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## Using the theoretical domains framework to determine the barriers and facilitators to medication adherence in Parkinson's disease

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#### ABSTRACT

Background: Patient medication adherence in Parkinson's Disease (PD) is often suboptimal. This may lead to poor symptom management, greater disease burden, decreased quality of life and increased healthcare costs. Use of psychological theory such as the Theoretical Domains Framework (TDF) has effectively captured barriers and facilitators to medication adherence in other long-term conditions. Applying this framework to medication adherence in PD could provide a better understanding of the challenges to inform the development of effective interventions.

*Objectives*: The aim of the study was to apply the TDF to determine the barriers and facilitators to medication adherence in people with PD.

Methodology: This qualitative study employed online interviews to explore medication adherence in a small group of people with PD recruited via Parkinson's UK and social media. A semi-structured interview schedule was designed informed by the 14 TDF domains. All interviews were audio-recorded, transcribed verbatim and mapped to the TDF using Framework Analysis.

Results: Twelve participants diagnosed with PD were interviewed, 11 of whom were currently taking prescribed medication plus another self-medicating with Vitamin B1. All TDF domains were evident in the data. Predominant facilitators were Domains 1 - Knowledge, 6 - Social Influence, and 12 - Beliefs about Consequences and barriers were 7 - Reinforcement, 10 - Memory, Attention and Decision Processes, and 11 - Environmental Context and Resources. Other themes were not related to medication adherence.

*Conclusion:* In this small group, all data relating to the barriers and facilitators for medication adherence in PD were successfully mapped onto the TDF. This indicates the utility of the framework for determining and structuring the factors to consider when providing medication support for this patient population in an accessible and coherent way. Further quantitative studies are needed to determine the extent to which these factors can be generalised to other PD patients.

#### 1. Introduction

Parkinson's disease (PD) is the second most common progressive neurodegenerative disease in the UK after Alzheimer's. PD is characterised by motor symptoms such as resting tremors, muscle rigidity, bradykinesia, and postural instability, and features non-motor symptoms such as cognitive impairment, sleep disorders, delirium, psychosis, apathy, anxiety, pain, fatigue and depression. The health and social care need of this population are high and can lead to complex medication regimens.

In the absence of disease modifying drugs, symptomatic treatments are largely focused on dopamine replacement to reduce the motor symptoms. <sup>5,6</sup> These are not without complications and common side effects which include acute nausea, hallucinations and impulse control disorders which cause further disease burden. Long term use of the dopamine precursor L-dopa is a necessity for symptom management for most patients, but with disease progression patients can also experience further complications with L-dopa therapy. This therapy can lead to unpredictable fluctuations in symptoms, whereby periods of good motor function and cognitive ability ("on") are broken by periods in which the

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medication ceases to alleviate symptoms ("off").<sup>7</sup> 'On' periods are also associated with abnormal involuntary movements known as L-dopa induced dyskinesia. Additional pharmacotherapy including peripheral catechol-o-methyl transferase (COMT) inhibitors and monoamine oxidase type B (MAOB) inhibitors can be used to enhance and prolong the actions of L-dopa.

The complex medication regimens associated with the management of PD can be perceived to dominate patients' lives; as symptoms can worsen before the next dose, medication regimens need to be followed accurately otherwise, patients may experience prolonged off periods and potential side effects of medication.<sup>8</sup> The complex treatment regimens, non-motor symptoms and comorbid conditions make self-management and medication adherence a challenge for people living with PD.<sup>9</sup> Adherence rates within the population are remarkably low and studies place only 10–20% of patients as being fully adherent to their prescribed medication schedule.<sup>10,11</sup> Suboptimal adherence to medicines leads to poor PD symptom control, greater disease burden and consequently reduced quality of life.<sup>12,13</sup>

Medication non-adherence can be categorised as either intentional or unintentional. 14 Intentional non-adherence is linked to motivation and patients' beliefs about the necessity of taking their prescribed medication (to maintain present health), and their concerns about taking it (potential for negative effects in the future). 15,16 Unintentional nonadherence is associated with patients' skills and physical abilities to act out the behaviour of medication taking. 15 According to the Necessity-Concerns Framework (NCF), an individual's beliefs about a specific medication can be broken down into the necessity of taking their prescribed medication and concerns about taking it. 14,15 Researchers have demonstrated that sociodemographic and clinical factors were only able to explain a small amount of the variance in medication nonadherence in asthma patients, whereas illness perceptions and patient beliefs contributed to significant proportions of the variance in nonadherence. 16 Similarly, negative beliefs about PD treatments have found to be associated with non-adherence and related to poorer quality of life (QoL) in this population.<sup>17</sup> Unsurprisingly, higher necessity beliefs about medication for PD have been found to be associated with greater disease severity, higher depression scores and motor fluctuations.

