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### ► **To cite this version:**

Charlotte Manceau, Emilie Constant, Elodie Brugallé, Emilie Wawrziczny, Bérengère Flinois, et al.. Couples facing the honeymoon period of Parkinson's disease: a qualitative study of dyadic functioning. 35th Annual Conference of European Health Psychology Society, Aug 2021, Online Conference, France. hal-04316008

**HAL Id: hal-04316008**

**<https://hal.univ-lille.fr/hal-04316008>**

Submitted on 30 Nov 2023

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# Couples facing the honeymoon period of Parkinson's disease: a qualitative study of dyadic functioning

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## Scientific context

- **Parkinson's disease (PD)**: the second most prevalent neurodegenerative disease<sup>1</sup>, characterized by motor (rigidity, tremor, slowness)<sup>2</sup> and non motor symptoms (cognitive troubles, anxiety, depression)<sup>3</sup>
- **"Honeymoon" stage** : the motor symptoms are well controlled by the treatments, whereas the non motor symptoms persist<sup>4</sup>
- Both the person with the disease and the care partner are affected by the disease<sup>5-11</sup>, and therefore, their **couple relationship is disrupted** at several levels : communication<sup>12</sup>, sexuality<sup>13</sup>, emotional sharing<sup>14</sup> ...
- **2 main limits to these results** :
  - we still don't understand the **nature of the relational dysfunctions** and the **underlying dyadic mechanisms**.
  - These studies do not differentiate the stages of the disease, which have specific issues and the **"honeymoon" stage is less represented**.

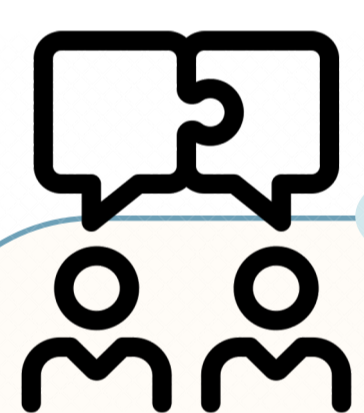
How do partners live the "honeymoon" stage of PD ?

## Method

- **Objectives**: to understand better the **couple's functioning during the "honeymoon" stage** and to identify the **dyadic processes** involved in the couple's experience
- **Participants** : **15 heterosexual couples**, recruited through the Neurology and Movement disorders department of Lille University Medical Center, in France.
- **Procedure** : semi-structured interviews, led with each partner
- **Data analysis** : Interpretative Phenomenological Analysis (Smith, Flowers, & Larkin, 2009)

## Results

4 patterns of couple's functioning :



### Coping together, as we always did

- Comprehensive functioning, emotional sharing, understanding of each partner's needs
- PD as the opportunity to reinforce the relationship (more proximity)
- ↳ trust in the resources for the future

3 couples

### Silence his fears and pretend

- Discrepancy concerning the vision of the future and the symptoms
- Silenced disease and rigid mutual protection
  - ↳ To protect each other from distress
  - ↳ To protect themselves from the reaction of the partner

4 couples



### Fight against time VS let time go

- Discrepancy concerning the management of symptoms :
  - ↳ Fight against symptoms and time (caregiver) VS let time go and enjoy the present moment (partner with disease)
  - ↳ Controlling behaviors towards the partner with disease
    - Tensions and conflicts
- Possibility to moderate conflicts with **individual efforts**

4 couples

### Resign to not understanding each other

- Discrepancy in experiences :
  - ↳ tensions and vicious circle of negative interactions
  - ↳ Worries about the vision of the future
- Affective separation : insufficient resources to ease the gap between partners
  - Echoes of past wounds within the couple

4 couples

## Discussion

These results highlight several implications :

- The importance of taking the **couple into account** as soon as possible after the diagnosis and to **prevent distress and emotional distance** within the couple, by helping partners **communicate** their emotions and concerns
- The need to favour the partner's agreement and a common vision of PD<sup>16</sup>, with psychoeducation tools for both partners
- The importance to compare these results with the other stages of the disease, in order to have a global vision of the couple's functioning throughout the disease, and to optimize their support