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ORIGINAL ARTICLE

The experiences of carers looking after people with Parkinson's disease who exhibit impulsive and compulsive behaviours: An exploratory qualitative study

Eamonn McKeown PhD, Senior Lecturer¹  |Tariq Saleem MSc, PD Local Advisor² |Cathy Magee RGN, MSc, Advanced Clinical Practitioner-Parkinson's Disease³ |Mark Haddad RGN, RMN, PhD, Senior Lecturer¹ ¹School of Health Sciences, City, University of London, London, UK²Parkinson's UK, London, UK³University College London Hospitals NHS Foundation Trust, London, UK**Correspondence**Eamonn McKeown, School of Health Sciences, City, University of London, UK.
Email: eamonn.mckeown.1@city.ac.uk**Abstract****Aim:** To understand the experiences of carers who were confronted by the development of impulsive and compulsive behaviours.**Background:** Impulsive and compulsive behaviours (ICBs) are a serious complication in Parkinson's disease (PD) strongly associated with dopamine replacement therapy used to treat patients. These behaviours comprise abnormal activities such as pathological gambling, binge eating, compulsive shopping and hypersexuality. These behaviours place a considerable burden on patients and on their carers and families.**Design:** An exploratory qualitative study.**Methods:** Using a convenience sampling approach, 13 carers were recruited to participate in semi-structured interviews. Interviews were conducted over the telephone. Verbatim transcripts were analysed using a thematic analysis approach. COREQ guidelines were adhered to in the reporting of this study.**Results:** Five main themes were identified: (a) realisation—developing awareness of ICB symptoms and their causes; (b) reacting—confronting and attempts to manage ICBs; (c) reaching out—help-seeking and selective disclosure; (d) reframing—shifting perspectives on ICBs over time; and (e) resignation—impact on relationships and facing the future.**Conclusions:** The profound impact of ICBs on quality of life, relationships and economic stability was clear in the carers' accounts. Possible avenues for future clinical research are suggested.**Relevance to clinical practice:** The potentially devastating effects of ICBs provide a strong imperative for nurses and other health professionals to ensure that close monitoring for symptom development together with patient education is always part of practice.

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KEYWORDS

carers, hypersexuality, impulsive and compulsive behaviour, Parkinson's disease, qualitative study

1 | INTRODUCTION

Parkinson's disease (PD) is a complex and progressive neurodegenerative disease characterised by bradykinesia, muscular rigidity, resting tremor and (typically in the later stages of the condition) postural instability. PD is the second most common neurodegenerative disorder after Alzheimer's disease; among the overall population, the age-adjusted prevalence rate is around 0.15%, and around 1% of people aged over 60 are affected (de Lau & Breteler, 2006).

The characteristic clinical features of PD are tremor, bradykinesia, rigidity and postural instability. Alongside these cardinal features, a range of nonmotor symptoms increasingly recognised are important aspects of PD. These features include sleep abnormalities, fatigue, pain, urinary urgency and constipation; and neuropsychiatric conditions such as apathy, depression, anxiety and increased risk of dementia (Jankovic, 2008). Within this group of neuropsychiatric nonmotor symptoms are a group of impulsive-compulsive behaviours (ICBs), which centre on the failure to resist an impulse to perform an act despite personal or relationship consequences, and involve pleasurable activities performed repetitively and compulsively, typically with a craving stage before engagement in the problem behaviours (Ceravolo et al., 2009).

Impulsive and compulsive behaviours are strongly associated with the use of dopamine replacement therapy, particularly dopamine agonists (DAs). They include four main behaviours, pathological gambling, compulsive shopping, hypersexuality and binge eating (Cossu et al., 2018; Weintraub et al., 2010), and occur relatively frequently in people with PD, with a 10% prevalence identified in a systematic review incorporating 29 studies across a range of cultures (Callesen et al., 2013). ICB symptoms arise or worsen following the initiation of D3 DA therapy, and often improve or disappear upon dosage decrease or discontinuation (Callesen et al., 2013). There is evidence to suggest DAs can cause neuroplastic changes in susceptible individuals for whom the ICBs may be irreversible (Averbeck et al., 2014; O'Sullivan, Wu et al., 2011). Additional risk factors include male sex, younger age of PD onset, and personal or family history of substance misuse and gambling problems (Averbeck et al., 2014).

Pathological gambling, the most extensively studied of these conditions among people with PD (Ceravolo et al., 2009), is defined as persistent, recurrent and problematic. It is done even when the person feels distressed or anxious, and the extent of engagement typically jeopardises relationships, work or education. Compulsive shopping involves a maladaptive preoccupation with buying or shopping, leading to more frequent purchases that can be afforded, unneeded items or prolonged shopping periods. Hypersexuality occurs more frequently among men and involves a marked increase in sexual

What does this paper contribute to the wider global clinical community?

