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# Social Identity of People With Parkinson's Disease: An Interpretation of the Disease[*]

Lucia Landolfi[a]

## Abstract

Considering the body as a communicative entity (Frank, 2022), Parkinson's disease is a social experience where physicality and identity are interdependent. Although symptoms are individually felt, the discomfort they cause is interpreted and labelled through social interactions. Therefore, a solely clinical perspective limits understanding by neglecting relational and social factors that hinder the fulfilment of people with Parkinson's disease (Lombi, 2022a). This study assumes that a Parkinson's diagnosis represents a 'biographical disruption' (Bury, 1982) that restructures social relationships. The research question focuses on how diagnosis redefines social identity across the life course. The aim is to analyse the transition from person to person with Parkinson's disease, highlighting loss of social roles, deviation from collective expectations, and experience of stigma (Goffman, 2003). Through a qualitative approach, interviews were conducted with people with Parkinson's and informal caregivers.

Results show that the diagnosis initiates a negotiation between pre-existing identity and that of a person with Parkinson's, with the disease closely intertwined with life experiences. Moreover, interpersonal relationships play a crucial role, as informal caregivers and associations provide essential support for daily adaptation. Coping strategies vary according to disease stage and sociocultural context, while digital technologies increasingly emerge as valuable supportive tools.

In conclusion, the interpretation of Parkinson's disease as lived daily by both people with the condition and their informal caregivers highlights how identity transformation profoundly affects everyday life. Recognizing these dynamics is essential to developing inclusive policies and interventions that support autonomy, foster social participation, and improve quality of life.

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[a] University of Salerno, Italy.

Corresponding author:
Lucia Landolfi
E-mail: llandolfi@unisa.it

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## 1. Preface

Since 1817, the year in which James Parkinson first described "the Shaking Palsy" (Parkinson, 2002), the disease has undergone significant scientific and social evolution.

Today, it is the second most common neurodegenerative disease worldwide after Alzheimer's disease (Deliz et al., 2024; Morris et al., 2024), with approximately 11.77 million cases globally in 2021 (Luo et al., 2025).The incidence is greater in highly industrialized countries, in particular among the Caucasian population, by the combined effect of aging, lifestyles and environmental factors such as pollutants, pesticides, solvents and metals (Zhu et al., 2024).

In Italy the epidemiological situation of Parkinson's disease (PD)[1] appears to be overall stable in time but has a significant territorial variability. Istat data[2] relating to 2013, 2015 and 2019 show a standardized rate of Parkinsonism – expressed for 1000 habitants and correct for age – which, albeit unchanged at national level, it highlights some noteworthy trends: in males there is a slight increase, going from 3.5 in 2013 to 4.2 in 2019, while in females there is one slight flexion, from 3.4 to 2.9 in the same time span. The values are generally higher between men, but the gender difference (Cattaneo & Pagonabarraga, 2025) is not homogeneous in the different areas of the country. The territorial disaggregation shows significant differences: in Southern Italy, for example, the highest figure in the series is 7.3 cases per 1000 inhabitants among women in 2015, while in the Islands, in 2019, a rate of 5.2 for 1000 for both sexes was reached, higher than the national average. These inequalities suggest a differentiated exposure to environmental and social risks, in addition to disparity in accessing services, early diagnosis and in taking charge. Age remains a decisive factor: prevalence increases significantly among those over 65, underlining the need for health policies targeting the elderly population, both in terms of prevention and care.

However, this study does not focus on the incidence and prevalence of PD as a neurological condition, also considering the methodological difficulties in

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[1] In the continuation of the article, the acronym PD will be used to refer to Parkinson's disease.

[2] Extracted from the Health for All database.

the effective esteem of the cases (Riccò et al., 2020), but rather in its social dimension and how the disease profoundly modifies the social identity. The body element, often taken for granted in everyday life, becomes the subject of attention and redefinition when the predictability of the body and the adjoining social actions fail, transforming itself into a vehicle of stigmatization and redefinition of social roles. The body affected by PD does not merely express symptoms such as tremors or rigidity; it also reflects changes, exclusions, and misalignments in relation to social expectations and shared norms.