The Theoretical Domains Framework (TDF) is a framework that can be used as a lens to explore medication adherence behaviour and allows for a comprehensive insight of key influences on the targeted behaviour, which are cognitive, affective, social, and environmental in nature. <sup>19,20</sup> The TDF encompasses 33 theories of behaviour and behaviour change, compacted into 14 domains which has been shown to be related to medication-taking behaviour. <sup>20</sup> Used to identify what influences the targeted behaviour, in this instance, medication adherence, the TDF aims to inform the design of effective interventions to bring about change in that behaviour. <sup>19</sup> The broad scope of the TDF makes it a useful tool to identify the barriers and facilitators of medication adherence in lifelong conditions and has been used in areas such as type II diabetes mellitus. <sup>4</sup> The aim of the current study is to examine the barriers and facilitators to medication adherence in patients diagnosed with PD through the lens of the TDF.

#### 2. Methods

This qualitative study used one-to-one semi-structured interviews (JS, male, postgraduate student with experience of conducting qualitative interviews), to explore perceptions of the barriers and facilitators to medication adherence in people diagnosed with PD. The COREQ checklist<sup>21</sup> was used to ensure transparency of reporting in this manuscript.

#### 2.1. Participant recruitment and setting

Convenience sampling was used to recruit adults with a pre-existing diagnosis of PD. The eligibility criteria stated that participants must be

over the age of 18 years, live in the United Kingdom (UK) and be prescribed at least one oral medication for managing symptoms of PD. The initial theme and recruitment for the study was driven by individual experience and a personal contact of JS. The participant pool was drawn from across the UK with a recruitment advert placed on the UK Parkinson's Disease Charity webpage (www.parkinsons.org.uk) and two social media (Facebook<sup>TM</sup>) support groups for early onset Parkinson's and Parkinson's football. The advert informed participants about the topic area, and that the study was for a MSc project. No participants dropped out of the study.

#### 2.2. Ethics

Ethical approval was provided by Cardiff Metropolitan University's ethics committee [Reference number PGT-4197].

#### 2.3. Data collection

The design of the interview schedule was informed by the 14 domains of the TDF<sup>19</sup> and developed by the research group (JS, DHJ, CHS) with input from one individual who had experienced PD for 12-years. The interview schedule contained open-ended questions to explore the barriers and facilitators to medication adherence adapted for each domain of the TDF [Appendix A]. One pilot interview was conducted with a PD patient known to the researcher to make sure that the questions were easily understandable and followed a logical order. This was not included in the analysis. Questions were reworded to provide further clarity for Domains 3, 4, 5, 8, 9, 11, 13 and 14. All interviews were all conducted by the researcher (JS) using Microsoft Teams and audio recorded. All interviews were transcribed verbatim for subsequent analysis and any personal identifying information removed. Two participants had their partner/spouse involved during the interview, to provide their perspectives and this data was incorporated into the analysis. JS wrote notes after each interview to reflect on their performance, in order to better improve interviewing skills. There was no intension to meet data saturation, but to test out the TDF on this population, as this had not been done before. Participants were given an opportunity to contact the researcher after their interviews, if they wished to withdraw their data or receive a copy of the findings. However, no participant asked for a copy, so no feedback was provided.