- This study reveals the impact of ICBs on patient-carer relationships and the ways that disclosure and access to support may be limited by the nature of these condition features.
- Commonly used drug treatments can induce or worsen ICBs, and health professionals need to be aware of the risks of these medication side effects.
- Health professionals have a key role in advising, supporting and monitoring for ICBs and need to be appropriately informed and alert to risks and onset at the initial stages of assessment and treatment in order to limit potential harms.

interest, arousal and behaviour. These changes are characterised by an increase in the varieties of sexual behaviours, with activities such as compulsive masturbation, habitual use of pornography, and involvement with sex workers and sex lines often occurring, and continued engagement in these activities despite adverse consequences (Codling et al., 2015). Binge eating involves altered consumption or absorption of food and which significantly impairs physical health or psychosocial functioning. There is a sense of loss of control over eating during these episodes, but the behaviour pattern is fluctuating with periods free of disturbance (Cossu et al., 2018).

There are also several related behavioural disorders that share similar features but do not meet formal impulse control criteria: dopamine dysregulation syndrome (DDS), which is a compulsive excessive overuse of dopaminergic medication; punding, which is a stereotyped, repetitive and non-goal-directed behaviour, typically involving handling, sorting or arranging objects; and hobbyism, which involves compulsive engagement in hobby activities such as fishing, gardening, Internet use or writing (Erga et al., 2017; Weintraub & Claassen, 2017).

Studies that have examined the stresses, burden and quality of life of carers have overwhelmingly used quantitative designs with standardised measures of these variables (Mosley et al., 2017), most commonly the Zarit Caregiver Burden Inventory (Grun et al., 2016; Martinez-Martin et al., 2008; Tan et al., 2019; Torny et al., 2018; Yuksel et al., 2018). Overall, the findings of these studies identify that caregiver stress and burden appears linked to more prolonged duration of disease (Tan et al., 2019), the extent of disability and risk of falls (Davey et al., 2004; Martinez-Martin et al., 2005),

and the presence of mental health problems such as depression or confusion (Fernandez et al., 2001; Martinez-Martin et al., 2015; Schraget al., 2006). Nonmotor clinical symptoms appear to be particularly important predictors of caregiver strain and depression, and have been found to contribute more to caregiver stresses than motor symptoms (Carter et al., 2008; Torny et al., 2018). One of the few studies to specifically examine relationships between behavioural disorders in PD and carer experience used quantitative measures of carer burden, depression and anxiety, and found significantly greater burden among carers of PD participants with ICBs (Leroi et al., 2012).

Nonmotor symptoms and particularly ICBs are important aspects of PD, and are associated with specific stresses for caregivers. Patients with ICBs often lack insight into this aspect of their condition and may either not recognise or attempt to conceal these behaviours (NICE, 2017), which complicates management and typically adds to the worry and distress experienced by carers. Although studies have explored the experiences of caregivers of people with PD, there has been very limited attention to the effect of ICBs on carers and family; and as described, the use of standardised questionnaire-based studies has predominated in the literature, which seriously limits the capture of carer's experiences in relation to these behaviours. It is likely that the experiences and responses of carers to ICBs are complex and attaining a detailed understanding of their feelings and approaches to managing these difficulties necessitate a qualitative method. This study was planned to increase understanding of caregivers' experiences in relation to ICBs, their responses and reactions to these and to the strategies and support structures provided for them.

2 | METHOD

2.1 | Design and sampling

The study adopted a qualitative study design using semi-structured interviews as the data collection method. Participants were recruited through posts advertising the study on the Parkinson's UK discussion forum, a moderated online space that provides support for people living with or affected by PD ($n = 9$), and from subsequent snowballing sampling ($n = 4$). Inclusion criteria were that participants should be adults over 18 years old and who: (a) had been a carer living with a person with PD who exhibits ICBs related to dopamine replacement therapy; (b) who lives in the UK; and (c) who had been a carer for at least 12 months.

2.2 | Procedure and interview

Ethics approval for the study was obtained from the School of Health Sciences Ethics Committee at City, University of London. All participants provided written informed consent in advance of the interview and had the capacity to give informed consent. A

flexible interview schedule was designed prior to the interviews and comprised of open-ended, nondirective questions to explore experiences related to impulsive-compulsive behaviours, including support systems and networks, and information provided by services and by user groups.

The interviews were carried out by telephone by the first author ($n = 8$) and another researcher ($n = 5$) and lasted between 45–90 min. The sample comprised 13 participants, twelve females and one male, all of whom were the spouses of persons with PD. The time since acquiring the carer role ranged from five–12 years. Participants were aged between 52–65. The telephone interview approach permitted participation from a wide range of locations, both urban and rural, across England ($n = 12$) with a further participant located in Wales. The main ICBs encountered and described by participants were hypersexuality, compulsive gambling and compulsive spending. Additionally, some carers also described instances of risk-taking and punding.

2.3 | Analysis

Interviews were recorded digitally and transcribed verbatim. Thematic analysis was used following the step-by-step approach described by Braun and Clarke (2006). In the first step, the interview transcripts were read by two members of the research team (EM and MH) to obtain a general sense of the overall interview narratives. The second step involved each researcher systematically coding the transcripts, identifying salient features across the data set, with the third step then involving the collation of the codes and the identification of initial cross-cutting themes. In steps 4 and 5, EM and MH reviewed and then agreed the final labelling of the themes as the output of the analysis. Analysis and data management were aided by QSR NVivo 11. Consolidated criteria for reporting qualitative research (COREQ) guidelines were followed (Appendix S1).

