

Adaptation of iSupport, a digital intervention for care partners of people with Parkinson's and cognitive impairment using the Person-Based Approach

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Background to the iSupport-PD project

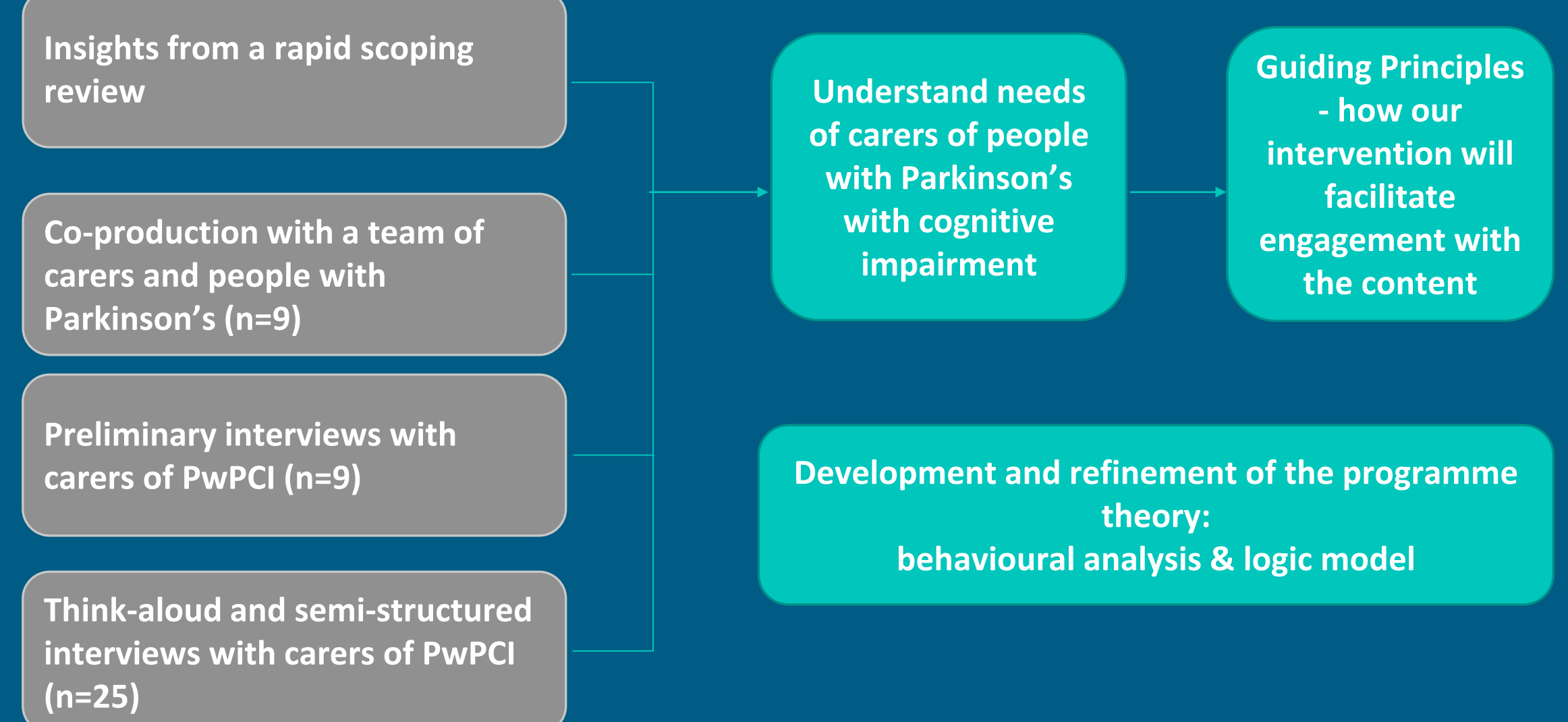
- Parkinson's is the second most common neurodegenerative condition in the UK.
- Cognitive impairment (CI) is a well-recognised complication of Parkinson's with significant clinical impact.
- Most care needs of people with Parkinson's with CI (PwPCI) are met by informal (unpaid) care partners.
- This role is often associated with reduced quality of life, and impaired physical and mental well-being.
- There is growing recognition of carers at policy level, but programmes that support training, or counselling are often insufficient or difficult to access.