#### 2.4. Data analysis

Transcripts were analysed (JS) using framework analysis<sup>22</sup> where the TDF was used as the underpinning theoretical framework.<sup>19</sup> This approach codes transcripts line by line as applied to the framework's indexing headlines (for example Belief about Consequences). The plan of analysis was to examine any remaining data that were incongruous to the TFD framework for further thematic analysis.<sup>23</sup> Secondary coding was completed by the wider research team (JS, DHJ, CHS), and any discrepancies were discussed and resolved by consensus to reach the final themes.<sup>24</sup>

#### 3. Results

#### 3.1. Participant characteristics

Twelve interviews were conducted and lasted between 25 and 50 min. All participants were White Caucasian ethnicity, six participants were female and six were male with an age range from 47 to 75 years (mean = 63; SD = 9.48). Participants lived in various geographical locations in the North, Mid and South of England (n = 9) and South Wales (n = 3), and were at various stages of disease progression, as shown via years being diagnosed with PD ranging from 3 to 21 years (mean = 8.17 and SD = 6.07). One participant (P 3) chose not to be prescribed medication, preferring to self-manage using vitamin B1 (Thiamine)

injections for their PD. Table 1 summarises participants' demographic and clinical characteristics.

#### 3.2. Medication adherence

All participants stated that they were nonadherent at least once since being prescribed medication. Participant 4 was suggested to be the most adherent to their prescribed medication regimen due to only forgetting to take medication on one occasion. Eleven participants indicated that they were unintentionally nonadherent. Seven participants indicated intentional nonadherence. This was uncovered by questions informed by the TDF [refer to Appendix 1], e.g., do you ever decide to take your medication outside of when you are supposed to take them?

#### 3.3. Mapping to TDF and key themes

Framework/analysis generated two overarching themes:

- 1) TDF domains that facilitated medication adherence.
- 2) TDF domains that acted as barriers to medication adherence.

Data for facilitators and barriers to medication adherence were mapped onto all fourteen domains of the TDF [refer to Appendix 2]. No other emergent themes relating to medication adherence were identified outside of the TDF.

Table 2 presents the facilitators and barriers to medication adherence in order of domain prominence. The three most prominent domains were Domain 1 – *Knowledge*, Domain 12 - *Social Influence* and Domain 6 – *Beliefs about Consequences* where reasons Data generated from all twelve participants were mapped to these three domains. In terms of barriers to adherence, one domain was featured in all participant responses, which was Domain 10 - *Memory, Attention and Decision Processes*. The other two most prominent domains were reported by nine participants which were Domain 11 – *Environmental Context and Resources* and Domain 7 – *Reinforcement.* One other domain which featured highly across both areas was Domain 4 – *Beliefs about Capabilities*. These seven key TDF domains which are of high relevance to this population group will be described in more detail below, whilst further elaboration of the other seven domains are presented in Appendix 2. Other themes captured from the data were not related to medication adherence.

**Table 2**Mapping to TDF Domains in Order of Prominence.

| TDF Domain Facilitating Medication    | TDF Domain Acting as Barriers to         |  |  |
|---------------------------------------|--|--|--|
| Adherence                             | Medication Adherence                     |  |  |
| TDF Domain 1 -                        | TDF Domain 10 -                          |  |  |
| Knowledge                             | Memory, Attention and Decision Processes |  |  |
| TDF Domain 12 –                       | TDF Domain 11 –                          |  |  |
| Social Influence                      | Environmental Context and Resources      |  |  |
| TDF Domain 6 –                        | TDF Domain 7 –                           |  |  |
| Beliefs about Consequences            | Reinforcement                            |  |  |
| TDF Domain 10 –                       | TDF Domain 13 –                          |  |  |
| Memory, Attention, and Decision       | Emotion                                  |  |  |
| Processes                             |  |  |  |
| TDF Domain 7 –                        | TDF Domain 12-                           |  |  |
| Reinforcement                         | Social Influence                         |  |  |
| TDF Domain 4 –                        | TDF Domain 4 -                           |  |  |
| Beliefs about Capabilities            | Beliefs about Capabilities               |  |  |
| TDF Domain 11 –                       | TDF Domain 8 -                           |  |  |
| Environmental Context and Resources   | Intentions                               |  |  |
| TDF Domain 8 –                        | TDF Domain 6 -                           |  |  |
| Intentions                            | Beliefs about Consequences               |  |  |
| TDF Domain 2 –                        | TDF Domain 14 -                          |  |  |
| Skills                                | Behavioural Regulation                   |  |  |
| TDF Domain 9 –                        | TDF Domain 1 -                           |  |  |
| Goals                                 | Knowledge                                |  |  |
| TDF Domain 13 –                       | TDF Domain 2 -                           |  |  |
| Emotion                               | Skills                                   |  |  |
| TDF Domain 5 –                        | TDF Domain 5 -                           |  |  |
| Optimism                              | Optimism                                 |  |  |
| TDF Domain 14 –                       | TDF Domain 9 –                           |  |  |
| Behavioural Regulation                | Goals                                    |  |  |
| TDF Domain 3-                         | TDF Domain 3 –                           |  |  |
| Social/Professional Role and Identity | Social/Professional Role and Identity    |  |  |
|                                       |  |  |  |