3 | FINDINGS

Five interconnected themes emerged when considering caregivers' experiences of living with a partner with Parkinson's disease, and impulsive and compulsive behaviour symptoms were identified. The themes and their related subthemes are presented in Table 1:

3.1 | Realisation: developing awareness of ICB symptoms

3.1.1 | Lack of prior warning

Limited understanding of the potential for the emergence of ICBs as a result of the DA medication was almost universal in the narratives of participants in the study. Several of the interview participants

Themes	Subthemes
Realisation—developing awareness of ICB symptoms and their causes	Lack of prior warning Gradual changes in behaviour Making connections between ICBs and DA treatment
Reacting—confronting and attempts to manage ICBs	Confronting partner Colluding with changed behaviour Practical strategies to manage the ICBs
Reaching out—help-seeking and selective disclosure	Seeking support from family and social networks Seeking support online Concerns about privacy, relationship and reputation
Reframing—shifting perspectives on ICBs over time	Separating partner from behaviour Downward comparison ICBs deemed better than PD symptoms
Resignation—impact on relationships and facing the future	ICBs transformed partner ICBs transformed relationship

TABLE 1 Table of themes and subthemes

noted that, although they had received information about potential DA side effects at initial consultations, they had paid little attention to this at the time. After diagnosis, the prescribed DAs were seen by carers as effective in controlling disease symptoms, and for many couples, there was a return to relative normality after the initial shock of the PD diagnosis itself.

There may have been something on the box about side effects but it was not something we focused on and at first it looked as if the drugs had helped the [PD] symptoms and we sort of forgot about it.

(Participant 2)

Many carers recounted that the assigned neurologist generally used subsequent clinical consultations to focus on reported symptoms related to PD and invariably failed to either ask about changes in behaviour after the DA medication regime commenced. Some participants reflected that even when relevant questions were asked, their partner was secretive and denied any changes in their behaviour.

3.1.2 | Gradual changes in behaviour

The emergence of the altered behaviours was often gradual, and the medication was invariably not initially suspected. For the following participants, it was some time until the connection between new patterns of spending and the medication was made:

It just started gradual. But then all of a sudden, what would happen is that, we'd start to have holidays, but not just holidays, it'd be exotic holidays. It'd be the likes of, to Thailand, it'd be the likes of, to the Maldives. But, that was starting to increase. Because, [she] was very, sort of like, careful with the money, very excellent with the accounts, and all that. But I

had no reason to think it was the DAs that were doing this.

(Participant 11)

When it started I thought, you're on the PC too much, you're not doing anything, you're on the laptop all the bloody time. And I mentioned it to the neurologist and the Parkinson's nurse, because she was in the meetings with the neurologist, oh no, no, no, oh, well just keep an eye on it. And I kept thinking, so every time I'd say, he's using it too much, well how do you mean? It was, and then they'd ask him how many times he was using it, which is stupid because he didn't tell them the truth.

(Participant 7)

Many of the interview participants described that their partners developed “exaggerated” features of their previous personality, or that established traits became more extreme and “bizarre.” For several carers, changes in their spouse's sexual behaviours were the initial and central feature, with increased demands for sex and sexual experimentation described:

... he just kept pushing boundaries, wanting sex when he was dressed up...

(Participant 7)

Other carers described the development of a more general disinhibition, which included angry or aggressive outbursts:

[He] would become very aggressive and he'd be screaming and shouting at everybody, swearing at everybody. He's gone from somebody who never used to swear or anything.

(Participant 13)

3.1.3 | Making connections between ICBs and DA treatment

Most participants were able to identify changes in their partner's behaviour but only in retrospect were they able to attribute this to the DA treatment regime.

Carers described identifying changes in their partner's behaviour as a process of "discovering" and "unravelling," and gradually becoming aware of the emergent pattern of behaviours, and then linking this both to PD and to the prescribed DA medications. A participant whose husband's behaviour had become sexually disinhibited noted:

I was just really confused at the time, although I said do you think it's about the medication, maybe we could talk to someone... I think if I'd known that information from the start, I would have known what to look out for...

(Participant 1)

3.2 | Reacting: confronting and managing ICBs

3.2.1 | Confronting partner

When the ICBs became established, many carers took practical steps to attempt to curtail the problematic behaviours through directly confronting their partner to bring about change. Initially unaware of the powerful drivers underpinning the ICBs, many believed that they would be able to check the behaviours through persuasion, bribes and threats. For the following participant, whose husband began to gamble and also engage in range of punning activities including compulsive DIY and ten-pin bowling, it was only later recognised that simply demanding that his change was going to be futile:

I told him I loved him but demanded he stop or I would leave him. I tried to be tough for all the good it did... It was not going to be that straightforward.

(Participant 10)

Other participants reported that their partners' responses to being challenged about their actions showed little or no insight into these being problematic. One interviewee described that when she tried to discuss her partner's extensive use of pornography with him, his responses were as follows:

He got quite angry initially, and [said] oh you're making it up... even though it was all there in front of him he continued to deny it... I think that had been going on for a long period of time.

