phone... I mean he didn't bother to disguise it because I don't think he could…" (Carer 6)

		"He goes into day care two days a week… I search the room… I look under the mattress… I look under the carpet… I look inside the pillowcases… it's turned me on to being hyper vigilant…" (Carer 8)
	8.3. Giving in to hypersexuality	"I thought 'God this poor man has been a repressed gay all his life… he's never indulged in it… I know he's ill… he hasn't got that many more years to live… if he wants to indulge in this why shouldn't he?' and so I said to him 'Look you can't drive now… if you want to go to gay bars and clubs I will take you there'… after you'd phoned me and said that there is some evidence that it does alter sexual orientation… I just sat and cried… I thought 'Poor man'… he must've been so confused with what's happening to him… utterly… and he couldn't resist it…(Carer 1)
		"Not like I feel it's a great suffering to me… it's… to me… about his needs… maybe more than mine…" (Carer 7)
Theme 9: Coping with hypersexuality	**9.1. Responsibility/guilt**	"I thought I had done something and I tried for twenty years to find out what it was and when I found out it had all been him I didn't feel responsible…" (Carer 8)
		"I sort of think well [laughing] maybe it is my fault… maybe it is my fault that you know I'm not... wanting to have sex every night or whatever... I don't know where desire's gone because it is practically... it is non-existent…" (Carer 5)
	9.2. Understanding the hypersexuality	"Kind of owning the fact that… that sex is not just with the other… it's your relationship with yourself as well as the other person so I'm able to separate how to be who I am and who he is so I don't actually feel exploited… like I'm able just to see that he has a greater need for sex than me and for our relationship to work I help him to meet that need and I'm having lots of other needs met in our relationship… it balances quite nicely…" (Carer 7)
		"I think I put it down to her transference and the peculiar relationship that is actually truly expected within... within a serious therapeutic relationship... I mean it is a relationship of huge power... and... I think in a way she was supposed to have this transference... I think that was part of the deal... he was meant to become her father and she felt a sort of way towards her father…" (Carer 4)
		"After you'd phoned me and said that there is some evidence that it does alter sexual orientation... I just sat and cried... I thought 'Poor man... he must've been so confused with what's happening to him... utterly... and he couldn't resist it…" (Carer 1)
		"She [GP] just let me cry and she said to me 'You know... you're always going to feel sad about this'… she didn't try and pretend it would go away… I said to her 'That's the most genuine response I've had so far'…" (Carer 8)
	9.3. Forgiveness	"on the road to forgiveness" (Carer 1)

		"some things can't be unsaid" (Carer 8)
	9.4. Difficulties with coping	"[I am] further back than I have ever been because I don't feel that safety and security that I feel I need to have" (Carer 2)
		"I just wished I didn't exist" (Carer 2)
		"[I] didn't want to commit suicide but I would like not to exist and there's a difference between not wanting to exist and wanting to be dead." (Carer 8)
Theme 10: Self-image	**10.1. Feeling unloved**	"I feel as if he is only interested in me sexually…" (Carer 2)
		"All the time it will end up in 'You don't know how much I love you and I wouldn't do anything to hurt you'… he used to always be telling me that he loved me and… I think that's what I miss a bit really… he isn't quite so affectionate… he used to say it on a daily basis how much he loved me and things and that was quite nice..." (Carer 5)
	10.2. Feeling used	"I've always thought of it very old fashioned as making love… sex of sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex… he was using me… like an animal really…" (Carer 1)
		"I feel… I'm competing with the women on the television or in his mind… I feel like he wants me to be one of them rather than… being me…" (Carer 5)
		"He has said he had had to imagine he was wearing women's clothes before he could get an erection with me and that makes me feel really creepy because I was in bed with someone who was going to imagine he was wearing women's clothes before he could touch me…" (Carer 8)
	10.3. Self-confidence	"On one occasion I said to my husband 'I don't understand how you can do this to me'… I've always stayed slim… I was always reasonably dressed… I was his official wife… had to go to functions and things with him… he always said how well dressed I looked… I could talk to people and do the proper job as a wife… that he had never been short of sex… so what was it?" (Carer 1)
		"At the time I felt completely worthless… completely and utterly worthless… I just felt so ugly and old…" (Carer 8)
		"[My] counselling training has helped me to be more confident in who I am so it doesn't rattle me as much as it might other people…" (Carer 7)
Theme 11: Stigma		"We're in our sixties so it's quite obvious that we're not going to feel how we did when we first met in our thirties… but he seems to be still back in that era and wants it in the same way…" (Carer 5)
		"I suppose the thing that bothered me most was the thought that other people would find out and laugh at me because I'd always... pride always comes before a fall... I'd always been proud of my happy marriage... we'd worked at it and the thought that

		my husband was gay and might be discovered to be gay are... yeah... that did worry me...” (Carer 1)
		“I can’t really spread the word because... I would... but because of the children and the embarrassment of you know having a father do that which is difficult …. Someone such as myself who has been through it... I’m actually quite free to talk about it away from home and I’m quite happy to talk about it away from home…” (Carer 6)
		“[laughing] she’d go straight to the… not too much foreplay… not too much… normally she likes tenderness and sweetness and this was sort of a bit more lust… go for it [laughing]…” (Carer 3)
		“I mean the change was there in just the amount of sex we were having and the sort of… you know… on the stairs as it were you know… which wasn’t something we’d done for many years not since our young days… sorry.” (Carer 3)
		“I’m being horribly honest here… is this alright?” (Carer 1)
Theme 12: Professional help-seeking	**12.1. Barriers**	“If somebody had said… well warning you that this might happen when he went on these drugs… I mean it says in the leaflets… it talks about hypersexuality… I looked at it and read the sheets through and I said ‘Oh hypersexual… he’ll be a bit frisky and that’ll be alright’… you know… the horrors of what were to come never occurred to me… if nobody speaks out then this will go on and other marriages will be ruined like mine was ruined… at least had we’ve been told it wouldn’t have been such a terrible shock…” (Carer 1)
		“I have tried to broach this a few times with my husband’s neurologist… I do a bit more than hint at the problems now and again but he never sort of takes it and runs with it… we’ve been seeing him for ten years and not once has he asked about hypersexuality… or hinted… that it could be a problem… he would spend more time talking about gambling…” (Carer 5)
		“No one cares enough … you just don’t feel listened to… the overwhelming feeling is of not being believed … even neurologist, even psychoneurologists… don’t know enough about it” (Carer 6)
	12.2. Aspirations	“necessity of full disclosure” (Carer 4)
		“[hypersexuality] has to become a specialty… I wish that they wouldn’t say to go to marriage guidance and counselling because… they are not equipped to handle [it]” (Carer 6)
		“[I need help] with managing the anger that I feel in a way that is useful… not in a way where somebody just sits there and tell me that my mantra should be that my husband can’t help it… I want somebody who can help me understand why I’m angry and who can help me resolve these angry feelings before my husband dies” (Carer 8)

University College London Hospitals NHS
NHS Foundation Trust

Carer Assessment Interview
Chief Investigator:
Patient Identification Number:
Date:

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

Carer Assessment Interview

Semi-structured interview schedule

Please note that not all carers are necessarily partners; therefore, there are some interview questions that can only apply to partners. Questions that only apply to partners are under a separate heading.

Interview length: 35-60 minutes

*About the patient (*to be extracted from patient notes)

Age of patient:

Neurological disorder of the patient:

Age of onset of neurological disorder:

Date:

Time:

INTRODUCTION

Thank you for agreeing to take part in an interview for this project.

This interview will be audio recorded. The main reason for this is to have an accurate set of data on this topic. This will help researchers analyze the data as the project develops. Rest assured that you would remain completely anonymous. All data collected is confidential. No records of the interview will be kept with your name or the name of the patient on it.

The following sections include questions about increased sexual behavior that has happened since the patient has developed (insert name of neurological disorder). This is called hypersexuality. Please remember that sexual acts involving physical harm to others or child abuse is against the law. For this reason, please do not answer any questions that show that the patient's sexual behavior has been a threat to others or that the patient has had sexual relationships with minors.

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Carer Assessment Interview

Chief Investigator:
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I understand how sensitive this topic is. If any questions make you uncomfortable, you are completely free not to answer, but we would be grateful if you can answer all questions. Also, if any questions are not understandable, please ask and they will be explained.

GENERAL BACKGROUND

1. **Question:** How old was the patient when they first became hypersexual?

2. **Question:** What is your relationship to the patient?

   Probe 1: How long have you been in this relationship?

   Probe 2: (if applicable) When did the relationship end?

   Probe 3: Was the hypersexuality a reason for the end of your relationship?

3. **Question**: Did the patient have any behavioral or cognitive disorders before the (insert name of neurological condition)?

   Example of behavioral disorder is obsessive-compulsive disorder.

   Example of cognitive disorder is perception and memory disorders.

   Probe: Can you tell me what they are?

4. **Question:** Does the patient have any previous addictions, such as drugs or alcohol?

   Probe: What addictions?

5. **Question:** Did/does the patient have any other impulse control disorders such as increased gambling behavior, increased eating behavior, or increased buying behavior?

   Probe 1: Which ones?

   Probe 2: When did they start?

   Probe 3: How severe were/are these behaviors?

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6. **Question:** Did/do you notice any other changes in the patient's behavior apart from these and the hypersexuality?

   Probe 1: What are they?

   Probe 2: When did these changes start?

7. **Question:** Did you notice that the hypersexuality developed after use of any medications?

   Probe: What medications?

SPECIFIC

8. **Question:** When did you first notice this increased sexual behavior?

   Probe 1: When you first noticed this behavior, how did you feel?

   Probe 2: Is the patient still showing this behavior?

9. **Question:** Do you believe the patient developed hypersexuality because of (insert name of neurological disorder)?

   Probe: Why do you think so?

10. **Question:** Since the patient's (insert name of neurological disorder) started, did/do you feel the patient has lost interest in sex in general?

    Probe: What makes you think so?

11. **Question:** Since the hypersexuality started, do you believe the patient has new sexual interests that were not there before the (insert name of neurological disorder)?

    Probe 1: What are the new interests?

    Probe 2: How did you notice them?

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12. **Question**: How much time do you think the patient spent/spends on their new sexual interests?

13. **Question:** Since the hypersexuality started, do you believe that your physical relationship with the patient has changed?
    Probe: Can you tell me how?

14. **Question:** Since the hypersexuality started, has the patient become more interested in sex with you?
    Probe: What is your reaction?

15. **Question:** Since the hypersexual behavior started, do you think the patient had/has no control over their hypersexuality?
    Probe: What makes you think so?

16. **Question:** Since the hypersexual behavior started, do you feel like the only thing the patient could/can think about is sex?
    Probe: What makes you think so?

17. **Question:** Does the patient's hypersexuality cause problems in your relationship?
    Probe 1: Can you please give elaborate? What kind of problems?
    Probe 2: How does this make you feel?
    Probe 3: How do you think this makes the patient feel?

18. **Question:** Do you believe the patient was/is more tempted to engage in sexual behavior when they have certain feelings, such as sadness or anxiety?
    Probe: What feelings?

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19. **Question:** Which of the following has your partner tried since developing hypersexuality? I will list them and you are required to just say yes or no to each.

    Internet porn?

    Pornographic novels?

    Uncontrollable masturbation?

    Prostitution?

    Voyeurism: getting sexual satisfaction from spying on sexual objects or acts?

    Exhibitionism: the act of showing your genitals to strangers?

    Affairs?

    Anonymous sexual encounters?

    One-night stands?

    Bath houses: communal bath places?

    Massage parlors?

    Strip clubs?

    Sexual encounters with gender not typically interested in?

    Sexual misconduct in the workplace?

    Being aggressive with sexual partner?

    Asking for sexual partner to be aggressive?

    Bestiality: sexual encounters with animals?

    Any others that I haven't listed?

1. **Question:** Do you think the hypersexuality has negatively affected the patient's life?

   Probe: Has it affected their

   Marital life? How so?

   Family life? How so?

   Social life? How so?

   Work? How so?

   Finances? How so?

   Health? How so?

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Mood? How so?

Sleep? How so?

Self-confidence? How so?

Quality of life? How so?

20. **Question:** To your knowledge, has the patient tried to control their sexual behavior or stop it altogether?

