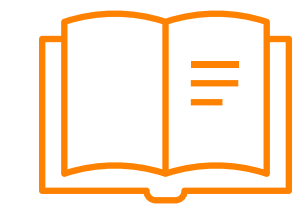


# "It's a lonely journey really": Carers' experiences of providing support to people with Parkinson's and cognitive impairment: a qualitative interview study

Greenwell, K.<sup>1\*</sup>, Slodkowska-Barabasz, J.<sup>1</sup>, McCarthy, A.<sup>2</sup>, Turton, S.<sup>3</sup>, Sultana, A.<sup>4</sup>, Hand, A.<sup>2,5</sup>

1. Primary Care Research Centre, University of Southampton, Southampton, UK; 2. Faculty of Health and Wellbeing, Northumbria University, UK; 3. Public contributor, UK; 4. School of Psychology, University of Southampton, Southampton, UK; 5. Newcastle Hospitals NHS Foundation Trust, UK; \* Presenting author; Email: K.Greenwell@soton.ac.uk



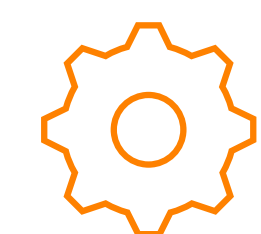
## Background

- Cognitive impairment (CI) is a well-recognised complication of Parkinson's, associated with significant clinical impact and increased carer distress<sup>1</sup>.
- Carers provide a vital role in helping maintain quality of life in people with Parkinson's and cognitive impairment (PwP-CI).
- However, a lack of adequate carer support can lead to carer breakdown and avoidable health and social care costs<sup>2</sup>.
- The iSupport-PD programme aimed to adapt a globally available digital cognitive behavioural intervention for dementia carers (iSupport)<sup>3</sup> to meet the needs of carers of PwP-CI (SPARC).



## Study Aim

- To explore the challenges faced by carers of PwP-CI to inform the intervention adaptation and understand how to better support this under-researched group.



## Methods

- Thirty-three semi-structured and think-aloud interviews were conducted with 31 carers of PwP-CI living in the UK as part of an intervention development study (See P13.07).
- Carers were recruited through charities, support groups, social media, and via the networks of our Patient and Public Involvement group.
- Purposive sampling was used to recruit diverse carers.
- Interviews were recorded, transcribed and analysed using inductive reflexive thematic analysis<sup>4</sup>.

## Results: Themes and Carer Quotes

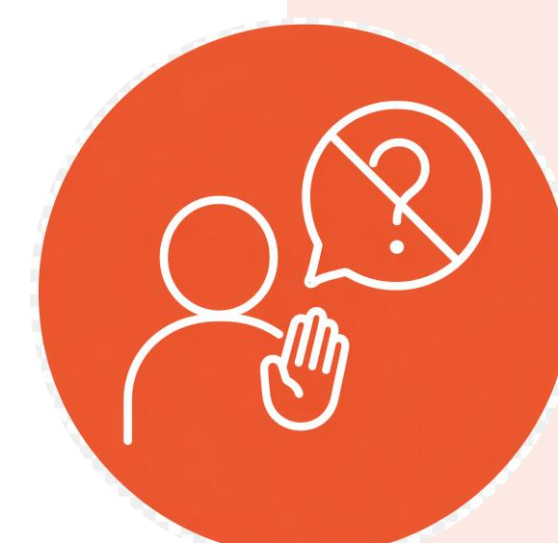


### Dealing with the fluctuating and complex nature of cognitive impairment

- Carers shared how the complex, gradual, and fluctuating nature of CI often led to a lengthy and frustrating diagnosis process for the PwP-CI.
- CI symptoms were confusing and difficult to understand.
- Health professionals sometimes missed cognitive symptoms and dismissed their concerns.
- This process was made even more challenging when the PwP covered up their symptoms or refused to discuss them with health professionals.

“As a carer, you know that things have changed, and they [PwP] can't [...] I've tried raise this with neurologists and Parkinson's nurse [...] [the PwP] will be in denial. Then, when we've come out [the appointment], she's been very upset and angry with me for even raising it. And so, it never really gets dealt with.”

“[My husband] was assessed and passed with almost full marks [...] but what frustrated me and my daughter [...] is that we obviously had a reason for referring him because he was showing difficulty with processing things. [...] But anyway, that was all kind of, 'No, no, he's passed his test. He's all right.'”



### Taking on the cognitive and emotional load alone

- Carers experienced feelings of exhaustion and anxiety and were often overwhelmed in the face of unpredictable and challenging behaviours (e.g. aggression, changes in judgement) and in response to taking on more of the 'cognitive load' from the PwP-CI.
- Carers were often reluctant to ask for help from others, due to feelings of pride or duty, or worries about asking 'too much' or being a 'burden'.

“The tiredness is there [...] because of the decision-making. I feel my story is not so much the physical stuff. I have to do everything with regard to bills, organising repairs, sorting the insurance out. All of that stuff is on me now.”

“You feel you shouldn't complain about your partner, especially to friends who are friends of both of us [...] [to avoid] feeling that you're kind of letting your partner down [...] sharing your worries about him [...] just with family kind of puts the burden on family as well, because then they start worrying about you, as well as the PwP.”



### Dealing with the feelings of loss

- Changes to the PwP-CI's personality and mood, evolving relationship dynamics, and restrictions to their social life left carers with a sense of loss that exacerbated feelings of loneliness.
- Participants talked about the PwP's emotional unavailability, "self-centred[ness]", and lack of empathy, affection, or interest in family life.
- The lack of emotional connection with the PwP-CI was equated to a loss of a partnership, both for romantic partners and in a child-parent relationship.

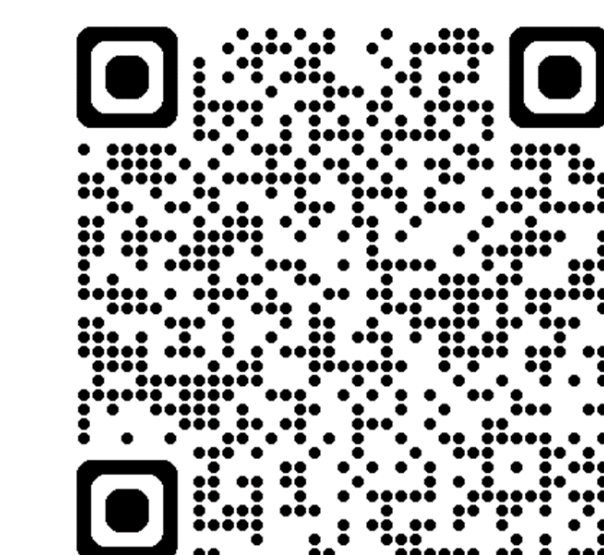
“I can't have an emotional breakdown because he can't hold me up anymore and if I get worried about something [...] I didn't tell him because it would upset him too much [...] You lose your best friend and you lose your confidence and you lose your support system and friends don't really get it, and family certainly don't.”

“In the past, dad was the one looking after me [...] it's a bit difficult for him to get used to the idea that I'm looking after him rather than the other way around [...] we're not as emotionally connected as we used to be because I feel like I'm this authority figure who tells him to eat more and all of this kind of thing.”



## Discussion

- Support interventions should be tailored to the unique needs of carers of PwP-CI, supporting them to navigate complex and fluctuating symptoms, overcome barriers to seeking professional and social support, maintain a quality relationship with the PwP-CI, and develop coping strategies to minimise the impact of the caring role on their own physical and mental health.



For further information about iSupport-PD and SPARC, please use the QR code