(Participant 3)

Other accounts described partners becoming defensive and denying any change in their behaviour, or protesting that the identification or interpretation of their behaviours was the problem. Several participants noted how these disputes and arguments would place considerable strain upon their relationships and that such discussions could culminate in abuse and violence:

...and if I talk about it... he would get violent, walk out, shout and yell.

(Participant 3)

3.2.2 | Colluding with changed behaviour

Some participants reported that they tried, at least at first, to accept and collude with the altered behaviour. This complicity was particularly associated with emergent hypersexual behaviour. Several narratives showed a degree of collusion in agreeing not to discuss the development of hypersexual behaviours with the neurologist, due to embarrassment, shame and awkwardness of discussing these sensitive issues.

For one participant, whose husband developed an increased sex drive after taking the DA medication, her initial reaction was positive:

Well initially it was great fun because it's like, more sex was brilliant, so I didn't object to that but we've always had a very good sex life, so that was quite nice.

(Participant 5)

Similarly, another participant recounted how she too was initially willing to accept her husband's more frequent sexual urges but that after a time his demands became excessive and increasingly accompanied by requests for sadomasochistic activity which she was unable to countenance:

I did start off with, I went along with it and then he wanted me to really hurt him and I said I can't do this anymore. I was willing to go a certain distance with it, to please him, but when it got to he wanted me to cause him real pain and I didn't feel able to do that.

(Participant 7)

3.2.3 | Practical strategies to manage the ICBs

Practical strategies to manage the ICBs included efforts to limit access to opportunities to engage in the behaviours. This approach included contacting local bookmaker shops to reduce the opportunities for gambling, blocking joint bank accounts in the case of spending and restricting access to the Internet in the home in cases of both gambling and spending and also of hypersexuality

associated with viewing pornography and chatroom use. These efforts often led to their partner attempting to surreptitiously find ways to circumvent the obstacles being put in their way, exacerbating a breakdown in trust in the relationship. Participant 1 recalled how, after she became aware of husband's gambling activities, she became increasingly vigilant in relation to the household finances and endeavoured to sabotage his efforts to secure access to money:

I thought that, well, if I can't persuade him not to gamble away our life savings then at least I was not going to make it easy for him. I was always hiding things, checking the post for bank statements, keeping the credit cards well away from where he could get his hands on them.

(Participant 1)

3.3 | Reaching out: help-seeking and selective disclosure

3.3.1 | Seeking support

In the face of the emergent and increasingly problematic ICBs, participants recounted how they sought support and solace from family members and from wider social networks, particularly online forums:

I get support from the online forums, that's where I got most of my help. I went online and lodged all my queries online and I got so many people helping it was lovely... people who'd been through it told me, told me their stories, were prepared to put their stories online...

(Participant 5)

Others recognised the limits to any support that others could provide, particularly in practical terms. For example, the following participant, who suffered bankruptcy as a result of his partner's compulsive spending, indicated that the need for emotional support was a secondary concern in the face of the grievous financial issues that his family faced:

That's it. I mean, so it's, it's quite a depressing state, because we've got people who will pat us on the back and say, there, there, but it's, patting on the back and giving us physical support are two different things. They've got the emotional support, but unfortunately that's not going to put the bread on the table or pay the bills. Although we're not knocking that, because we love our families dearly, but, and they're doing the best they can. Occasionally

my mum or dad will help us with, like, food and the odd bill or two.

(Participant 12)

3.3.2 | Concerns about privacy, relationship and reputation

This desire to seek help from family, friends and even professionals was often weighed up against a reluctance to reveal the full extent and details of the ICBs in order to both protect the reputation of their partner and preserve an impression of the stability of their relationship:

I couldn't tell anybody about the violence and aggression or the pornography – my daughter would have been shocked and that is not the way I want him to be remembered.

(Participant 3)

My sister is the only one I can talk to, it's not the sort of thing I want my children to know. I don't want them to see him in a different way, although they're both adults I still want them to think of him in the nice way that they do think of him. I don't want them to think of him in a perverted sort of way.

(Participant 7)

These concerns extended beyond family; one participant described her sense of embarrassment and shame when a neighbour discovered her husband buying women's clothes to cross-dress, and how she felt conflicted between unburdening herself or trying to invent some explanation, but chose to try to conceal the reality of the situation.

3.4 | Reframing: cognitive shifts on ICBs

3.4.1 | Separating partner from behaviour

Many participants endeavoured to reframe their perceptions of the ICBs encountered by mentally detaching and isolating the behaviours exhibited by their partner as a means of absolving them of culpability for their conduct. They placed increased emphasis on the fact that the ICBs were a direct outcome of the medications used to manage the PD symptoms and that these drugs, not the individual themselves, were responsible for the problematic behaviour they encountered:

He would never have done this had he not been on drugs, these drugs...

(Participant 5)

A drug caused all this, not him... That's what I had to tell myself. It was not actually him.