    Probe 1: Has it been successful?

    Probe 2: How does this make the patient feel?

21. **Question:** To your knowledge, does the patient want to overcome their hypersexuality?

    Probe: How can you tell?

22. **Question:** Did the patient ever seek advice for their sexual behavior?

    Probe: What was the result of that?

23. **Question:** How did/does the patient's hypersexuality make you feel?

    Probe 1: Do you think the patient knows this?

    Probe 2: Have you tried to make them aware?

    Probe 3: What has been the patient's reaction?

24. **Question:** Do you believe the hypersexual behavior was/is out of the patient's control?

    Probe 1: Did/do you discuss this issue with the patient?

    Probe 2: What has resulted from those conversations?

PARTNER QUESTIONS

25. **Question:** Since the hypersexual behavior started, did/do you feel there was/is less intimacy and confidence between you and your partner when you have sex?

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Probe: Why do you think this has happened?

26. **Question:** Since the hypersexual behavior started, did/do you feel your partner was/is not sexually interested in you anymore?

    Probe 1: How does this make you feel?

    Probe 2: Have you talked to your partner about this?

    Probe 3: What did they reply?

27. **Question:** Before the patient's (insert name of neurological condition) started, how often did you and your partner have sex?

28. **Question:** In the period between the start of the patient's (insert name of neurological condition) but before the start of hypersexuality, how often did you and your partner have sex?

29. **Question:** Since the hypersexuality started, how often do you and your partner have sex?

30. **Question**: Did/do you find your partner repulsive?

31. **Question**: Did/do you feel you lost respect for him?

32. **Question**: Do you think you will ever be able to forgive him?

33. **Question:** Do you ever blame yourself for the patient's hypersexuality?

CLOSURE

We have reached the end of our interview. I would like to thank you for being so patient. However, do you believe there is anything we have missed out that you would like to add?

Do you have any other comments about what we have discussed, or about the research as a whole?

University College London Hospitals NHS
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Carer Assessment Interview

Chief Investigator:
Patient Identification Number:
Date:

The National Hospital for Neurology and Neurosurgery
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We will send you a summary of the research findings when it becomes available.

Thank you so much for your participation.

BMJ Open

The Impact of Hypersexuality on Spousal Carers of Patients with Parkinson's Disease and Frontotemporal Dementia: A Qualitative Study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2024-090870.R2
Article Type:	Original research
Date Submitted by the Author:	24-Mar-2025
Complete List of Authors:	Tayim, Natalie; Doha Institute for Graduate Studies, Psychology Panicker, Jalesh; University College London Hospitals NHS Foundation Trust, Department of Uro-Neurology; University College London, Department of Brain Repair and Rehabilitation Foley, Jennifer; University College London Hospitals NHS Foundation Trust National Hospital for Neurology and Neurosurgery, Neuropsychology Selai, Caroline; University College London Hospitals NHS Foundation Trust, Department of Uro-Neurology; University College London, Department of Clinical and Movement Neurosciences El Sheikh, Walaa; American University of Beirut, Faculty of Medicine
Primary Subject Heading:	Mental health
Secondary Subject Heading:	Qualitative research
Keywords:	Caregivers, Parkinson-s disease < NEUROLOGY, Dementia < NEUROLOGY

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The Impact of Hypersexuality on Spousal Carers of Patients with Parkinson's Disease and Frontotemporal Dementia: A Qualitative Study

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Conflict of Interest
The authors declare that there are no conflicts of interest relevant to this work.

Funding Sources
This study received no specific grants from funding agencies in the public, commercial, or not-for-profit sectors. JNP is supported in part by funding from the United Kingdom's Department

of Health NIHR University College London Hospitals Biomedical Research Centres funding scheme.

Keywords:
hypersexuality, spousal carers, Parkinson's disease, frontotemporal dementia

Word Count: 7245

Abstract

Objectives:
Hypersexuality involves an inability to control intense, recurring sexual impulses, resulting in repetitive sexual behaviors. It frequently manifests in patients with neurodegenerative disorders such as Parkinson's disease (PD) and dementia. Using a qualitative approach, this study aims to explore the impact of hypersexuality on spousal carers of patients with PD and dementia.

Design:
Qualitative study using semi-structured interviews and thematic analysis.

Setting:
This study was conducted in secondary care settings, including movement disorder and dementia clinics, as well as through patient support organizations. Participants were recruited from multiple centers across the UK. Interviews were conducted in a clinical research setting.

Participants:
Eight spousal carers (five caring for patients with PD, three for patients with dementia) participated in the study. Participants were selected based on their role as primary carers and their experience managing hypersexuality in their partners.

Results:
Thematic analysis identified twelve themes: manifestations, sexual practices, impact, control, emotional formulations, beliefs in causes of hypersexuality and attributions, relationship with the partner, dealing with hypersexuality, coping with hypersexuality, self-image, stigma, and professional help-seeking. Hypersexuality altered patients' sexual cognitions and behaviors, causing distress and strain on carers' mental health and marital life. Carers struggled to cope with their partners' hypersexuality, facing emotional burden and barriers to seeking professional help.

Conclusions:
Hypersexuality significantly impacts spousal carers of patients with PD and dementia, affecting their emotional well-being and relationships. Healthcare professionals should recognize and address hypersexuality's psychological and relational consequences. Psychoeducation, support groups, and tailored interventions for patients and carers are recommended to alleviate emotional distress. Future research should explore the broader familial impact of hypersexuality and develop effective management strategies.

Keywords:
hypersexuality, spousal carers, Parkinson's disease, frontotemporal dementia

Strengths and limitations of this study:
1. This study provides qualitative insights into the experiences of spousal carers managing hypersexuality in PD and dementia.
2. The use of semi-structured interviews allows for an in-depth exploration of carer perspectives.
3. Potential underreporting of hypersexuality due to stigma may have influenced the data.

4. The study focuses solely on spousal carers, excluding experiences of other family members or care professionals.

Introduction

Hypersexuality, classified under compulsive sexual behavior disorder in the International Classification of Diseases 11th Revision (ICD-11), involves an inability to control intense, recurring sexual impulses, resulting in repetitive sexual behaviors, which can lead to distress and impairment in personal, social, or occupational functioning [1]. Hypersexuality frequently manifests as a disorder in patients with neurodegenerative disorders such as Parkinson's disease (PD) and dementia [2]. It typically arises as a side effect of dopamine replacement therapy (DRT) in PD [3] and as a result of frontal lesions in dementia [4]. The management of hypersexuality often involves the reduction or cessation of the behavior-inducing drug in PD and a switch to alternative medications like levodopa, catechol-O-methyltransferase (COMT) inhibitors, or monoamine oxidase B (MAO-B) inhibitors [5, 6].

As patients get older, they tend to become increasingly dependent on family members for support [7]. Accumulating responsibilities on the carer can lead to carer burden, which encompasses a range of negative responses such as a decrease in quality of life and physical and psychological deterioration [8]. For example, spouses and female carers of patients with frontotemporal dementia (FTD) tend to experience distress, increased rates of depression, and poor sleep [9]. Hypersexuality can worsen carer burden and be detrimental to the patients' and their partners' quality of life [10, 11]. Accounts of spousal carers of patients with neurological disorders suffering from hypersexuality are lacking in the literature. Therefore, using a qualitative approach, the current study aims to explore the impact of hypersexuality on spousal carers of patients with PD and dementia.

Methods

Ethics

This study (ethics application ID: 15/LO/0557) was approved by the London-Hampstead National Research Ethics Committee (NREC).

Study Design

This study employed a phenomenological qualitative approach. This approach was deemed most appropriate for the present study since the intention of this study is to understand the spousal carers' personal experiences of the phenomenon of hypersexuality and how they view and interpret their experiences.

This study was conducted from April 2015 to August 2017. It was part of a broader UCL project examining hypersexuality in neurological disorders [12, 13].

Eligibility Criteria

Carers were included in the study if they are spouses or partners of patients with clinically diagnosed PD according to the UK Brain Bank Criteria or clinically diagnosed FTD, indicated hypersexuality either in the past or present since developing PD or dementia, and having the ability to provide informed consent.

Carers were excluded from the study if they are spouses or partners of patients with hypersexuality predating the onset of PD or FTD, having co-existing neurological disorders as determined by clinical history, or difficulty understanding/speaking English.

Measure

Carer Assessment Interview (Supplementary Appendix 2). The interview is a semi-structured thirty-four item interview, developed by NT. During the interviews, the participants were asked to reflect on, describe, and/or recount their experience with hypersexuality and its impact on their lives to the best of their abilities considering the sensitive nature of the topic.

Procedure

Spouses of patients with PD who indicated hypersexuality as being an issue during patients' clinical appointments and who were prepared to discuss it in further detail with a researcher were contacted by NT. These carers as well as the carers who contacted the researchers after reading information leaflets about the study circulated by Parkinson's UK were further informed about the study's aims, methods, potential risks and benefits, and confidentiality over the phone.

Carers of patients with FTD or Alzheimer's disease (AD) were informed about the study by the clinical staff at the Dementia Research Centre (DRC), through either the newsletter that was sent out periodically which contained blurbs about the study and the contact details of the members of the research team, or through the carer leaflets passed out at the Frontotemporal Dementia Support Group (FTDSG) March 5th, 2016 Seminar, which took place at 33 Queen Square. These carers were further informed about the study's aims, methods, potential risks and benefits, and confidentiality over the phone, as well as that the interview portion of the study was going to be audio-recorded using a Dictaphone and that the recorded material was only to be used in writing up the transcripts, which was completed almost immediately after assessment. Participants were assured that the recorded material would not be passed on and that it would be deleted at the end of transcription. Participants, however, who did not consent to the use of the Dictaphone were informed that they were still eligible to take part in the study.

Interested carers were then asked to come into the Department of Uroneurology at the National Hospital for Neurology and Neurosurgery (NHNN) where any of the available rooms on the scheduled dates was used to provide the participants with written information about the study, obtain written consent, and consequently complete assessment.

A total of twelve carers indicated hypersexuality as having been or still being an issue, eight of whom were carers of patients with PD, four of whom were carers of patients with FTD, and none of whom were carers of patients with AD. Eight carers were successfully recruited into the study. Five PD carers were recruited from the Movement Disorders Centre (MDC) at the NHNN, Edgware Community Hospital (ECH), as well as from Parkinson's UK. Three FTD carers were recruited from the DRC at the NHNN. **Figure 1** presents a summary of recruitment results for PD and dementia carers.

Insert Figure 1.

The interviews were conducted by NT, a PhD candidate at the time of the research. As part of her doctoral thesis, she drew on her undergraduate background in psychology to inform her approach to qualitative data collection. NT had no prior relationship with the study participants before the research commenced. Participants were informed about the study's purpose through a leaflet, which explained the association between neurological disorders and changes in sexual desire, as well as the study's aims to understand these changes and their impact. The leaflet also provided details about the study's collaboration between the DRC and the Department of Uroneurology at Queen Square, emphasizing the potential benefits of the research in improving care and developing psychological interventions. Additional details regarding the interviewer's background and role were available in the study materials provided to participants. The interviews ranged from two hours to nearly four hours in duration with as many breaks as required by the participants.

Sample Size

The sample for this qualitative study comprised eight carers, a size considered sufficient for exploratory research within qualitative methodologies. Qualitative research prioritizes in-depth understanding over statistical generalizability, with sample size determined by the principle of thematic saturation. Saturation, in this context, refers to the point where additional data collection yields no new insights relevant to the research questions [14, 15]. This approach aligns with Fusch and Ness (2015), who emphasize that "more is not necessarily better than less," challenging the notion of a fixed target number for saturation [15]. Instead, saturation is reached when the data adequately represent the phenomenon under study, enable study replication, and further coding produces redundant information. Moreover, Guest et al. (2006) posit that a sample of six can generate "basic elements for metathemes", especially in studies involving sensitive topics [16]. Consequently, the data obtained from eight carers allowed for a thorough exploration of individual experiences, contributing to theory development within the inherent constraints of qualitative research.

Patient and Public Involvement

It was not appropriate or possible to involve patients or the public in the design, or conduct, or reporting, or dissemination plans of our research.