### 3.4. Facilitators and barriers to medication adherence mapped to the TDF domains

#### 3.4.1. TDF domain 1 - Knowledge

Knowledge was the most dominant facilitator reported by all participants when mapping the facilitators of medication adherence data to the TDF. This theme suggested that medication should be taken regimentally, specific to medication regimen. Also, knowledge of medication type and potential side effects. Illustrated by the following:

"You're supposed to take it absolutely bang on time and it's supposed to work a lot better" (P1).

Knowledge was far less prominent when mapping the barriers to

Table 1 Participant Characteristics (n = 12).

| Participant Identifier<br>Code | Age<br>(Years) | Sex | Time Since Diagnosis<br>(Years) | Medication/s - Generic Name                  | Medication/s –Trade Name  | Area of UK                  |
|--------------------------------|----------------|-----|---------------------------------|--|---|-----------------------------|
| P 1                            | 57             | F   | 10                              | Carbidopa-Levodopa                           | Sinemet <sup>TM</sup>   | Lancashire, England         |
| P 2                            | 57             | F   | 13                              | Carbidopa-Levodopa                           | $Sinemet^{TM}$  | Tyne and Wear, England      |
| P 3                            | 65             | M   | 3                               | Vitamin B1                                   | Thiamine™   | Glamorgan, Wales            |
| P 4                            | 47             | M   | 3                               | Levodopa Ropinirole                          | Sinemet™<br>Requip™   | Glamorgan, Wales            |
| P 5                            | 49             | М   | 4                               | Ropinirole Carbidopa-<br>Levodopa<br>Azilect | Requip <sup>™</sup><br>Sinemet <sup>™</sup> Rasagiline <sup>™</sup> | Glamorgan, Wales            |
| P 6                            | 64             | M   | 12                              | Levodopa Ropinirole                          | Sinemet™<br>Requip™   | Nottinghamshire,<br>England |
| P 7                            | 68             | F   | 3                               | Co-beneldopa Opicapone                       | Madopar <sup>TM</sup> Ongentys <sup>TM</sup>                        | Manchester, England         |
| P 8                            | 74             | F   | 8                               | Co-beneldopa<br>Azilect                      | Madopar™ Rasagiline™  | Yorkshire, England          |
| P 9                            | 75             | M   | 21                              | Carbidopa-Levodopa                           | Sinemet <sup>TM</sup>   | Suffolk,<br>England         |
| P 10                           | 59             | F   | 2                               | Ropinirole                                   | $Requip^{TM}$   | Staffordshire,<br>England   |
| P 11                           | 66             | M   | 4                               | Carbidopa-Levodopa<br>Azilect<br>Ropinirole  | Sinemet $^{TM}$ Rasagiline $^{TM}$<br>Requip $^{TM}$                | East Sussex,<br>England     |
| P 12                           | 75             | F   | 15                              | Carbidopa-Levodopa<br>Entacapone             | $Stalevo^{TM}$<br>$Sinemet^{TM}$                                    | Greater London, England     |

medication adherence. Some showed a lack of knowledge of specific types of medication and knew that they should be following regimen but chose not to.

"Sinemet is ...umm... is uhm (.) I'm unclear about" (P11).

#### 3.4.2. TDF domain 12 - Social influence

Social influence was seen as a facilitator for all participants' here many examples of positive social influences on adherence were reported. The role of PD nurses was important in helping to inform appropriate medication-taking behaviour and helping to prevent or stopping inappropriate self-medicating behaviours. Partners and family members were also referred to as providing valuable input in helping to check or track medication taking. The use of alarms by family members, to prompt adherence was mentioned. Along with the presence of motor symptoms serving as a prompt for them to encourage medication taking.

"Me [sic] daughter knows that but if she is, if she does come up, if me husband is in work and I need help, she ...she [is] knows exactly what I would need to take" (P2).