(Participant 13)

3.4.2 | Downward comparison

Another approach used to reframe their view of the ICBs was for the carers to reassure themselves, through the use of downward comparison, that while the specific ICBs exhibited by their partner may have been taxing, these might in fact have been different and much worse:

I think for the time that this went on for, with the violence and the pornography and the lying, I think in some ways, from stuff I've read, I think I, we probably got off lightly, especially from the financial aspect.

(Participant 3)

Similarly, another participant, whose husband engaged in compulsive gambling, recounted how she felt fortunate that he did not exhibit hypersexuality as one of his ICBs:

I know about the hypersexuality and the stuff that some people have to put up with which is really terrible and we never experienced anything like that so maybe we were lucky in that way, if that makes sense...

(Participant 1)

3.4.3 | ICBs better than PD symptoms

Some participants tried to express appreciation, albeit ambivalently, for the drugs for effectively controlling the potential symptoms of PD and concluded that the ICBs were the price that had to be paid for this control. Participant 12, whose wife engaged in compulsive spending and increased risk-taking, reflected as follows:

Unfortunately [she] most probably would've committed suicide, because of the poor quality of life she had. But, given the two parallels between not taking the DAs, I don't think we'd be in this debt. But, in the same breath, they did help physically with her. Didn't help her mentally wise, but physically wise they did help.

(Participant 12)

This ambivalent relationship with the medication extended to cases where the carer recognised that without the drugs their spouse would most likely suffer debilitating PD symptoms and sometimes felt that they would prefer this scenario to the ICBs which they themselves had to endure. Such was her frustration with her husband's desire to engage prostitutes among a range of manifestations of hypersexuality,

the following participant related how she battled internal feelings of remorse and shame for often wishing that her husband's medication was stopped even at the cost of his relative health:

I just felt guilty that if I'd flagged it all up that they'd obviously take, wouldn't, he wouldn't be able to stay on the [DAs] and obviously he'd be back to being housebound most of the time, so I suppose that was my guilt, my guilt that... I suppose I did end up feeling quite guilty about really wanting that.

(Participant 3)

3.5 | Resignation: impact on relationships and facing the future

3.5.1 | ICBs transformed partner

After the ICBs became established and the practical strategies to confront and manage the altered behaviour were deemed ineffective, many carers spoke of resignation and a gradual social and psychological distancing from their partner.

Oh absolutely, he was a different man. He's not the man I married, he's a different person. He doesn't have any sort of understanding of the way he's behaving.

(Participant 4)

Before the dopamine agonist he was renowned among all our friends as one of the most gentle and kindly caring people... he'd changed into a completely different person.

(Participant 3)

Now he's just like, I look upon him as an adolescent child.

(Participant 5)

A sense of loss was common, with a fatalistic discourse of transformation dominating many of the narratives. Even though the medication was seen as effective in managing the symptoms of PD, it was seen as robbing them of the person they married by irrevocably changing them into someone they no longer recognised:

Because basically, the medication just took [my wife] away from me, and just replaced her with this other person. And although the [DAs] were brilliant at stopping the physical side of things, it just replaced her with this monster...

(Participant 12)

3.5.2 | ICBs transformed relationship

Along with the theme of their partner being transformed by the medication, carers invariably saw their relationships as also irretrievably altered by the negative impact and strain caused by the ICBs.

So we have got a house over our heads, but we're stuck in it together whether we want to be or not. I don't know, I don't know what the future holds... It's ruined our marriage. We ain't got a marriage any more, we're living in the same house, but we don't have a marriage any more. I can't afford to leave, I've nowhere else to go.

(Participant 6)

It's absolute, I'm a prisoner, I feel as if I am a prisoner. If he wasn't ill I could walk away from it, I can't. He's the father of my sons, how can I possibly leave him? It's not fair on them, I just, I don't know, he's not in any fit state to look after himself.

(Participant 3)

Others reported that the impact of the ICBs was felt further than their relationship but in their wider family and social network as well.

It's not just him that's having to live with the consequences, it's everybody and it's not only our family, the direct family that it affects it affects like my mum and dad and my brothers and sisters, his mum and dad and his brothers and sisters because of the repercussions within our family... it's hard to get your head round that a drug's caused it.

(Participant 1)

4 | DISCUSSION

Our thematic analysis of interview material has revealed carer's perspectives on the typically insidious or hidden development of ICBs, the difficulties encountered in managing and accessing support for these behaviours, their distressing impact and potentially devastating consequences, and the means employed to try to cope during and in the aftermath of these behavioural disturbances.

The profound impact of ICBs on quality of life, relationships and economic stability was clear in the carers' accounts, and while there was a recognition of the key causal role of DAs in these behaviours, there was also an acknowledgement of their positive beneficial effects on motor symptoms. Despite an increased understanding of the risks of developing ICBs evident in the academic literature, and resulting clear recommendations about the information needs of

patients and carers (Macphee et al., 2013; NICE, 2017), the carers in this study reflected on limited preparation or forewarning about these potential side effects of treatment at the time of diagnosis. While some had valuable support from PD nurse specialists, depending on their geographical area, other carers described variable support from health professionals, reporting that clinical consultations were often overly focused on typical physical symptoms. These difficulties extended beyond professional support, with the carers noting reluctance to access informal supports such as family and friends because of shame and stigma associated with these behaviours. Online forums were identified as important and useful sources of information and support where details of ICBs and the effects could be shared and which provided a sense of not being alone with these experiences. This mode of support appeared to be particularly well suited to the personal and sensitive nature of ICBs.