Data Analysis

Virginia Braun and Victoria Clarke's (2006) thematic analysis approach was used to analyze the qualitative data for this study [17]. We adhered to the thematic analysis process, which included becoming familiar with the data, organizing the data, generating initial codes, generating themes, naming and defining themes, producing the report, and determining the quality of analysis.

Initially, interview transcripts were reviewed and organized into an Excel chart to facilitate data accessibility and ensure comprehensive analysis. This systematic arrangement allowed researchers to examine participant responses to each interview question without repeatedly referring to full transcripts. Following data familiarization, key extracts were identified through annotation and highlighting, capturing recurring words, ideas, and patterns. These extracts were systematically grouped into codes by NT and study supervsiors.

Researchers then compared and refined codes through discussion, establishing coherent relationships and categorizing them into preliminary themes. Themes were subsequently reviewed for coherence, consistency, and distinctiveness. Based on this evaluation, themes were retained, modified, or removed as necessary. Subthemes were identified where applicable, representing distinct yet interconnected elements within overarching themes.

Finally, the thematic analysis was checked against a 15-point checklist of criteria for good thematic analysis, which was produced by Braun and Clarke (2006; p. 96).

Rigor and Reflexivity

To ensure methodological rigor, we adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) [18]. Strategies to enhance trustworthiness included investigator triangulation, whereby multiple researchers participated in coding, theme generation, and data interpretation to minimize individual biases. Member checking was conducted informally, allowing participants to clarify or expand on their responses during interviews, ensuring the authenticity of the data. Reflexivity was maintained throughout the research process, with researchers critically examining their own preconceptions and potential influences on data collection and analysis. Regular discussions within the research team facilitated awareness of positionality and its impact on interpretation, thereby strengthening the credibility and dependability of the findings.

Results

Characteristics of the sample

A total of N = 8 carers (PD: n = 5 and FTD: n = 3) decided to participate in this study. **Table 1** summarizes the descriptive characteristics of the carer sample.

Insert Table 1.

Qualitative thematic analysis

Twelve themes emerged from the interview data of PD and FTD carers and are as follows: manifestations, sexual practices, impact, control, emotional formulations, beliefs in causes of hypersexuality and attributions, relationship with the partner, dealing with hypersexuality, coping with hypersexuality, self-image, stigma, and professional help-seeking (**Figure 2**).

Insert Figure 2.

Quotes under each theme are presented in **Table S1**.

Theme 1: Manifestations

This theme outlines the carer-perceived manifestations of hypersexuality in their partners, encompassing five identified subthemes.

1.1. Indicators

The carers provided accounts of how they became cognizant of the hypersexuality. These instances, termed 'indicators', fell broadly into three categories: (1) their partners told them directly about their hypersexuality, (2) they found out based on changes in their partners' sexual behaviors towards them, or (3) they discovered their partners' clandestine behaviors (Carer 1).

> *"I found a till receipt for a gay magazine… I sat on the knowledge for a couple of weeks but first of all I went straight up to WH Smith and bought a copy of the magazine thinking that either it wasn't what I thought it was… it was Gay Times… or this had been bought by mistake… I got a copy… I sat there outside and read it and realised it was highly unlikely that it had been bought by mistake…" (Carer 1)*

1.2. Desires

Increased desire following the onset of hypersexuality was evident in carers' accounts. The predominant response involved partners exhibiting heightened desire in sexual activity within and outside the relationship, as well as engaging in self-pleasure through masturbation and the use of pornographic material (Carer 7).

> *"That's the only thing he's interested in … to have sex…" (Carer 7)*

1.3. Behaviors

Furthermore, the hypersexuality apparently caused changes in pre-existing behavior or the development of new behaviors. These changes fell broadly into two categories: (1) the adoption of pornographic materials or new sexual behaviors involving others and (2) an increase in the levels or forms of sexual behaviors towards partners or the intensification of old sexual behaviors (Carer 4).

> *"Normally she likes tenderness and sweetness and this was sort of a bit more lust… go for it… behavior was extreme if you like because she's a reserved person … who has other high standards of good behavior… so this was like nature in the raw really…" (Carer 4).*

1.4. Preoccupation

One of the main manifestations of hypersexuality was preoccupation with sexual thoughts (Carer 3).

> *"her thoughts are uncontrollable and come so much of the time…" (Carer 3)*

1.5. Compulsivity

Carers perceived that their partners' preoccupation with sexual thoughts translated into compulsive behavior, another main manifestation of hypersexuality. Reported compulsive behaviors varied and encompassed frequent or intense consumption of pornographic materials, visiting prostitutes, and generally indulging in sexual behaviors throughout the day (Carer 3).

"Hypersexuality is present all throughout the day and during the night while I am asleep…" (Carer 3)

Theme 2: Sexual practices

This theme outlines the carer-perceived impacts of hypersexuality on their partners' sexual practices, encompassing four identified subthemes.

2.1. Practices with the partner

Sexual practices with the partner underwent changes in both the frequency and nature of sexual acts. Certain carers reported that their partners, upon developing hypersexuality, expressed an increased demand for sexual activity with them (Carer 7).

"And now [he was asking for sex] every morning… every evening… sometimes he's asking during the day…" (Carer 7)

Additionally, a majority of carers noted changes in the nature of their partners' sexual demands or behaviors, often describing them as being out of character with the person they were before developing hypersexuality. These changes included, for instance, more aggressive sexual tendencies, demands for role play, and a shift towards more adventurous sexual practices, such as oral or anal sex, which deviated from their previous patterns (Carer 4).

"She didn't ask for Fifty Shades of Grey no… but still … a little hint of S&M which really wasn't part of our repertoire…" (Carer 4)

Moreover, certain carers reported a decrease in sexual activity with their partner – in some cases because they started to resist their frequent or inappropriate advances. In other cases, the decline in marital sexual activity seemingly occurred as the partner sought gratification from alternative sources.

2.2. Practices with themselves

The majority of carers reported that their partners also indulged in masturbation and use of pornographic material.

2.3. Practices with others

Sexual practices with others included anonymous sexual encounters, paying for sex, and developing sexual interest in individuals other than the spouse.

2.4. Deviant sexual behavior

Lastly, desires did not appear to translate into paraphilic deviant practices as only one carer reported this (Carer 8).

"It needs to be more upfront that it's not just about a decrease in sex or an increase in sex… it could be a decrease in a normal sexual relationship and a… a subverted or a hidden cover increase in some kind of deviant sexual behavior which had been what was going on for twenty years and I didn't know about…" (Carer 8)

Themes 1 and **2** illustrate the clinical phenomenology of hypersexuality. These changes can be summarised using the categories presented in **Figure 3**.

Insert Figure 3.

Theme 3: Impact

This theme outlines the carer-perceived impacts of hypersexuality on their partners' different areas of daily living, encompassing three identified subthemes.

3.1. Marital life

Nearly all carers conveyed that hypersexuality had adverse effects on their marital lives, resulting in diminished intimacy, increased emotional distance between themselves and their partner, and a spectrum of negative emotions on their part. These included feelings of anger, betrayal, despair, disapproval, embarrassment, reduced self-confidence, sadness, and self-blame. Primarily, the impersonal or mechanical nature of their partners' increased demand for sexual activity had generated feelings of disgust or resentment on the part of their spouses. Additionally, these demands altered the nature of their sexual relationship in ways that were unwelcome to the spouses (Carer 1).

"It was dreadful… devastating … I couldn't make head and the tail of it… it just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)

Furthermore, certain responses indicated a significant transformation in the nature of the marital relationship. This shift was characterized by a growing lack of respect for the partner and, in some instances, a perceived need to exert control over them in an effort to preserve the marriage (Carer 8).

"I've lost respect for him… how can you respect someone that gets off of watching little boys being humiliated… I've said to him I won't collude or condone with anything he's done… and I won't accept those things either… and that whilst he lives in the house with me he behaves in a way I would want him to behave legally..." (Carer 8)

Many carers emphasized that their partners had become markedly less affectionate and loving towards them in general since the onset of hypersexuality (Carer 1).

"I've always thought of it very old fashioned as making love… sex for sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to

come and have sex with me was really meaning he was just using me to have sex..." (Carer 1)

3.2. Family, social life and daily activities

Half of the carers reported that hypersexuality had a detrimental impact on their family lives, noting effects on their children that ranged from fathers being absent much of the time to children experiencing trauma or stress due to their father's hypersexuality (Carer 1).

"My kids were shocked, so mentally and emotionally distanced themselves…" (Carer 1)

Moreover, hypersexuality had a negative impact on the partners' finances, particularly for those whose hypersexual behaviors involved visits to sex shops for purchases or spending time with prostitutes (Carer 1).

"I decided that if he agreed… and he did agree… that I would take his credit and debit cards off him… hide any money I'd got in the house… I left him… I think we agreed on fifteen pounds which would be enough for taxi and whatever so he couldn't do that… I hid the cheque books and hid any money I'd got in the house so he didn't have any access to cash… and that worked well for a couple of months and then he remembered that he had an account that I'd forgotten about…" (Carer 1)

3.3. Health and well-being

Half of the carers reported that their partners experienced sleep disturbances, mood deterioration, and overall poor mental health, as a result of hypersexuality (Carer 8).

"He seemed very withdrawn… he was completely locked into this mad behavior… there was no happiness… there was no joy… he never smiled… he was apathetic… he was almost irritable… he was quite angry… he doesn't get irritable… he doesn't show it… if he is and this is what frightens me about him… I feel it's like watching a pressure cooker and there's going to be a time when it pops…" (Carer 8)

Concerning the impact of hypersexuality on their partners' self-confidence, the findings were not clear-cut, with some participants noting a positive and some a negative impact, while others were unsure whether their partner's self-confidence had been affected at all (Carer 4).

"Probably more confident… I mean she was writing at the time… that's her identity… she's a writer…" (Carer 4)

Regarding the impact of hypersexuality on their partners' quality of life, the findings were similarly mixed. Four carers mentioned a negative impact, with one providing an explanation. This carer specified that her husband felt he now had a wife who did not love him as much as before, leading to a general sense of deflation.

Theme 4: Control

This theme outlines the carers' perceptions regarding how much control they believed their partners had over their hypersexuality. We identified three subthemes:

4.1. Loss of control

All carers believed their partners lacked control over their sexual behavior, but the extent of this loss varied across individuals (Carer 1).

> *"He couldn't resist it… it was hopeless… he couldn't stop it…" (Carer 1)*

Carers of patients with dementia characterized them as "*disinhibited*" (Carer 8).

> *"There is a difference… the impulse to do something and the ability to know right from wrong… he knows what's right and what's wrong but he chose to take a risk and his risk-taking has increased… he is the one with his hand on his penis…" (Carer 8)*

4.2. Attempt to reduce/stop

Half of the carers reported that their partners attempted to reduce or stop their hypersexuality, with varying degrees of success reported among them (Carer 2).

> *"I think he's doing a good job in trying to keep a lid on it… it's still there but more controlled…" (Carer 2)*

4.3. Desire to overcome

More than half of the carers noted that their partners expressed a desire to overcome their hypersexuality. This was either conveyed through direct verbalization to the carers or others, or inferred from observable efforts to control their behaviors, such as reduced requests for sex (Carer 1).

> *"[He] desperately wanted to stop it… he just couldn't work out what had hit him…" (Carer 1)*

Theme 5: Emotional formulations

This theme outlines the emotional formulations that the carers had around their partners and/or around the hypersexuality itself.

5.1. Around hypersexuality

At least half of the carers found hypersexuality to be a perplexing phenomenon, leading to a negative emotional formulation marked by shock, confusion, and horror, as they grappled with the profound changes in their long-term partners' feelings and behaviors (Carer 8).

> *"I just didn't know what had happened ... it's like waking up on the other side of the mirror like Alice in... Through the Looking Glass... it was just so abnormal... he was cold towards me…" (Carer 8)*

Other carers expressed more positive emotional formulations around the hypersexuality. For instance, one carer conveyed emotions like amusement and interest in response to his wife's newly developed lustful approach (Carer 4).

> *"Normally she likes tenderness and sweetness and this was sort of a bit more lust... go for it... [laughing]... and in a way that was fresh and amusing... again one took that as a positive thing... for a while anyway…" (Carer 4)*

5.2. Around partner

With the exception of one carer, all carers developed negative emotional formulations around their partners due to hypersexuality. These negative emotions encompassed annoyance, betrayal, despair, embarrassment, hurt, irritation, pity, and repulsion. These emotions often evolved and changed over time in tandem with the partner's shifting behaviors (Carer 8).