Study Aim

- To adapt The World Health Organization (WHO) digital intervention for dementia carers (iSupport) to meet the specific needs of care partners of people with PwPCI (iSupport-PD).
- To assess the feasibility and acceptability of iSupport-PD.

Methodology

- The person-based approach to intervention development, which combines stakeholder and Patient and Public Involvement (PPI) co-production with in-depth qualitative research, was adopted to understand and accommodate the perspectives of care partners of PwP with cognitive impairment to ensure their needs are met.
- PPI group was recruited and led by PPI and consisted of 6 diverse care partners of people with Parkinson's and 1 person with Parkinson's.
- Further details of the methods is provided in the diagram (right)



Phase 1: Initial feedback and modifications

- Generally, care partners felt topics of the original iSupport were relevant.
- They valued its focus on their own needs, not just on how to better manage symptoms.
- New content was developed to address the complexities of cognitive impairment in Parkinson's (e.g., causes, interacting symptoms).
- Aspects of iSupport were deemed patronising and were swapped for more empathetic design features (e.g., stories).
- Terminology changed to promote inclusivity, recognising 'partnership', and avoided suggesting that the person with Parkinson's was 'impaired'.

Example Guiding Principles

User context	Key design objective	Intervention feature
Stigma associated with the condition	To empower care partners to talk about and seek help with symptoms	Education about CI, Stories and information normalising talking, practical advice on how to ask for help
Different types of carers & CI is individual, different symptoms, severity	To engage a diverse group of care partners	Core and optional modules Stories, inclusive terminology (Care partners)
Focusing on care partners rather than the condition	To improve carers' confidence regarding non-medical aspect of their role	Minimise medical content Information to support care partners well-being

Phase 2: Think Aloud Interview Methods

- 25 think-aloud interviews were conducted with care partners to gain feedback on the intervention.
- Participants (16 females, 6 males) mostly spouses (but 3 daughters, 1 son) were White British.
- Good range of ages (30-78 yrs.) and length of providing care (1.5-23 yrs.).
- Participants viewed the website while on a video call and asked to say out loud any thoughts they had as they worked through it.
- We tabulated feedback using the Table of Changes.
- We made modifications in line with our Guiding Principles, and prioritised them based on the MoSCoW criteria (must have, should have, could have, would have).

Phase 2: Findings

- Participants generally liked the website content, they found it relevant, helpful and easy to understand.
- Participants valued the stories and advice from other care partners.
- They liked that the intervention focused on them, that we provide information on how to deal with symptoms of cognitive impairment, and the non-medical aspects of caring (e.g. communication, involving others).

Everybody thinks [the problem is Parkinson's] it's this physical, shaky issue when it isn't. It is actually, I think I said that at the start, it's the memory and the mental health issues that I'm finding the hardest to manage. So, the fact that it's recognised straightaway it's great!

Oh, my gosh, it sounds like me. [laughs] Yes, I like that quote from Fatima. That's... I like that very much. Yeah, I agree with that.

Phase 2: Findings

- We received mixed feedback regarding module on thinking and memory changes in Parkinson's. Very helpful vs. not relevant at the moment. → Made this module optional but included signposting on the homepage.
- Some participants said that they would like to have some explicit advice on how to deal with some issues (e.g., slowness in thinking, problems with making decisions). → Provided practical tips on how to deal with symptoms of memory and thinking changes in Parkinson's.
- Certain content about planning for the future care was described as useful but overwhelming by some participants. → Divided this information into two parts: planning for early and late care. Information provided in accordions.

Conclusion

- This project provides an example of how the Person-Based Approach to intervention development can be applied to the adaptation of established interventions.
- Guiding Principles highlight some of the important behavioural challenges, support needs and design features to consider when developing interventions for this population.

Next steps

A 12-month feasibility randomised controlled trial with 100 care partners commenced in July 2024 to assess the feasibility and intervention acceptability.