Although existing research has clarified the extent, features and risks for ICBs (Averbeck et al., 2014), as well as providing quantification of the carer burden associated with PD, typically by using rating scales such as Zarit Burden Inventory (Hagell et al., 2017), there is a paucity of studies providing detailed exploration of the accounts of carers. Although research has consistently identified nonmotor features of PD to be associated with increased personal and role-related toll on the caregiver, there has been a lack of exploration of the detail of carer experience. NICE (2017), (section 4.1.4 - Evidence statements <https://www.nice.org.uk/guidance/ng71/evidence/full-guideline-pdf-4538466253>) specifically note that the Guideline Development Group found no qualitative evidence reporting the experience of carers for people with ICBs. Those studies that have explored the perspectives of patients and carers indicate that a limited awareness of illness trajectory and of the type and extent of illness features may affect help-seeking. A qualitative study undertaken in England using focus groups, individual case studies and in-depth interviews found that issues such as difficulties in acceptance of the diagnosis of PD and low levels of understanding about social care needs and provision impacted the timely receipt of care and occurrences of crises (Tod et al., 2016). A study using interviews with caregivers for people with PD in Singapore found the emotional aspects of care to be the most challenging and that there was a need for more information about how to manage PD (Tan et al., 2012). This unmet need for information together with a lack of care coordination was highlighted in an interview study with family caregivers in Northern Ireland (McLaughlin et al., 2011). Another study conducted in four English local authorities using case study methodology identified that outcomes identified as important to service users were often inadequately addressed in assessment or monitoring; among the wider psychosocial and emotional needs encountered by service users were stresses on spousal and partner relationships resulting from the condition (Aspinal et al., 2014). These issues concur with the findings of a UK Government inquiry concerning the care needs of people with PD (All Party Parliamentary Group for Parkinson's Disease, 2009), which similarly identified limited information provision and signposting, especially with regard to social care, poor

understanding of PD amongst some of the professionals, and a lack of integrated working between the range of services involved in the different aspects of care with mental health needs particularly under-served.

The key strength of this study is its qualitative methodology. The feelings of embarrassment associated with ICBs, particularly compulsive sexual behaviours, as well as the frequent denial of their occurrence, necessitate a careful and sensitive approach to recruitment and the conduct of interviews. In this study, we were able to identify and engage with spouse carers to elicit detailed accounts of their experiences, which provided a richness of detail that is not possible using structured survey instruments and methods.

Limitations of this study relate to its recruitment methods. Participants were recruited via a convenience sampling approach, and it is possible that carers with more distressing and burdensome experiences of ICBs were more inclined to volunteer to take part in the study than those carers whose experiences were less severe. Additionally, the principal means of recruitment used the Parkinson's UK Forum, and because of this, we may have an unrepresentative view of the extent of use of online supports and of their value and benefits for this group. Our study participants highlighted the value of this mode of support, which accords with our understanding of the growth and popularity of online discussion forums in general—as accessible and beneficial at individual and societal levels with especial value for stigmatised group members (Pendry & Salvatore, 2015), but we cannot assume such forum use to be typical of PD carers. Our participants were also disproportionately the female spouses of men with PD, which potentially limits the transferability of the themes we identified.

5 | CONCLUSION

The carer role for people with PD is known to be demanding; the adaptations and contributions required to provide support for this progressive condition are associated with substantial burden (Mosley et al., 2017). ICBs are a complication of standard treatments that have particularly disruptive and long-lasting effects on PD patients and their carers. The accounts of spousal carers analysed in this study indicate that although evidence-based guidelines explicitly recommend the initial provision of information about the risk of emergence of these disorders and ongoing monitoring for their development, there remain unmet needs for this vital patient education in practice. The characteristics and effects of ICBs limit its routine disclosure, and specific efforts and procedures on the part of professionals are needed to facilitate early identification and the minimisation of harmful consequences. The nature and features of ICBs similarly limit the support sources that carers of people experiencing these behaviours feel able to access. Participant accounts revealed how feelings of stigma impede help-seeking and the use of familial supports; however, these aspects of ICBs appear to make online support especially important.

6 | RELEVANCE TO CLINICAL PRACTICE

This study adds to the literature that describes the nature and prevalence of ICBs by providing insight into the lived experiences of carers and their responses to these condition features. Nurses have a key role and relationship with their patients and may often be the health professional in whom patients and carers feel they can confide. Although awareness and understanding of ICBs has expanded in recent years and the risk of their incidence is highlighted in patient resources and professional guidance, the nature of these behaviours means that the nurse is particularly well placed for ICB education and recognition. The carers' accounts that form the basis of this study provide a clear indication of the clinical practice importance of ongoing specific assessment and education for this potentially catastrophic range of behaviours.