> *"I was so angry… it wasn't just emotion… there was anger… I felt very angry about what he'd done … I wouldn't want him to touch me because I don't know who he is… he was doing things that are completely unacceptable… sad… I was very sad… I felt rejected… I felt confused… I feel such a fool… let down…" (Carer 8)*

It is noteworthy that carers found it challenging to separate their emotional formulations around their partners from those around the hypersexuality in itself. This may be indicative that the effects of the hypersexuality are overwhelming enough to cause the carers to regard them as being one and the same.

Theme 6: Beliefs in the causes of hypersexuality and attributions

This theme outlines the carers' opinions about the perceived reasons for the onset and progression of the hypersexuality. We identified three subthemes:

6.1. Self-blame

Certain carers attributed the onset of the hypersexuality to themselves (Carer 5).

> *"The longer he's not having sex the worse it's making him… so basically that might be my fault…" (Carer 5)*

6.2. Blame on neurological disease and/or its management

Attribution of the hypersexuality to the neurological disease and/or its management was the main reason given by carers for the development of their partner's hypersexuality. All five carers of the PD patients attributed the hypersexuality to the PD and its management (pharmacological and surgical) (Carer 5).

"I suppose now I can point to Ropinirole and say it's Ropinirole's fault…" (Carer 5)

The three carers of the FTD patients, on the other hand, attributed the hypersexuality to the FTD as there had been no sign of it before its onset (Carer 6).

"I think it just came with the disease… right before he passed I said to him 'You couldn't help it… it wasn't you… it wasn't what you were like… it was a disease and you've got two of them and they're both serious'…" (Carer 6)

6.3 Blame on partners and their past experiences

Half of the carers attributed at least some aspects of the hypersexuality to their partner' past experiences (Carer 1).

"[Husband's] parents were away… he was allowed… for a night… and he was allowed to ask his friend from his school to stay overnight which he did… and then some sort of homosexual activity occurred… I mean the implication has always been that he was a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him... allowing him... whatever... stimulating him to pursue the homosexuality as he never had done as far as I know..." (Carer 1)

Carer 6 suggested that her husband's hypersexuality might stem from two previous experiences. First, he had been sexually abused as a seven-year-old child by the headmaster of his school. Second, he had an ex-girlfriend of Indian descent during his twenties who died in a car accident. She indicated that both prostitutes her husband had been involved with were dark-skinned and considered that there might be a link between this and the evolution of his hypersexuality (Carer 6).

Theme 7: Relationship with the partner

This theme outlines the carer-perceived impacts of hypersexuality on the carers' relationships with their partners, encompassing three identified subthemes.

7.1. Impact on marriage

Certain carers highlighted changes in the nature of marital sexual activity, a decrease in affection between partners, and a shift in the overall balance of the relationship (Carer 7).

"It's not like an intimate loving relationship… it's more mechanical and ritual-like…" (Carer 7)

7.2. Image of partner

Some carers stressed that their image of their partners had changed due to their hypersexual behaviors. It seemed that these carers no longer regarded their partners as the same

individuals they were before developing hypersexuality, indicating a difficulty in distinguishing between their partners as individuals and the hypersexuality itself (Carer 1).

> *"It just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)*

7.3. Aggression

Evidently, certain carers, experiencing stress and frustration from dealing with their partners and their hypersexuality, expressed either a desire or an actual instance of having an aggressive response to their partners' hypersexuality (Carer 2).

> *"I think the worst thing was that on one occasion I actually momentarily considered violence towards him… he'd had one of his trips to the sex shop… he got stuff… I'd been out in the garden… and I'd seen him through the window of his office… obviously he was busy looking at some stuff… and it was lunch time and I came in to give him his lunch… and I stood behind him and I really can't believe it now but I've got to tell you… it's the truth… I stood behind him with this big hammer in my hand… and I thought quite clearly 'A couple of blows to your skull with this and this would all be over'… and then I put the hammer away and served his lunch…" (Carer 2)*

Theme 8: Dealing with hypersexuality

This theme outlines the various ways in which the carers dealt with their partners' hypersexuality, encompassing three identified subthemes.

8.1. Attempt to limit hypersexuality

Carers attempted to limit hypersexuality by placing blocks on the computer, for instance, so that their partner could no longer access any pornography (Carer 8).

> *"If he did continue to do something and the police came… I would step aside… I would explain that he had a degenerative brain disease but I'm not going to protect him if he's doing something illegal which he was… I think there's a limit to how much protection I can afford someone who has done nothing to deserve protection…" (Carer 8)*

8.2. Attempt to uncover facts about hypersexuality

Half of the carers reported actively attempting to investigate their partner's hypersexual behaviors. This included actions such as searching for hidden pornographic materials, checking computers or phones for evidence of visits to sex sites, and examining phones for messages from other individuals that they might be involved with sexually (Carer 1).

> *"I certainly looked for materials he'd obtained and was using… when I realised that he had bought a gay magazine… because I found the receipt by chance… after it when I thought about it he just said he was just curious… when he was out I went and unlocked the case and found more magazines… so yes I did go looking for them… yes I did go and look in his case and see what he'd got…" (Carer 1)*

8.3. Giving in to hypersexuality

Approximately half of the carers acknowledged their partner's hypersexual behaviors, albeit with dissatisfaction. For a small number, this acceptance extended to a greater degree of understanding and even support in helping their partner to indulge their hypersexual desires outside of the marital relationship (Carer 1).

> *"I thought 'God this poor man has been a repressed gay all his life… he's never indulged in it… I know he's ill… he hasn't got that many more years to live… if he wants to indulge in this why shouldn't he?' and so I said to him 'Look you can't drive now… if you want to go to gay bars and clubs I will take you there'… after you'd phoned me and said that there is some evidence that it does alter sexual orientation… I just sat and cried… I thought 'Poor man'… he must've been so confused with what's happening to him… utterly… and he couldn't resist it…" (Carer 1)*

Theme 9: Coping with hypersexuality

This theme outlines the various ways in which the carers coped with their partners' hypersexuality, encompassing three identified subthemes.

9.1. Responsibility/guilt

Except for one carer, all indicated no responsibility for their partners' hypersexuality. This lack of perceived responsibility may aid in maintaining necessary psychological and emotional distance to cope with the situation's stress and pressure (Carer 8).

> *"I thought I had done something and I tried for twenty years to find out what it was and when I found out it had all been him I didn't feel responsible…" (Carer 8)*

9.2. Understanding the hypersexuality

All carers recognized the neurological origin of hypersexuality, yet this understanding did not uniformly translate into effective coping. Certain carers exhibited a more nuanced comprehension of the condition and its manifestations (Carer 7).

> *"Kind of owning the fact that… that sex is not just with the other… it's your relationship with yourself as well as the other person so I'm able to separate how to be who I am and who he is so I don't actually feel exploited… like I'm able just to see that he has a greater need for sex than me and for our relationship to work I help him to meet that need and I'm having lots of other needs met in our relationship… it balances quite nicely…" (Carer 7)*

9.3. Forgiveness

Certain carers could forgive their partners for their hypersexuality, while others saw no need for forgiveness. Those considering forgiveness found it challenging and could only be achieved

sometime in the future. Carer 1, for example, reported that she was "*on the road to forgiveness*".

9.4. Difficulties with coping

Coping with hypersexuality is challenging, with around half of carers facing difficulties, and for a few, leading to a desire to no longer exist (Carer 8).

> *"[I] didn't want to commit suicide but I would like not to exist and there's a difference between not wanting to exist and wanting to be dead…" (Carer 8)*

Theme 10: Self-image

This theme outlines the carer-perceived effects of hypersexuality on the carers' self-image, encompassing three identified subthemes.

10.1. Feeling unloved

Half of the carers felt unloved by their husbands, especially when the sexual relationship became mechanical and non-affectionate due to hypersexuality. This evoked sadness and nostalgia for the previous loving relationships, highlighting shifts in relationship roles (Carer 5).

> *"All the time it will end up in 'You don't know how much I love you and I wouldn't do anything to hurt you'… he used to always be telling me that he loved me and… I think that's what I miss a bit really… he isn't quite so affectionate… he used to say it on a daily basis how much he loved me and things and that was quite nice..." (Carer 5)*

10.2. Feeling used

The same four carers felt not only unloved but also "*used*" by their husbands for sexual gratification. This signaled to them a shift from a normal loving sexual relationship to one primarily focused on satisfying their husbands' hypersexual needs (Carer 1).

> *"I've always thought of it very old fashioned as making love… sex of sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex… he was using me… like an animal really…" (Carer 1)*

10.3. Self-confidence

Three of the carers who expressed feeling unloved and used by their partners also asserted that hypersexuality and their husbands' consequent demeanor had adversely affected their self-confidence (Carer 8).

> *"At the time I felt completely worthless… completely and utterly worthless… I just felt so ugly and old…" (Carer 8)*

Theme 11: Stigma

This theme outlines the two carer-perceived forms of stigma associated with hypersexuality: personal stigma and social stigma.

One carer's reference to the older age group implies a stereotype that older people are less sexual, which may be used to reinforce the belief that hypersexuality is unnatural (Carer 5).

> *"We're in our sixties so it's quite obvious that we're not going to feel how we did when we first met in our thirties… but he seems to be still back in that era and wants it in the same way…" (Carer 5)*

Three carers expressed concerns about the social stigma associated with hypersexuality, fearing that others discovering their partner's condition would reflect negatively on themselves and their families (Carer 1).

> *"I suppose the thing that bothered me most was the thought that other people would find out and laugh at me because I'd always... pride always comes before a fall... I'd always been proud of my happy marriage... we'd worked at it and the thought that my husband was gay and might be discovered to be gay are... yeah... that did worry me..." (Carer 1)*

During interviews, carers often hesitated, laughed nervously, and apologized when asked sexually-specific questions or prompted to discuss their partners' sexual experiences. This may be attributed to the embarrassment of discussing sex, concerns about crossing social boundaries, and fear of being perceived as inappropriate (Carer 3).

> *"[laughing] she'd go straight to the… not too much foreplay… not too much… normally she likes tenderness and sweetness and this was sort of a bit more lust… go for it [laughing]…" (Carer 3)*

Theme 12: Professional help-seeking

This theme outlines the professional help-seeking barriers regarding hypersexuality, as well as certain aspirations with regards to professional help.

12.1. Barriers

Issues with seeking professional help encompassed communication barriers, lack of understanding, insufficient education, neglect by health professionals, stigma related to hypersexuality, and challenges in discussing sex. All eight carers experienced difficulty obtaining adequate information and assistance for their partners' newly developed hypersexuality, expressing frustration, sadness, and anger over the unavailability of help. A key concern raised is that patients are not adequately informed about the likelihood and implications of hypersexuality when taking drugs for PD (Carer 1).

"If somebody had said… well warning you that this might happen when he went on these drugs… I mean it says in the leaflets… it talks about hypersexuality… I looked at it and read the sheets through and I said 'Oh hypersexual… he'll be a bit frisky and that'll be alright'… you know… the horrors of what were to come never occurred to me… if nobody speaks out then this will go on and other marriages will be ruined like mine was ruined… at least had we've been told it wouldn't have been such a terrible shock…" (Carer 1)

Certain carers noted a key issue: medical professionals lack knowledge about hypersexuality and show an apparent reluctance to investigate further or take patients' and carers' concerns seriously (Carer 5).

"I have tried to broach this a few times with my husband's neurologist… I do a bit more than hint at the problems now and again but he never sort of takes it and runs with it… we've been seeing him for ten years and not once has he asked about hypersexuality… or hinted… that it could be a problem… he would spend more time talking about gambling…" (Carer 5)

12.2. Aspirations

Due to these barriers, certain carers expressed specific aspirations for professional help for individuals with hypersexuality and their carers. Over half of the carers expressed a desire for health professionals to be educated about hypersexuality and its consequences. This education is seen as a means to enable professionals to educate patients and carers about the condition, with the ultimate goals of alleviating the patient and carer burden of living with hypersexuality and facilitating more effective help-seeking behavior (Carer 8).