Some of the positive aspects reported by participants relating to this domain were the good therapeutic relationships formed with their PD nurse and access to information. This in turn could have provided the social support needed to facilitate medication adherence.

"Uhh but but the Parkinson's nurse is well everything" (P12).

"I deal directly with my Parkinson's nurse, so I don't feel like I don't need to go to the doctors" (P5).

Social influence was seen as a barrier for many, and this was related to a lack of social support to aid medication adherence. Hiding medication taking from family/friends made medication taking harder, and social situations could distract them from taking medication.

"...other times it's just kind of having a drink or trying to do it subtlety I guess because you don't want to have a conversation maybe" (P4).

Lack of access to healthcare support is also related to this domain since is can also influence medication adherence. Some of the challenges reported by participants related to the lack of provision of therapies for their PD, delayed access to PD information, healthcare services and barriers to accessing medication.

#### 3.4.3. TDF domain 6 - Beliefs about consequences

The beliefs about consequences domain that facilitated medication adherence was prevalent across all participant responses. Participants understood that poor medication adherence/abstinence resulted in the onset of motor symptoms (off periods), side effects, and reduced quality of life. Participants believed that they needed medication for symptom control, increased functioning, and wellbeing.

"...if I don't have Sinemet I can't function so therefore it's quite important to me" (P5).

"I'll go into an 'off' period" (P8).

The beliefs about consequences domain was identified as a barrier for some. For example, a lack of trust was show in "generic" medication was reported. Medication was taken outside of prescribed regimen due to experimentation with dosage timings. They considered missing medication to not matter, often for misplaced reasons.

"Umm and it's it is sometimes (.) it concerns me that they depend on it [antiparkinsonian medication] so much that then they need it all the time... if I can hold that off for as long as I possibly can [antiparkinsonian medication] I'll have more benefit in the future" (P3).

"...it was my decision to to...to change it because I'd be on it for so long and I didn't know what the benefits of it were (.) and I wanted to see that if I withdrew from it if I was any worse or any better" (P5).

"I suppose I think I'm seventy-four you know I think it doesn't really matter if I miss a dose" (P8).

#### 3.4.4. TDF domain 10 - Memory, attention, and decision processes

This domain was reported as a facilitator for most participants, however it was also a barrier reported by all twelve individuals. Participants described deliberately taking medication outside of their prescribed regimen due to perceived benefits, e.g., improved control over motor/non-motor symptoms, increased ability to function for daily activities/tasks. Some relied on memory alone, which caused them to forget to take medication at the correct time, and not taking medication immediately after an alarm could result in them to forgetting. They forgot to plan and bring extra medication with them when out of the house, which could cause a delay in medication adherence. Finally, daily tasks/activities could distract and cause medication nonadherence.

"Because if I'm doing something outside or I'm reading I forget or I'm not hearing the important alarm on my phone" (P9).

Related facilitators were evident when participants considered and planned medication taking around daily activities and ensured that they have extra medication, so doses were not missed. Additionally, medication was organised ready for the day or the next, with alarms and apps used to prompt medication taking, to improve the accuracy of their adherence.

"I've got a reminder on me ...on me phone as well for the times you know I've got an alarm that reminds us" (P2).

#### 3.4.5. TDF domain 11 - Environmental context and resources

'Environmental context and resources' were the second most commonly reported domain mapped to barriers to adherence. For example, medication packaging was viewed as challenging to access, especially when motor symptoms were present. Environmental influences outside of their control could also hinder medication taking.

"It's tightly sealed in some form of foil rap stuff and there isn't a hope in hell you're gonna get that out of the box if you've got dicey hands" (P1).

The negative influence of the COVID-19 pandemic on medication-taking was captured in this domain. There was reduced contact with the healthcare system and therapies, which may have contributed to medication non-adherence and disease management challenges. Taking medication was not considered safe in public without hand sanitiser, which could delay medication adherence. An inability to order medication online made restocking medication harder; this was exacerbated if they are provided a small medication supply. Physical impairments could act as a physical barrier to medication taking. Prescribed timers made to aid medication taking were suggested to be too complicated to operate.