CONFLICT OF INTEREST

No conflict of interest to declare.

AUTHOR CONTRIBUTIONS

Study conception and design: EM and TS; conduction of the majority of the interviews: EM; data analysis: EM, TS and MH; manuscript drafting: EM, TS, CM and MH. All authors have read and approved the final manuscript.

ORCID

Eamonn McKeown  <https://orcid.org/0000-0002-4183-5376>

Mark Haddad  <https://orcid.org/0000-0002-4822-5482>

REFERENCES

- All Party Parliamentary Group for Parkinson's Disease (2009). *Please mind the gap: Parkinson's disease services today*. Retrieved from https://www.lgcplus.com/journals/1/files/2009/7/10/APPG_Report_Please_Mind_the_Gap.Pdf
- Aspinal, F., Bernard, S., Spiers, G., & Parker, G. (2014). Outcomes assessment for people with long-term neurological conditions: A qualitative approach to developing and testing a checklist in integrated care. *Health Services and Delivery Research*, 2(9), 1–164. <https://doi.org/10.3310/hsdr02090>
- Averbeck, B. B., O'Sullivan, S. S., & Djamshidian, A. (2014). Impulsive and compulsive behaviors in Parkinson's disease. *Annual Review of Clinical Psychology*, 10, 553–580. <https://doi.org/10.1146/annurev-clinpsy-032813-153705>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77–101.
- Callesen, M. B., Scheel-Kruger, J., Kringelbach, M. L., & Moller, A. (2013). A systematic review of impulse control disorders in Parkinson's disease. *Journal of Parkinson's Disease*, 3, 105–138. <https://doi.org/10.3233/JPD-120165>
- Carter, J. H., Stewart, B. J., Lyons, K. S., & Archbold, P. G. (2008). Do motor and nonmotor symptoms in PD patients predict caregiver strain and depression? *Movement Disorders: Official Journal of the Movement Disorder Society*, 23, 1211–1216. <https://doi.org/10.1002/mds.21686>
- Ceravolo, R., Frosini, D., Rossi, C., & Bonuccelli, U. (2009). Impulse control disorders in Parkinson's disease: Definition, epidemiology, risk factors, neurobiology and management. *Parkinsonism & Related Disorders*, 15(Suppl 4), S111–S115. [https://doi.org/10.1016/S1353-8020\(09\)70847-8](https://doi.org/10.1016/S1353-8020(09)70847-8)