"[I need help] with managing the anger that I feel in a way that is useful… not in a way where somebody just sits there and tell me that my mantra should be that my husband can't help it… I want somebody who can help me understand why I'm angry and who can help me resolve these angry feelings before my husband dies" (Carer 8)

Discussion

Using a qualitative approach, the current study aimed to explore the impact of hypersexuality on spousal carers of patients with PD and dementia. This study captured twelve themes illustrated in **Figure 2**.

In terms of clinical phenomenology, hypersexuality manifested through changes in patients' sexual cognitions and behaviors. These changes can be summarised using the categories presented in **Figure 3**.

These findings resonate with existing literature on hypersexuality in neurological disorders, particularly PD and dementia. Similar sexual changes have been documented in systematic reviews, aligning with our observations [19]. Notably, patients with PD and hypersexuality often exhibit sexual compulsivity and impulsivity [19-22], while those with dementia may show sexual disinhibition and inappropriateness [23]. Our study partially supports this distinction, with carers of patients with FTD describing behaviors as "*disinhibited*,"

although overlap with sexual preoccupation and compulsivity was evident. A larger sample size might clarify these distinctions further.

Contrary to expectations, despite increased sexual urges, patients often engaged less frequently in sexual activities with partners post-onset of hypersexuality, often due to partner discontent. Patients sought gratification through masturbation, pornography, prostitution, promiscuity, or affairs, influenced by partner satisfaction or absence. This association between heightened desires and actual sexual practices underscores the role of external factors, echoing literature on marital dynamics where dissatisfaction can lead to extramarital pursuits [24].

Psychologically, carers reported disturbed moods and diminished mental health in patients, consistent with anxiety often coexisting with PD [25]. The emotional toll on carers was profound, reflecting themes of burden and distress documented in carer literature [26-28].

While all carers attributed their partners' hypersexuality to their neurological diseases, some believed its development is linked to the patients' past experiences. For example, Carer 1 indicated that her husband had a homosexual experience at the age of fifteen with a school friend. She claimed that her husband "*might have been a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him… allowing him… stimulating him to pursue the homosexuality as he had never done*" before. Carer 6 indicated that her husband had an ex-girlfriend of Indian descent during his twenties who died in a car accident. She indicated that both prostitutes her husband had been involved with, and one of whom he fell in love with, were dark-skinned and considered that there might be a link between this and the evolution of his hypersexuality. Two potential reasons for this link can be considered. First, it is possible that past behaviors had never disappeared but rather their partners had been successful in suppressing them. These behaviors resurfaced due to neurological disorders affecting inhibitions. Second, the biological and molecular effects of medications used to manage neurological disorders, like PD, may trigger latent tendencies, although this area remains unexplored within the scope of this research.

The study revealed that hypersexuality profoundly affected carers and strained their relationships with their partners. Some carers, overwhelmed by frustration and despair in dealing with their partners' hypersexuality, reported experiencing desires or actual instances of aggressive reactions towards their partners.

Despite efforts to cope, carers struggled with responsibility, guilt, and at times, aggressive feelings toward their partners, mirroring the challenges seen in sex addiction research [29-32] [31, 32]. Extended discussions during assessments, with one lasting over 3.5 hours instead of the anticipated two hours, indicate significant distress among carers. This underscores the urgent need for support and avenues for emotional expression and sharing experiences.

The stigma surrounding hypersexuality emerged as a significant concern for carers, influencing disclosure and help-seeking behaviors. Fear of stigma led some carers to conceal hypersexuality, decline study participation, or avoid healthcare appointments, reflecting broader societal discomfort with sexual topics [33, 34]. The barriers to seeking professional help include inadequate communication and education among healthcare providers, exacerbating carer distress and prolonging their silence on the issue.

Implications

This study highlights the critical need for healthcare professionals to educate patients and carers about ICDs associated with PD and dementia, including hypersexuality, and to provide ongoing support and monitoring [23, 35]. Targeted psychological and behavioral strategies could help carers manage distress and improve coping mechanisms. Acceptance and commitment therapy (ACT) [36] may be particularly beneficial, as it encourages carers to accept the challenges of their partners' hypersexual behaviors while fostering psychological flexibility and values-based action. Group-based interventions, such as structured peer-support programs modeled after Al-Anon [37], could provide a shared space for carers to exchange experiences, reduce isolation, and develop practical coping strategies. Additionally, cognitive-behavioral therapy (CBT) tailored for carers could address maladaptive thought patterns and emotional distress related to managing hypersexual behaviors. Psychosocial interventions, including couple-based therapy and family counseling, may also facilitate communication and adaptive strategies.

Limitations

This study encountered several limitations. Firstly, while the sample included carers of patients with PD and FTD, the intended inclusion of carers of patients with AD was not realized. This restricted our ability to compare the impact of hypersexuality across dementia subtypes, specifically AD. Future research should prioritize recruiting a diverse sample, including carers of patients with AD, to achieve a more comprehensive understanding. Secondly, the study's focus on spousal carers limited the scope of investigation. The impact of hypersexuality extends to other family members and professional carers, warranting broader investigation. Thirdly, inherent to qualitative research, response biases, such as social desirability, may have influenced participant disclosures, particularly given the sensitive nature of hypersexuality. Although a confidential and nonjudgmental interview environment was established, future studies could consider incorporating anonymous surveys or mixed-methods designs to mitigate this potential bias. Finally, while this qualitative approach yielded rich, in-depth insights, a mixed-methods design, integrating quantitative analyses, would provide greater triangulation of findings and enhance the robustness of conclusions, offering a more complete understanding of the phenomenon.

Future directions

Future research should employ mixed methods to mitigate underreporting and explore comprehensive management strategies for hypersexuality in PD and dementia. Addressing stigma through public education and improving healthcare providers' readiness to discuss sexual health are crucial steps in supporting carers and patients alike.

Conclusion

In conclusion, hypersexuality in neurological disorders profoundly affects patients and carers, demanding tailored interventions and support mechanisms to alleviate its emotional and psychological toll.

Author Roles

1. Research project: A. Conception, B. Organization, C. Execution;

2. Qualitative Analysis: A. Design, B. Execution, C. Review and Critique;
3. Manuscript Preparation: A. Writing of the first draft, B. Review and Critique;

NT: 1A, 1B, 1C, 2A, 2B, 3A
JNP: 1A, 1B, 1C, 3B
JF: 2A, 2B, 2C, 3B
CS: 2A, 2B, 2C, 3B
WGES: 3A, 3B

Guarantor is Natalie Tayim / NT.

Disclosures

- **Funding Sources and Conflict of Interest**

This study received no specific grants from funding agencies in the public, commercial, or not-for-profit sectors. JNP is supported in part by funding from the United Kingdom's Department of Health NIHR University College London Hospitals Biomedical Research Centres funding scheme.

The authors declare that there are no conflicts of interest relevant to this work.

- **Financial Disclosures for the previous 12 months**

The authors declare that there are no additional disclosures to report.

Ethical Compliance Statement

This study (ethics application ID: 15/LO/0557) was approved by the London-Hampstead National Research Ethics Committee (NREC).

Declaration of patient consent – Interested carers were asked to come into the Department of Uroneurology at the NHNN where any of the available rooms on the scheduled dates was used to provide the participants with written information about the study, obtain written consent, and consequently complete assessment.

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Figure Legends

Figure 1. Flowchart summarizing the recruitment results for Parkinson's disease and dementia carers.
AD: Alzheimer's disease; FTD: Frontotemporal dementia; HS: hypersexuality; PD: Parkinson's disease

Figure 2. Themes and subthemes identified in the interviews.

Figure 3. Summary of categories for clinical phenomenology of hypersexuality in Parkinson's disease and dementia.

Table 1. Carer sample descriptives.

Variable	Carer 1	Carer 2	Carer 3	Carer 4	Carer 5	Carer 6	Carer 7	Carer 8
Neurological disorder	PD	PD	PD	PD	PD	FTD	FTD	FTD
Medications at the time of hypersexuality*+	Stalevo Rasagiline Clonazepam Fludrocortisone Movicol Atropine	Ropinirole Amantadine Selegiline Madopar Stalevo	Ropinirole Madopar Citalopram	Ropinirole Rasagiline Entacapone Amantadine	Ropinirole Madopar Stalevo	-	-	-
Implicating medications*+	Stalevo	Ropinirole	Unsure (Ropinirole)	Rasagiline	Ropinirole	-	-	-
Implicating medication reduced or discontinued*+	Yes discontinued	Yes discontinued	Yes discontinued	Yes discontinued	No	-	-	-
Still hypersexual+	Deceased	Yes	Yes	No	Yes	Deceased	Yes	Yes
DBS*	No	Yes	No	No	No	-	-	-
Type	-	Bilateral STN	-	-	-	-	-	-
Associated symptoms								
Sexual behavior	Preoccupation with sex Increased desire for sex generally Change in sexual orientation Uncontrollable masturbation Pornography Sex phone lines Sex channels	Preoccupation with sex Increased desire for sex with wife and generally Having sex more frequently Increased masturbation Pornography Fetishism	Preoccupation with sex Increased desire for sex with husband and generally Having sex more frequently Insatiable desire for masturbation	Increased desire for sex with husband Having sex more frequently Sexual attraction for therapist Having sex on stairs Hint of S&M Pornography	Preoccupation with sex Increased desire for sex with wife and generally Increased masturbation Pornography Sex phone line Dating sites	Preoccupation with sex Increased desire for sex generally Pornography Sex phone lines Dating sites Massage parlors Prostitutes	Preoccupation with sex Increased desire for sex with wife and generally Having sex more frequently Increased masturbation	Preoccupation with sex Increased desire for sex generally Increased masturbation Pornography Deviant interests Fantasies of dressing in women's underwear

	Visiting sex shops							
Other impulse control disorders	None	Compulsive eating Compulsive buying	None	Compulsive eating	None	Compulsive buying	Compulsive eating	Compulsive eating Compulsive buying
Other compulsive behaviors	None	None	None	Desire to move	None	None	None	Clock-watching Writing down electricity and water readings

DBS: deep brain stimulation; FTD: frontotemporal dementia; PD: Parkinson's disease; STN: subthalamic nucleus
*. There is no data available for the respective variables for Carers 5, 6, and 7 criteria only applicable to PD patients.
+. Information obtained from patient's clinical notes.