Aspects of 'Environmental context and resources' were also described as facilitators, for example, carrying liquid outside of the home was indicated to aid the physical act of taking medication. Blister packs tailored towards their medication regimen helped organise and track medication. Repeat prescription and ordering online meant that restocking medication was more consistent and easier. Those in the earlier disease stages found their medication regimens easier to follow due to reduced complexity.

"They'll see the doctor will order... orders it to the pharmacist to put to split your tablets up into days you get them in a pile of blister pack" (P7). "Yes, it is helpful cause then you know what you've missed (laughs)." (P7).

The influence of the COVID-19 pandemic on medication-taking was also captured in this domain where working from home was reported to have had a positive impact on medication adherence.

#### 3.4.6. TDF domain 7 - Reinforcement

Reinforcement was identified as a barrier for many participants and was the joint second most prominent domain relating to barriers to medication adherence. Deviating from prescribed regimen was suggested to benefit PD related symptoms, which reinforced nonadherence. For those in earlier disease stages, missing a dose of medication was not noticed due to no noticeable onset of symptoms. Whilst those in later disease stages experiences 'off' periods even when fully adherent to medication regimen, suggesting that accurate medication adherence behaviour was not being reinforced.

"I didn't really see a uhh (.) physical or... or mental kind of difference as a result of missing it" (P4).

This domain was mapped as a facilitator for many participants. These

participants indicated that the onset of nonmotor and/or motor symptoms suggested that the dosage time was approaching, or that they had forgotten to take medication. The onset of these symptoms provided a cue to take medication. Participants also fitted their routine around their regimen, and took medication in the same place, so that their adherence was facilitated through reinforced cues. The onset of motor symptoms due to medication dosage time approaching appeared to be related to those in the later disease stages of PD, due to symptoms becoming more prominent and noticeable.

"...your body just knows when the medication is wearing off and you just know they're due" (P2).

"I think as my symptoms are getting slightly worse (.) I know when I need to take a tablet" (P5).

#### 3.4.7. TDF domain 4 - Beliefs about capabilities

For those participants who reported *Beliefs about Capabilities* relating to facilitators they mentioned a high confidence in their ability to follow their medication regimen and did not consider the act of medication taking to require much effort. They also understood their body's physical capabilities when medicated and when unmedicated.

"I stick to it rigidly so I'm very confident yeah" (P2).

This domain was also reported as a barrier where participants found medication taking difficult, and the presence of motor symptoms made the physical act of medication taking challenging. Additionally, trying to stay optimally medicated was suggested to be difficult. Participant P3 found following B1 treatment easy due to low frequency, compared to antiparkinsonian medication.

"first of all you've got to get it out of the packet then you've got to try and hold them in your hands stupid little tablets that fall out of your hands (.) you know (.) it it is mad and then if you're on a bus because I use the bus to go places then you go on the bus and think oh I must take my tablets (.) and that's you know (.) there's challenges" (P1).

#### 4. Discussion

The aim of the current study was to use the TDF to explore the barriers and facilitators of medication adherence in people diagnosed with PD. Previous studies have explored the factors influencing medication use in PD patients, but to our knowledge this is the first time that the TDF has been applied in this way. This methodological approach has enabled structured identification of the key determinants of adherence in this debilitating and challenging disease with complex medication needs. Overall use of the TDF was effective in both eliciting information from participants about their medication use as well as analysing the data generated which were successfully mapped to all 14 TDF domains.

The three most prominent facilitators for medication adherence were Knowledge, Beliefs about Consequences and Social Influence, where data from all participants mapped onto the domains. The most prominent barrier for medication adherence were Memory, Attention and Decision-Making since data from all participants mapped onto this domain Reinforcement and Environmental Context and Resources were also the key domains capturing barriers to medication adherence in this population group.

Using an alarm system was thought by participants to be one of the most important factors to aid and prompt medication adherence. This is evident due to the presence of alarm systems across three facilitator domains: 8) Intentions, 10) Memory, Attention and Decision Processes and 14) Behavioural Regulation. 6 found that adherence strategies for people with PD commonly involved alarms, smartphone apps and pill boxes whilst 13 identified embedding in daily routines, blister packs, explanation of drug side-effects and simplified drug regimens were also enablers of medication adherence. Furthermore, fitting medication regimens around routines and taking medication in the same place helped reinforce medication taking (Reinforcement). Blister packs were suggested to not only be useful for organising and tracking medications but were also practical aids for taking medication, especially where motor symptoms

were present. Disease stage impacted on adherence in that those in the earlier disease stages found medication taking easier due to reduced complexity of medication regimen, but conversely did not have the reinforcement of symptom re-emergence following a missed dose.