- Codling, D., Shaw, P., & David, A. S. (2015). Hypersexuality in Parkinson's disease: Systematic review and report of 7 new cases. *Movement Disorders Clinical Practice*, 2, 116–126. <https://doi.org/10.1002/mdc3.12155>
- Cossu, G., Rinaldi, R., & Colosimo, C. (2018). The rise and fall of impulse control behavior disorders. *Parkinsonism & Related Disorders*, 46(Suppl 1), S24–S29. <https://doi.org/10.1016/j.parkrelidis.2017.07.030>
- Davey, C., Wiles, R., Ashburn, A., & Murphy, C. (2004). Falling in Parkinson's disease: The impact on informal caregivers. *Disability and Rehabilitation*, 26, 1360–1366. <https://doi.org/10.1080/09638280400000195>
- de Lau, L. M., & Breteler, M. M. (2006). Epidemiology of Parkinson's disease. *The Lancet Neurology*, 5, 525–535.
- Erga, A. H., Alves, G., Larsen, J. P., Tysnes, O. B., & Pedersen, K. F. (2017). Impulsive and compulsive behaviors in Parkinson's disease: the Norwegian ParkWest study. *Journal of Parkinson's Disease*, 7, 183–191.
- Fernandez, H. H., Tabamo, R. E., David, R. R., & Friedman, J. H. (2001). Predictors of depressive symptoms among spouse caregivers in Parkinson's disease. *Movement Disorders: Official Journal of the Movement Disorder Society*, 16, 1123–1125. <https://doi.org/10.1002/mds.1196>
- Grun, D., Pieri, V., Vaillant, M., & Diederich, N. J. (2016). Contributory factors to caregiver burden in Parkinson disease. *Journal of the American Medical Directors Association*, 17, 626–632. <https://doi.org/10.1016/j.jamda.2016.03.004>
- Hagell, P., Alvariza, A., Westergren, A., & Arestedt, K. (2017). Assessment of burden among family caregivers of people with Parkinson's disease using the Zarit burden interview. *Journal of Pain and Symptom Management*, 53, 272–278. <https://doi.org/10.1016/j.jpainsymman.2016.09.007>
- Jankovic, J. (2008). Parkinson's disease: Clinical features and diagnosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, 79, 368–376. <https://doi.org/10.1136/jnnp.2007.131045>
- Leroi, I., Harbisetar, V., Andrews, M., McDonald, K., Byrne, E. J., & Burns, A. (2012). Carer burden in apathy and impulse control disorders in Parkinson's disease. *International Journal of Geriatric Psychiatry*, 27, 160–166. <https://doi.org/10.1002/gps.2704>
- Macphee, G. J., Chaudhuri, K. R., David, A. S., Worth, P., & Wood, B. (2013). Managing impulse control disorders in Parkinson's disease: Practical guidelines. *British Journals of Hospital Medicine*, 74(3), 160–166.
- Martinez-Martin, P., Arroyo, S., Rojo-Abuin, J. M., Rodriguez-Blazquez, C., Frades, B., & de Pedro Cuesta, J. & Longitudinal Parkinson's Disease Patient Study (Estudio longitudinal de pacientes con enfermedad de Parkinson-ELEP) Group (2008). Burden, perceived health status, and mood among caregivers of Parkinson's disease patients. *Movement Disorders: Official Journal of the Movement Disorder Society*, 23, 1673–1680. <https://doi.org/10.1002/mds.22106>
- Martinez-Martin, P., Benito-Leon, J., Alonso, F., Catalan, M. J., Pondal, M., Zamarbide, I., Tobias, A., & de Pedro, J. (2005). Quality of life of caregivers in Parkinson's disease. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 14, 463–472. <https://doi.org/10.1007/s11136-004-6253-y>
- Martinez-Martin, P., Rodriguez-Blazquez, C., Forjaz, M. J., Frades-Payo, B., Aguera-Ortiz, L., Weintraub, D., Riesco, A., Kurtis, M. M., & Chaudhuri, K. R. (2015). Neuropsychiatric symptoms and caregiver's burden in Parkinson's disease. *Parkinsonism & Related Disorders*, 21, 629–634. <https://doi.org/10.1016/j.parkrelidis.2015.03.024>
- McLaughlin, D., Hasson, F., Kernohan, W. G., Waldron, M., McLaughlin, M., Cochrane, B., & Chambers, H. (2011). Living and coping with Parkinson's disease: Perceptions of informal carers. *Palliative Medicine*, 25, 177–182. <https://doi.org/10.1177/0269216310385604>
- Mosley, P. E., Moodie, R., & Dissanayaka, N. (2017). Caregiver burden in Parkinson disease: A critical review of recent literature. *Journal of Geriatric Psychiatry and Neurology*, 30, 235–252. <https://doi.org/10.1177/0891988717720302>
- NICE (2017). *Parkinson's disease in adults: Diagnosis and management*. National Institute for Health and Care Excellence NICE Guideline NG71.
- O'Sullivan, S. S., Wu, K., Politis, M., Lawrence, A. D., Evans, A. H., Bose, S. K., Djamshidian, A., Lees, A. J., & Piccini, P. (2011). Cue-induced striatal dopamine release in Parkinson's disease-associated impulsive-compulsive behaviours. *Brain*, 134(4), 969–978.
- Pendry, L. F., & Salvatore, J. (2015). Individual and social benefits of on-line discussion forums. *Computers in Human Behaviour*, 50, 211–220. <https://doi.org/10.1016/j.chb.2015.03.067>
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2006). Caregiver-burden in Parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism & Related Disorders*, 12, 35–41. <https://doi.org/10.1016/j.parkrelidis.2005.06.011>
- Tan, M. M. J., Lim, E. C., Nadkarni, N. V., Lye, W. K., Tan, E. K., & Prakash, K. M. (2019). The characteristics of patients associated with high caregiver burden in Parkinson's disease in Singapore. *Frontiers in Neurology*, 10, 561. <https://doi.org/10.3389/fneur.2019.00561>
- Tan, S. B., Williams, A. F., & Morris, M. E. (2012). Experiences of caregivers of people with Parkinson's disease in Singapore: A qualitative analysis. *Journal of Clinical Nursing*, 21, 2235–2246. <https://doi.org/10.1111/j.1365-2702.2012.04146.x>
- Tod, A. M., Kennedy, F., Stocks, A. J., McDonnell, A., Ramaswamy, B., Wood, B., & Whitfield, M. (2016). Good-quality social care for people with Parkinson's disease: A qualitative study. *British Medical Journal Open*, 6, e006813. <https://doi.org/10.1136/bmjopen-2014-006813>
- Torny, F., Videaud, H., Chatainier, P., Tarrade, C., Meissner, W. G., & Couratier, P. (2018). Factors associated with spousal burden in Parkinson's disease. *Revue Neurologique*, 174, 711–715. <https://doi.org/10.1016/j.neuro.2018.01.372>
- Weintraub, D., & Claassen, D. O. (2017). Impulse control and related disorders in Parkinson's disease. *International Review of Neurobiology*, 133, 679–717.
- Weintraub, D., Koester, J., Potenza, M. N., Siderowf, A. D., Stacy, M., Voon, V., Whetteckey, J., Wunderlich, G. R., & Lang, A. E. (2010). Impulse control disorders in Parkinson disease: A cross-sectional study of 3090 patients. *Archives of Neurology*, 67, 589–595. <https://doi.org/10.1001/archneur.2010.65>
- Yuksel, B., Ak, P. D., Sen, A., Sariahmetoglu, H., Uslu, S. C., & Atakli, D. (2018). Caregiver burden and quality of life in early stages of idiopathic Parkinson's disease. *Idegyogyaszati Szemle*, 71, 343–350.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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