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Figure Legends

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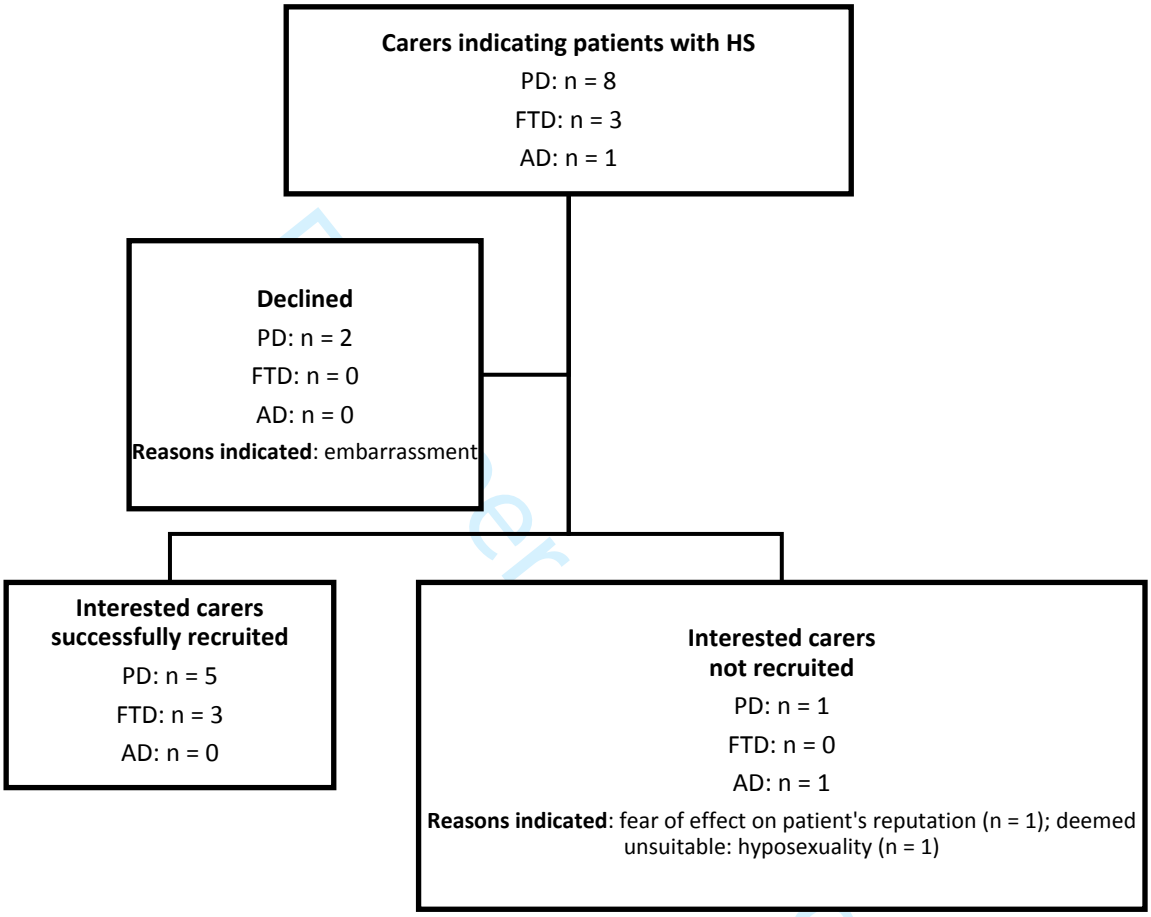
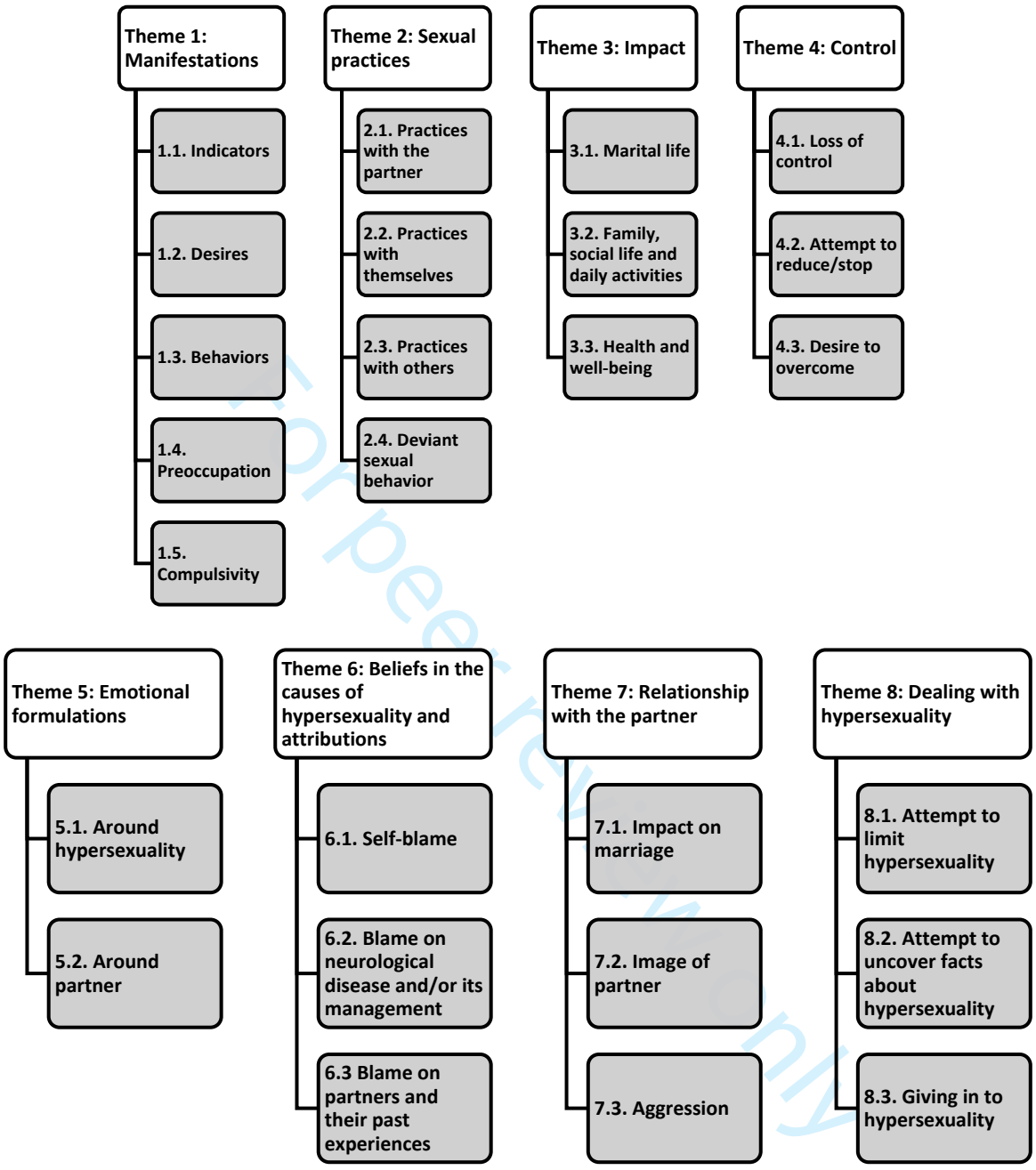
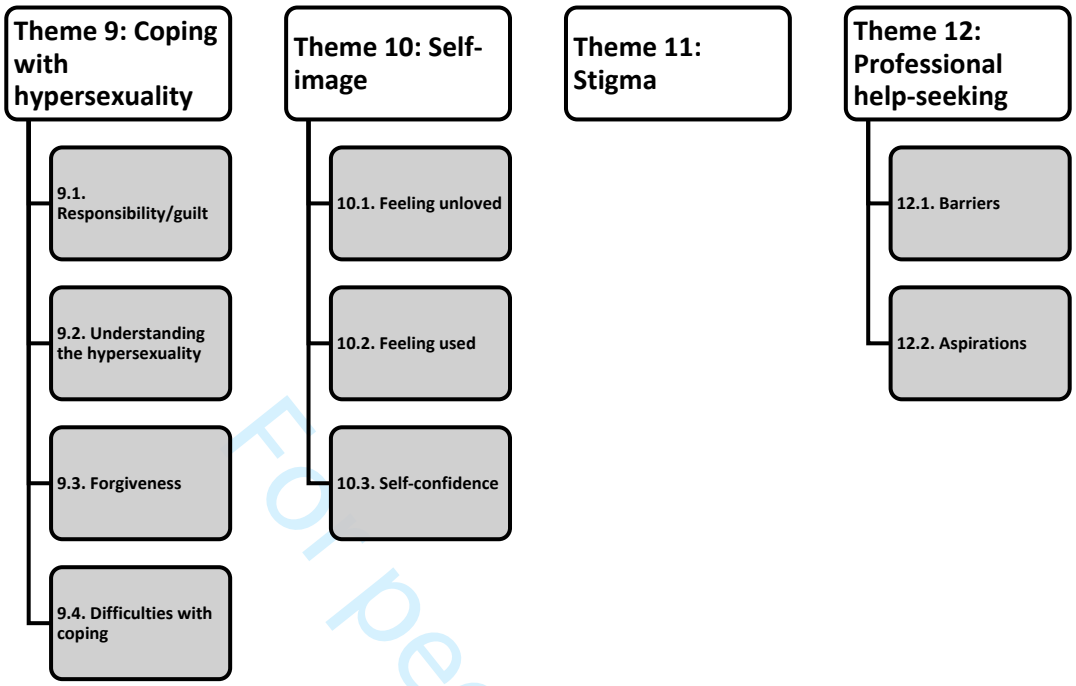


Figure 2. Themes and subthemes identified in the interviews.





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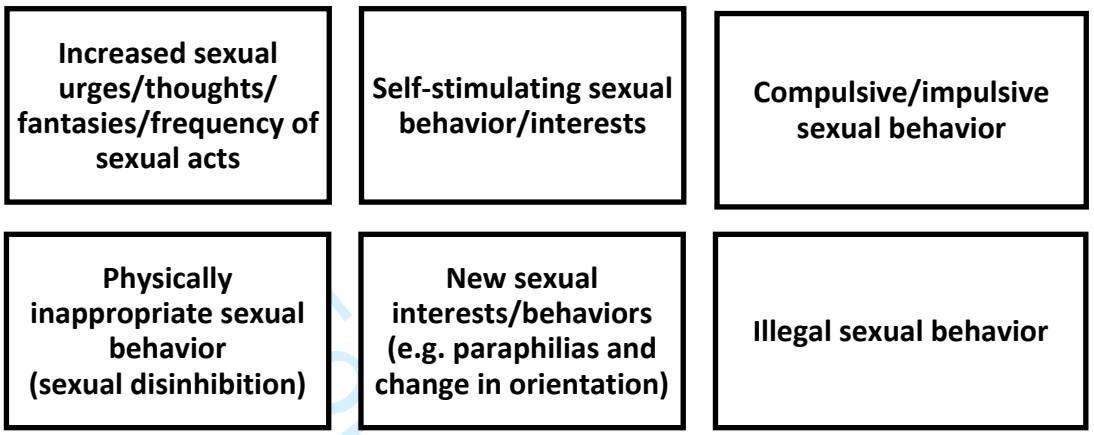

Table S1. Emergent themes, subthemes, and quotes analyzed for Parkinson's disease/frontotemporal dementia carers.

Themes	Subthemes	Quotes
Theme 1: Manifestations	**1.1. Indicators**	"I found a till receipt for a gay magazine… I sat on the knowledge for a couple of weeks but first of all I went straight up to WH Smith and bought a copy of the magazine thinking that either it wasn't what I thought it was… it was Gay Times… or this had been bought by mistake… I got a copy… I sat there outside and read it and realised it was highly unlikely that it had been bought by mistake…" (Carer 1)
	1.2. Desires	"That's the only thing he's interested in … to have sex." (Carer 7)
		"I don't know where desire's gone because it is practically... it is non-existent… they happened about the same time I think... I think it must be... it must be a good five or six years as far as he's concerned... and I honestly think that things changed for me around sixty..." (Carer 5)
	1.3. Behaviors	"Normally she likes tenderness and sweetness and it was sort of a bit more lust… go for it… behavior was extreme if you like because she's a reserved person … who has other high standards of good behavior… so this was her nature in the raw really…" (Carer 4).
	1.4. Preoccupation	"her thoughts are uncontrollable and come so much of the time…" (Carer 3)
	1.5. Compulsivity	"Hypersexuality is present all throughout the day and during the night while I am asleep…" (Carer 3)
Theme 2: Sexual practices	**2.1. Practices with the partner**	"And now [he was asking for sex] every morning… every evening… sometimes he's asking during the day…" (Carer 7)
		"She didn't ask for Fifty Shades of Grey no… but still … a little hint of S&M which really wasn't part of our repertoire…" (Carer 4)
		"Things like going outside the door and knocking on the door and coming in or something… you know… I'm somebody he's picked up outside or something and who knocks on his door and slips in with exotic underwear on or something… never had all this before… it's just weird… like he was sort of switched off… he's actually thinking he's with a prostitute or something I don't know…" (Carer 5)
	2.2. Practices with themselves	
	2.3. Practices with others	
	2.4. Deviant sexual behavior	"It needs to be more upfront that it's not just about a decrease in sex or an increase in sex… it could be a decrease in a normal sexual relationship and a… a subverted or a hidden cover increase in some kind of deviant sexual behavior which had been what was going on for twenty years and I didn't know about…" (Carer 8)