All participants suggested at least one instance of unintentional nonadherence. Relying on memory alone, not taking medication immediately after an alarm and forgetting to bring extra medication when out of the house resulted in unintentional nonadherence. In the context of Parkinson's disease cognitive impairment is often an inherent part of the disease and many present with mild cognitive impairment at diagnosis. <sup>25</sup> This is likely to be a contributing factor to the unintentional nonadherence. Organisation was suggested to be a crucial part of medication adherence in PD. Much of the data mapped to the 10) Memory, Attention, and Decision Processes domain supported this. Participants indicated the importance of planning daily activities around medication regimen and thinking ahead to make sure they had extra medication if they were not back home on time. A systematic review identified and mapped psychological determinants of medication adherence in stroke survivors via the TDF. 26 The researchers found patient planning and organisational skills to have a significant influence on medication adherence.

However, deliberate nonadherence is also linked to planning and conscious decision making due to the perceived benefits of nonadherence. Perceiving that dopamine is a finite resource, some describe managing it accordingly through the day, optimising intake against periods of high demand (e.g., exercise) to mitigate for anticipated 'off' periods, rather than adhering to a schedule. Leventhal's self-regulatory model (SRM) can be used to explain this behaviour. According to the SRM the individual is considered an active problem solver with coping behaviour (e.g., intentional nonadherence) which represents a common-sense response derived from their cognitive and emotional interpretation of experiences (e.g., going into an extended off period due to physical exercise). 16 The behaviour (taking medication before exercise) is reliant on an assessment on whether it has been successful (e.g., not experiencing an extended off period). The SRM suggests that concrete symptom experiences such as these formulate the individual's representations, which guide the judgement of the effectiveness of coping behaviours. Additionally, perceptions of the disease determine coping behaviour, as well as subsequent judgement and the conceptualisation of the disease. 16 Disease perceptions are structured around five factors: identity (symptoms), cause (attribution), timeline (belief around the duration of the disease), consequences, and controllability/curability.<sup>28</sup> This theory illustrates how some participants may have develop their coping behaviours (e.g., intentionally taking medication before exercise) from disease representations and cognitive and emotional interpretational experiences, in order to suit their lifestyle, which in turn influences medication adherence/nonadherence.

Participant beliefs also acted as a barrier to medication adherence, and this was captured in the 6) Beliefs about Consequences domain. Participants expressed a lack of trust in taking "generic" medication; that it was fine to experiment with medication and did not consider missing medication to matter. Applying the necessity concerns framework (NCF), these participants seemed to have lower necessity to take medication as prescribed due to a lack of concerns about the possible adverse effects of medication nonadherence, with no perceived consequences on their disease. 14 In addition, this domain also captured individuals' beliefs about medication nonadherence causing the onset of motor symptoms (off periods) and side effects. Medication was believed to be crucial for symptom control, increased wellbeing, and physical functioning. This information could be used to determine what classification of attitudinal groups PD participants may be in (accepting, ambivalent, sceptical, and indifferent).<sup>29</sup> The current study has highlighted potential modifiable beliefs to medication adherence in PD. Addressing these beliefs could then in turn change necessity and concerns, as well as behavioural coping strategies of nonadherence.

Social influence was also another dominant influence on medication

adherence. Previous studies found family members provided feedback on participants' PD symptoms and reminders about medication taking. This was found in the current study, with the presence of symptoms causing friends/family to prompt medication taking. Moreover, family members that also used alarms on their phones provided an extra prompt to medication taking. Lower social support has been associated with medication nonadherence in PD<sup>30</sup> and those with low social support are therefore at greater risk of nonadherence. Providing social support may be a challenge for healthcare systems, but fortunately healthcare provision in the UK has utilised nurses to support people with PD. All participants expressed a positive relationship with their PD nurse, suggesting that they were valuable sources of information for medication taking, medication adjustments and prescription of therapies (e.g., physiotherapy). One participant suggested that they did not self-medicate as a result of advice from their PD nurse. Research has uncovered self-medicating behaviour in a participant due to the breakdown of the therapeutic relationship between them and their PD nurse, resulting in poor symptom control and extra prescription to manage symptoms. 31 This evidence highlights how the therapeutic alliance from the PD nurse may stop detrimental behaviours that could result in poor