Theme 3: Impact	**3.1. Marital life**	"It was dreadful… devastating … I couldn't make head and the tail of it… it just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)
		"It's awful really because he's not the same person… apart from everything else that's going on… I feel like I'm sort of living a double life and sort of have to live his life as well and double check everything … life's so difficult so it's not surprising that I'm tired…" (Carer 5)
		"I've always thought of it very old fashioned as making love… sex for sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex..." (Carer 1)
		"It's kind of became more of ritual… more of a… I mean he would say things like 'I need a fuck'… like every morning and every evening, I have felt really pursued… that's the only thing he's interested in… is to have sex" (Carer 7)
		"It's difficult to separate if it's the dementia or more the sexual aspect of it… it's kind of loss of companionship in all areas so it has affected the relationship…" (Carer 7)
		"I'm competing with the women on television… sometimes I'm thinking… does he think that he's making love to me or does he think he's making love to somebody off the television…" (Carer 5)
		"I've lost respect for him… how can you respect someone that gets off of watching little boys being humiliated… I've said to him I won't collude or condone with anything he's done… and I won't accept those things either… and that whilst he lives in the house with me he behaves in a way I would want him to behave legally..." (Carer 8)
	3.2. Family, social life and daily activities	"My kids were shocked, so mentally and emotionally distanced themselves…" (Carer 1)
		"The children just could not understand it… he never denied it… both the children were irritable… they couldn't understand it you know because [of] the way he'd been brought up and how he'd brought them up…" (Carer 6)
		"I decided that if he agreed… and he did agree… that I would take his credit and debit cards off him… hide any money I'd got in the house… I left him… I think we agreed on fifteen pounds which would be enough for taxi and whatever so he couldn't do that… I hid the cheque books and hid any money I'd got in the house so he didn't have any access to cash… and that worked well for a couple of months and then he remembered that he had an account that I'd forgotten about…" (Carer 1)
	3.3. Health and well-being	"He couldn't sleep because I was working so hard and he was messing around… he said he cried most nights…" (Carer 6)

		"He was anxious and depressed… worried about everything…" (Carer 1)
		"He was more stressed because he just couldn't understand what he was doing…" (Carer 6)
		"He seemed very withdrawn… he was completely locked into this mad behavior… there was no happiness… there was no joy… he never smiled… he was apathetic… he was almost irritable… he was quite angry… he doesn't get irritable… he doesn't show it… if he is and this is what frightens me about him. I feel it's like watching a pressure cooker and there's going to be a time when it pops." (Carer 8)
		"Probably more confident… I mean she was writing all the time… that's her identity… she's a writer…" (Carer 4)
		"When I asked him when he stopped loving me … he said he didn't know and he eventually said 'I think I'm narcissistic and I'm in love with myself…" (Carer 8)
		"I think that as with the madness of love or something… it raises you up but it also is a madness so it is a sickness… it is a sickness we all enjoy." (Carer 4)
		"I knew he was dating again… he'd go out looking quite handsome in something that I'd suggested to upgrade his wardrobe… go out looking attractive…" (Carer 6)
Theme 4: Control	**4.1. Loss of control**	"He couldn't resist it… it was hopeless… he couldn't stop it…" (Carer 1)
		"It's become like a bit of a habit… like something he asks for… it's a bit like asking for a bit more wine…" (Carer 7)
		"There is a difference… the impulse to do something and the ability to know right from wrong… he knows what's right and what's wrong but he chose to take a risk and his risk-taking has increased… he is the one with his hand on his penis…" (Carer 8)
		"I think she probably hadn't got [control]… I think she probably felt a bit out of control… but she didn't seem distressed…" (Carer 4)
	4.2. Attempt to reduce/stop	"I think he's doing a good job in trying to keep a lid on it… it's still there but more controlled…" (Carer 2)
	4.3. Desire to overcome	"[He] desperately wanted to stop it… he just couldn't work out what had hit him…" (Carer 1)
		"[It] absolutely drives her mad and does not make her happy… if clitoris removal existed she would have gone for it…" (Carer 3)
		"I don't think that he admits that he's hypersexual… because whenever it's come up like now or even when the neuropsychologist was there… it's not something that he'd actually readily say 'Yes I have got a problem'… I don't think he thinks he's got a problem…" (Carer 5)
		"I don't think he understands actually…" (Carer 7)

Theme 5: Emotional formulations	**5.1. Around hypersexuality**	"I just didn't know what had happened ... it's like waking up on the other side of the mirror like Alice in... Through the Looking Glass... it was just so abnormal... he was cold towards me..." (Carer 8)
		"I was shocked... I couldn't make head and the tail of it... it just didn't add up to the man I'd been living with for nearly fifty years..." (Carer 1)
		"Normally she likes tenderness and sweetness and this was sort of a bit more lust... go for it... [laughing]... and in a way that was fresh and amusing... again one took that as a positive thing... for a while anyway..." (Carer 4)
	5.2. Around partner	"I just felt really sorry for him... the only pleasure he has in life is to have sex so I didn't find it difficult for me to... you know... have sex with him... because I felt sorry for him... it was fine for me as well..." (Carer 7)
		"I was so angry... it wasn't just emotion... there was anger... I felt very angry about what he'd done ... I wouldn't want him to touch me because I don't know who he is... he was doing things that are completely unacceptable... sad... I was very sad... I felt rejected... I felt confused... I feel such a fool... let down..." (Carer 8)
		"I was a bit unquestioned maybe looking back... it wasn't that extreme you know... it was extreme if you like because she's a reserved person who you know... who has other high standards of good behavior you know... so this was like nature in the raw really... which didn't in the least turn me off..." (Carer 4)
Theme 6: Beliefs in the causes of hypersexuality and attributions	**6.1. Self-blame**	"The longer he's not having sex the worse it's making him... so basically that might be my fault..." (Carer 5)
	6.2. Blame on neurological disease and/or its management	"I suppose now I can point to Ropinirole and say it's Ropinirole's fault..." (Carer 5)
		"He was already on this medication then so you know... and we tried to work out which it was... I thought it was when the entacapone had been added..." (Carer 4)
		"Part of the pain in the neck of the disease... awfulness of package that's changed our lives..." (Carer 3)
		"I think it just came with the disease... right before he passed I said to him 'You couldn't help it... it wasn't you... it wasn't what you were like... it was a disease and you've got two of them and they're both serious'..." (Carer 6)
		"I recognised that it isn't his fault... it doesn't make it any easier to bare..." (Carer 8)
	6.3 Blame on partners and their past experiences	"[Husband's] parents were away... he was allowed... for a night... and he was allowed to ask his friend from his school to stay overnight which he did... and then some sort of homosexual activity occurred... I mean the implication has always been that he was a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him... allowing him... whatever... stimulating him to pursue the homosexuality as he never had done as far as I know..." (Carer 1)

Theme 7: Relationship with the partner	**7.1. Impact on marriage**	"It's not like an intimate loving relationship… it's more mechanical and ritual-like…" (Carer 7)
		"Hypersexuality is his way of being masculine… not for sexual gratification but rather for me to enjoy it as well… but he doesn't understand that I don't…" (Carer 2)
		"It's not making love to me or me making love to him in the way that I used to know… it's not that anymore…" (Carer 5)
		"I stopped being a wife and became a housekeeper and a carer…" (Carer 1)
		"I'm just there to put food on the table… to clean the house… and he's polite to me because that's how he's been brought up… to be polite… but it's not a marriage…" (Carer 8)
		"I actually feel now that I'm… it's a role reversal… I don't think he's looking after me… I think I'm looking after him…" (Carer 5)
		"I half felt amused in a way because I don't really feel insecure … you know… it's a good relationship…" (Carer 4)
	7.2. Image of partner	"It just didn't add up to the man I'd been living with for nearly fifty years…" (Carer 1)
		"I'm losing the husband that I had… he's just not the same anymore…" (Carer 5)
		"The man I married was intelligent… vibrant… really, really fun to be with… very very loving… I'm now living with not just the fact that I lost my husband but that my husband was never who I thought he was… I don't know who this person is and in fact I got him to move out of our bedroom the night I found out about the pornography… and I lay in bed that night on my own… he was in the other room… and I had the duvet and my arms underneath and I thought 'Put your arms on top' and then I thought 'Why did I think that?' and I thought 'Because he might come in… I'm frightened' then I got up and I locked my bedroom door… because I was so frightened of who this person was because he was not the man I married and I now had proof he was not the man I married… this is a man who was having to imagine he was wearing women's clothes before he could get an erection with me… who is this man and did I ever know? It made me question everything…" (Carer 5)
	7.3. Aggression	"I think the worst thing was that on one occasion I actually momentarily considered violence towards him… he'd had one of his trips to the sex shop… he got stuff… I'd been out in the garden… and I'd seen him through the window of his office… obviously he was busy looking at some stuff… and it was lunch time and I came in to give him his lunch… and I stood behind him and I really can't believe it now but I've got to tell you… it's the truth… I stood behind him with this big hammer in my hand… and I thought quite clearly 'A couple of blows to your skull with this and this would all be over'… and then I put the hammer away and served his lunch…" (Carer 2)

		"Even after I'd found out, I couldn't get him to talk to me about it and I remember going to his workshop one day like this and I asked him and asked him and he just stood there like a defiant little boy… and I picked him up… I'm only five feet… he's five foot six… he's much bigger… I picked him up by his boiler suit and I walked him backwards to the wall… just lifted him off the floor, banged him against the wall and I said 'Talk to me' and he just stood there till I let go of him… nothing moves him… nothing moves him… my GP said 'Make sure you're not near the knife block when you do hit him… get out of the kitchen'… she said 'Don't put yourself in danger' and what she meant was danger of being arrested I think…" (Carer 8)
Theme 8: Dealing with hypersexuality	**8.1. Attempt to limit hypersexuality**	"If he did continue to do something and the police were… I would step aside… I would explain that he had a degenerative brain disease but I'm not going to protect him if he's doing something illegal which he was… I think there's a limit to how much protection I can afford someone who has done not to deserve protection…" (Carer 8)
		"I would switch the television off and take the [pornographic] DVD out… I think I became very controlling... and I'm not sure if that was the right thing or the wrong thing to do but I did… for a start because I found it offensive… very offensive…" (Carer 1)
		"I don't like going to bed first because I lay in bed trying to listen whether he's changing channels… whether it's really Match of the Day or something else… and he started going to the second living room a bit too… the guest accommodation next door… he goes in there occasionally and says it's because he wants to watch something different to what I'm watching and then she starts putting the DVD player on… and again it's probably all okay but I think maybe… has he got some funny DVD or something…" (Carer 5)
	8.2. Attempt to uncover facts about hypersexuality	"I certainly looked for materials he'd obtained and was using… when I realised that he had bought a gay magazine… because I found the receipt by chance… after it when I thought about it he just said he was just curious… when he was out I went and unlocked the case and found more magazines… so yes I did go looking for them… yes I did go and look in his case and see what he'd got…" (Carer 1)
		"Partly I snooped... when I saw two thousand pounds being taken out of... you don't just take that out... but partly I did a ring back... a 1471 and got connected to the sex line on our phone... I mean he didn't bother to disguise it because I don't think he could…" (Carer 6)

		"He goes into day care two days a week… I search the room… I look under the mattress… I look under the carpet… I look inside the pillowcases… it's turned me on to being hyper vigilant…" (Carer 8)
	8.3. Giving in to hypersexuality	"I thought 'God this poor man has been a repressed gay all his life… he's never indulged in it… I know he's ill… he hasn't got that many more years to live… if he wants to indulge in this why shouldn't he?' and so I said to him 'Look you can't drive now… if you want to go to gay bars and clubs I will take you there'… after you'd phoned me and said that there is some evidence that it does alter sexual orientation… I just sat and cried… I thought 'Poor man'… he must've been so confused with what's happening to him… utterly… and he couldn't resist it…(Carer 1)
		"Not like I feel it's a great suffering to me… it's… to me… about his needs… maybe more than mine…" (Carer 7)
Theme 9: Coping with hypersexuality	**9.1. Responsibility/guilt**	"I thought I had done something and I tried for twenty years to find out what it was and when I found out it had all been him I didn't feel responsible…" (Carer 8)
		"I sort of think well [laughing] maybe it is my fault. Maybe it is my fault that you know I'm not... wanting to have sex every night or whatever... I don't know where desire's gone because it is practically... it is non-existent…" (Carer 5)
	9.2. Understanding the hypersexuality	"Kind of owning the fact that… that sex is not just with the other… it's your relationship with yourself as well as the other person so I'm able to separate how to be who I am and who he is so I don't actually feel exploited… like I'm able just to see that he has a greater need for sex than me and for our relationship to work I help him to meet that need and I'm having lots of other needs met in our relationship… it balances quite nicely…" (Carer 7)
		"I think I put it down to her transference and the peculiar relationship that is actually truly expected within... within a serious therapeutic relationship... I mean it is a relationship of huge power... and... I think in a way she was supposed to have this transference... I think that was part of the deal... he was meant to become her father and she felt a sort of way towards her father…" (Carer 4)
		"After you'd phoned me and said that there is some evidence that it does alter sexual orientation... I just sat and cried... I thought 'Poor man... he must've been so confused with what's happening to him... utterly... and he couldn't resist it…" (Carer 1)
		"She [GP] just let me cry and she said to me 'You know... you're always going to feel sad about this'… she didn't try and pretend it would go away… I said to her 'That's the most genuine response I've had so far'…" (Carer 8)
	9.3. Forgiveness	"on the road to forgiveness" (Carer 1)