Given the context and timing of this study, although not an explicit study aim, the 11) Environmental Context and Resources domains uncovered the effect of the COVID-19 pandemic on medication taking. Working from home meant that taking medication was easier yet the pandemic perceived risks of contracting the COVID-19 virus when out of the house and taking medication without first using hand sanitiser was a hinderance, leading to intentional nonadherence.

#### 4.1. Strengths and limitations

Using a well-established theoretical framework provided rigour to the conduct and analysis for this study. Use of the TDF allowed for a comprehensive understanding of the full range of barriers and facilitators to medication adherence in PD<sup>20</sup> as shown in other studies of medication adherence. The inclusion of a participant who chose not to take medication for their PD symptoms was a strength of this study. This participant chose to self-inject Vitamin B1 (Thiamine) instead of taking prescribed antiparkinsonian medication. Typically, a participant such as this would be reluctant to take part in studies such as this or may be excluded from the analysis, due to the vast differences in beliefs and behaviour. The interview schedule, informed by the TDF, extracted relevant explanations from this individual, highlighting why they chose to take an alternative treatment over the licensed antiparkinsonian medication. For the purpose of analysis, facilitators of B1 treatment were coded as a barrier to taking antiparkinsonian medication and vice versa. The inclusion of this participant provided in-depth insight as to why someone may choose not to adherence with prescribed medication, preferring to use alternative unlicensed options to treat their PD.<sup>19</sup> However, when using the TDF to inform the design of an interview schedule, careful consideration is needed to how the domain question is worded and the best order to allow the interview to flow, which does not necessarily follow the numbering of the TDF domains 1 to 14. This can reduce the participants' ability to answer spontaneously and influence the way that the question was answered.33

Although this study included an equal number of participants who were men and women and draw participants from a wide range of geographical area of the UK, no ethnic minorities were included in the sample. Importantly there was also limited socioeconomic diversity within the group and participants were largely very knowledgeable about their Parkinson's. The use of a purposive sampling approach based on characteristics such as demographic factors (e.g., ethnicity, years diagnosed with PD, gender and age) could have been used to recruit participants to achieve a better representation of the PD population in the UK.

#### 4.2. Future research

The next stage of this research is to map the findings i.e., target TDF domains onto the Behaviour Change Wheel (BCW) and behaviour change techniques (BCT) taxonomy. 33,34 The BCTs have been preassigned to each TDF domain<sup>35</sup> and they show promising effectiveness for supporting medication adherence in chronic conditions.<sup>36</sup> For example, a meta-analysis and meta-regression of BCTs have shown to significantly improve medication adherence in cardio-metabolic conditions.<sup>37</sup> A systematic review of randomised control trials (RCTs) measuring the effectiveness of mHealth interventions on medication adherence in cardiovascular diseases. Although the effectiveness of BCTs on medication adherence in PD merits further investigation, this current study provides good initial evidence to support its potential. Future research is needed in this area to determine the effectiveness of interventions of this nature, as well as their cost effectiveness. Further quantitative studies are also needed to determine the extent to which these factors can be generalised to other PD patients.

#### 4.3. Implications for practice

The current study has highlighted that use of the TDF captures the plethora of factors that influence medication adherence in PD. More importantly it has shown how barriers and facilitators of medication adherence in PD are unique to the individual and therefore a personcentred approach is needed. The TDF would be useful in uncovering an individual's barriers and facilitators of medication adherence, to help tailor an intervention that suits their specific circumstances.

#### 5. Conclusion

In this small participant group, all data relating to the barriers and facilitators for medication adherence in PD were successfully mapped onto the TDF. This indicates the utility of the framework for determining and structuring the factors to consider when providing medication support for this patient population in an accessible and coherent way. This in turn advocates future research utilising the TDF with a mixed methods approach to best identify domains relevant to the wider population of people with PD. This would aid the selection of the most appropriate BCTs to be used in interventions to improve medication adherence in PD.

#### **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.rcsop.2023.100309.

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