		"some things can't be unsaid" (Carer 8)
	9.4. Difficulties with coping	"[I am] further back than I have ever been because I don't feel that safety and security that I feel I need to have" (Carer 2)
		"I just wished I didn't exist" (Carer 2)
		"[I] didn't want to commit suicide but I would like not to exist and there's a difference between not wanting to exist and wanting to be dead." (Carer 8)
Theme 10: Self-image	**10.1. Feeling unloved**	"I feel as if he is only interested in me sexually…" (Carer 2)
		"All the time it will end up in 'You don't know how much I love you and I wouldn't do anything to hurt you'… he used to always be telling me that he loved me and… I think that's what I miss a bit really… he isn't quite so affectionate… he used to say it on a daily basis how much he loved me and things and that was quite nice..." (Carer 5)
	10.2. Feeling used	"I've always thought of it very old fashioned as making love… sex of sex's sake for me is nothing… so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex… he was using me… like an animal really…" (Carer 1)
		"I feel… I'm competing with the women on the television or in his mind… I feel like he wants me to be one of them rather than… being me…" (Carer 5)
		"He has said he had had to imagine he was wearing women's clothes before he could get an erection with me and that makes me feel really creepy because I was in bed with someone who was going to imagine he was wearing women's clothes before he could touch me…" (Carer 8)
	10.3. Self-confidence	"On one occasion I said to my husband 'I don't understand how you can do this to me'… I've always stayed slim… I was always reasonably dressed… I was his official wife… had to go to functions and things with him… he always said how well dressed I looked… I could talk to people and do the proper job as a wife… that he had never been short of sex… so what was it?" (Carer 1)
		"At the time I felt completely worthless… completely and utterly worthless… I just felt so ugly and old…" (Carer 8)
		"[My] counselling training has helped me to be more confident in who I am so it doesn't rattle me as much as it might other people…" (Carer 7)
Theme 11: Stigma		"We're in our sixties so it's quite obvious that we're not going to feel how we did when we first met in our thirties… but he seems to be still back in that era and wants it in the same way…" (Carer 5)
		"I suppose the thing that bothered me most was the thought that other people would find out and laugh at me because I'd always... pride always comes before a fall... I'd always been proud of my happy marriage... we'd worked at it and the thought that

		my husband was gay and might be discovered to be gay are... yeah... that did worry me...” (Carer 1)
		“I can’t really spread the word because... I would... but because of the children and the embarrassment of you know having a father do that which is difficult …. Someone such as myself who has been through it... I’m actually quite free to talk about it away from home and I’m quite happy to talk about it away from home…” (Carer 6)
		“[laughing] she’d go straight to the… not too much foreplay… not too much… normally she likes tenderness and sweetness and this was sort of a bit more lust… go for it [laughing]…” (Carer 3)
		“I mean the change was there in just the amount of sex we were having and the sort of… you know… on the stairs as it were you know… which wasn’t something we’d done for many years not since our young days… sorry.” (Carer 3)
		“I’m being horribly honest here… is this alright?” (Carer 1)
Theme 12: Professional help-seeking	**12.1. Barriers**	“If somebody had said… well warning you that this might happen when he went on these drugs… I mean it says in the leaflets… it talks about hypersexuality… I looked at it and read the sheets through and I said ‘Oh hypersexual… he’ll be a bit frisky and that’ll be alright’… you know… the horrors of what were to come never occurred to me… if nobody speaks out then this will go on and other marriages will be ruined like mine was ruined… at least had we’ve been told it wouldn’t have been such a terrible shock…” (Carer 1)
		“I have tried to broach this a few times with my husband’s neurologist… I do a bit more than hint at the problems now and again but he never sort of takes it and runs with it… we’ve been seeing him for ten years and not once has he asked about hypersexuality… or hinted… that it could be a problem… he would spend more time talking about gambling…” (Carer 5)
		“No one cares enough … you just don’t feel listened to… the overwhelming feeling is of not being believed … even neurologist, even psychoneurologists… don’t know enough about it” (Carer 6)
	12.2. Aspirations	“necessity of full disclosure” (Carer 4)
		“[hypersexuality] has to become a specialty… I wish that they wouldn’t say to go to marriage guidance and counselling because… they are not equipped to handle [it]” (Carer 6)
		“[I need help] with managing the anger that I feel in a way that is useful… not in a way where somebody just sits there and tell me that my mantra should be that my husband can’t help it… I want somebody who can help me understand why I’m angry and who can help me resolve these angry feelings before my husband dies” (Carer 8)

University College London Hospitals NHS
NHS Foundation Trust

Carer Assessment Interview
Chief Investigator:
Patient Identification Number:
Date:

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

Carer Assessment Interview

Semi-structured interview schedule

Please note that not all carers are necessarily partners; therefore, there are some interview questions that can only apply to partners. Questions that only apply to partners are under a separate heading.

Interview length: 35-60 minutes

*About the patient (*to be extracted from patient notes)

Age of patient:

Neurological disorder of the patient:

Age of onset of neurological disorder:

Date:

Time:

INTRODUCTION

Thank you for agreeing to take part in an interview for this project.

This interview will be audio recorded. The main reason for this is to have an accurate set of data on this topic. This will help researchers analyze the data as the project develops. Rest assured that you would remain completely anonymous. All data collected is confidential. No records of the interview will be kept with your name or the name of the patient on it.

The following sections include questions about increased sexual behavior that has happened since the patient has developed (insert name of neurological disorder). This is called hypersexuality. Please remember that sexual acts involving physical harm to others or child abuse is against the law. For this reason, please do not answer any questions that show that the patient's sexual behavior has been a threat to others or that the patient has had sexual relationships with minors.

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Carer Assessment Interview

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I understand how sensitive this topic is. If any questions make you uncomfortable, you are completely free not to answer, but we would be grateful if you can answer all questions. Also, if any questions are not understandable, please ask and they will be explained.

GENERAL BACKGROUND

1. **Question:** How old was the patient when they first became hypersexual?

2. **Question:** What is your relationship to the patient?

   Probe 1: How long have you been in this relationship?

   Probe 2: (if applicable) When did the relationship end?

   Probe 3: Was the hypersexuality a reason for the end of your relationship?

3. **Question**: Did the patient have any behavioral or cognitive disorders before the (insert name of neurological condition)?

   Example of behavioral disorder is obsessive-compulsive disorder.

   Example of cognitive disorder is perception and memory disorders.

   Probe: Can you tell me what they are?

4. **Question:** Does the patient have any previous addictions, such as drugs or alcohol?

   Probe: What addictions?

5. **Question:** Did/does the patient have any other impulse control disorders such as increased gambling behavior, increased eating behavior, or increased buying behavior?

   Probe 1: Which ones?

   Probe 2: When did they start?

   Probe 3: How severe were/are these behaviors?

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6. **Question:** Did/do you notice any other changes in the patient's behavior apart from these and the hypersexuality?

   Probe 1: What are they?

   Probe 2: When did these changes start?

7. **Question:** Did you notice that the hypersexuality developed after use of any medications?

   Probe: What medications?

SPECIFIC

8. **Question:** When did you first notice this increased sexual behavior?

   Probe 1: When you first noticed this behavior, how did you feel?

   Probe 2: Is the patient still showing this behavior?

9. **Question:** Do you believe the patient developed hypersexuality because of (insert name of neurological disorder)?

   Probe: Why do you think so?

10. **Question:** Since the patient's (insert name of neurological disorder) started, did/do you feel the patient has lost interest in sex in general?

    Probe: What makes you think so?

11. **Question:** Since the hypersexuality started, do you believe the patient has new sexual interests that were not there before the (insert name of neurological disorder)?

    Probe 1: What are the new interests?

    Probe 2: How did you notice them?

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12. **Question**: How much time do you think the patient spent/spends on their new sexual interests?

13. **Question:** Since the hypersexuality started, do you believe that your physical relationship with the patient has changed?

    Probe: Can you tell me how?

14. **Question:** Since the hypersexuality started, has the patient become more interested in sex with you?

    Probe: What is your reaction?

15. **Question:** Since the hypersexual behavior started, do you think the patient had/has no control over their hypersexuality?

    Probe: What makes you think so?

16. **Question:** Since the hypersexual behavior started, do you feel like the only thing the patient could/can think about is sex?

    Probe: What makes you think so?

17. **Question:** Does the patient's hypersexuality cause problems in your relationship?

    Probe 1: Can you please give elaborate? What kind of problems?

    Probe 2: How does this make you feel?

    Probe 3: How do you think this makes the patient feel?

18. **Question:** Do you believe the patient was/is more tempted to engage in sexual behavior when they have certain feelings, such as sadness or anxiety?

    Probe: What feelings?

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19. **Question:** Which of the following has your partner tried since developing hypersexuality? I will list them and you are required to just say yes or no to each.

    Internet porn?

    Pornographic novels?

    Uncontrollable masturbation?

    Prostitution?

    Voyeurism: getting sexual satisfaction from spying on sexual objects or acts?

    Exhibitionism: the act of showing your genitals to strangers?

    Affairs?

    Anonymous sexual encounters?

    One-night stands?

    Bath houses: communal bath places?

    Massage parlors?

    Strip clubs?

    Sexual encounters with gender not typically interested in?

    Sexual misconduct in the workplace?

    Being aggressive with sexual partner?

    Asking for sexual partner to be aggressive?

    Bestiality: sexual encounters with animals?

    Any others that I haven't listed?

1. **Question:** Do you think the hypersexuality has negatively affected the patient's life?

   Probe: Has it affected their

   Marital life? How so?

   Family life? How so?

   Social life? How so?

   Work? How so?

   Finances? How so?

   Health? How so?

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Mood? How so?

Sleep? How so?

Self-confidence? How so?

Quality of life? How so?

20. **Question:** To your knowledge, has the patient tried to control their sexual behavior or stop it altogether?

    Probe 1: Has it been successful?

    Probe 2: How does this make the patient feel?

21. **Question:** To your knowledge, does the patient want to overcome their hypersexuality?

    Probe: How can you tell?

22. **Question:** Did the patient ever seek advice for their sexual behavior?

    Probe: What was the result of that?

23. **Question:** How did/does the patient's hypersexuality make you feel?

    Probe 1: Do you think the patient knows this?

    Probe 2: Have you tried to make them aware?

    Probe 3: What has been the patient's reaction?

24. **Question:** Do you believe the hypersexual behavior was/is out of the patient's control?

    Probe 1: Did/do you discuss this issue with the patient?

    Probe 2: What has resulted from those conversations?

PARTNER QUESTIONS

25. **Question:** Since the hypersexual behavior started, did/do you feel there was/is less intimacy and confidence between you and your partner when you have sex?

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Probe: Why do you think this has happened?

26. **Question:** Since the hypersexual behavior started, did/do you feel your partner was/is not sexually interested in you anymore?
    Probe 1: How does this make you feel?
    Probe 2: Have you talked to your partner about this?
    Probe 3: What did they reply?

27. **Question:** Before the patient's (insert name of neurological condition) started, how often did you and your partner have sex?

28. **Question:** In the period between the start of the patient's (insert name of neurological condition) but before the start of hypersexuality, how often did you and your partner have sex?

29. **Question:** Since the hypersexuality started, how often do you and your partner have sex?

30. **Question**: Did/do you find your partner repulsive?

31. **Question**: Did/do you feel you lost respect for him?

32. **Question**: Do you think you will ever be able to forgive him?

33. **Question:** Do you ever blame yourself for the patient's hypersexuality?

CLOSURE

We have reached the end of our interview. I would like to thank you for being so patient. However, do you believe there is anything we have missed out that you would like to add?

Do you have any other comments about what we have discussed, or about the research as a whole?

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We will send you a summary of the research findings when it becomes available.

Thank you so much for your participation.