## 2. Introduction

The experience of the disease marks the moment when the body stops being transported and predictable, becoming a problematic and central element (Frank, 2022; Cersosimo, 2016). In this interruption of normality, the body proves to be communicative: when Parkinson enters a person's life, it does not affect only the body, but also his being-in-the-world. The body that trembles, stiffens, and slows down is not only that of the individual, but a social body exposed to the gaze of others, brought into relation and subjected to labelling, interpretation, and judgment. Corporeality and identity are interdependent, making it difficult to trace a clear border between the experience of the disease and the disease itself (Frank, 2022).

Starting from this assumption, the paper intends to interpret PD as a social experience in which the clinical dimension is only one among several.

An exclusively clinical vision limits understanding, neglecting the relational and social implications that hinder the fulfillment of people with PD (Lombi, 2022a). In fact, the subjective experience of the disease inevitably intertwines with the relational context in which it is lived, and in this intertwining the individual's social identity is redefined. In this theoretical framework, this contribution aims to understand how PD influences the person in social interactions, helping to forge the self in relation to others. The diagnosis of PD represents a "biographical disruption" (Bury, 1982), an event that interrupts the continuity of the self and profoundly reshapes social relations. Since social life is based on shared expectations which regulate the behavior deemed appropriate, the loss of body control typical of PD can hinder the possibility of adhering to these social norms. In light of these considerations, the research question guiding this research concerns how the diagnosis and experience of living with PD contribute to reshaping social identity along the trajectory of life. The main objective is to understand the transition from individual to person with PD, examining how this process involves the loss of social roles and the emergence of perceived deviance from collective expectations (Parsons, 1966) and the experience of stigma (Goffman, 2003).

Therefore, the specific objectives of the research are to highlight the transformations of identity produced by the disruption caused by the disease, aiming to understand how individuals reconfigure their sense of self in everyday life contexts. The research also aims to investigate how social norms influence self-perception and perceptions of others, experiences of recognition or exclusion, and the role of social interactions.

In this regard, the research adopts a symbolic interactionist approach, which views society as a dynamic constellation of individuals engaged in daily activities, where actions develop and are defined in relation to encountered situations (Blumer, 2008). This framework offers valuable tools for understanding how the experience of PD is constructed, enacted, and interpreted in relation to others. The aim is to restore complexity and depth to a lived experience too often reduced to a mere clinical condition, paving the way for initiatives that extend beyond the biomedical domain to include the socio-health dimension, recognizing that "one lives with Parkinson's" (Cipolla et al., 2020). This implies an approach that does not take for granted the support needed by people with PD but that takes into account the experiences and narratives of those living with the disease – and, above all, recognizes that people with PD are not defined by the disease, but by their life experience in which it emerges, amid various contingencies and transitions.

## 3. Method

The research was carried out through exploration and inspection (Blumer, 2008) in order to gain an analytical understanding of the empirical world through a flexible and attentive methodology to the complexity of reality. Exploration, as a preliminary phase of approaching the empirical field, has made it possible to identify definitions, relationships, classifications and key concepts, orienting the investigation towards the areas of meaning relevant to the subjects involved. The subsequent inspection phase is focused on the in-depth analysis of the findings that emerged during exploration, examining each aspect asking heterogeneous questions and returning repeatedly to these aspects to refine the comprehension. The research tool was the individual and joint semi-structured qualitative interview, designed to obtain a situated and contextualized understanding of lived experiences, relationships, and social definitions related to PD.

### *3.1. Collection and analysis of the information*

The research adopted a sampling strategy based on the criterion of theoretical saturation (Glaser & Strauss, 1967; Saunders et al., 2018), with the objective of diversifying participants by age, gender, and territorial origin in order to achieve a socially representative sample of the phenomenon under investigation (Bichi, 2000, pp. 45-46).

A total of 76 semi-structured interviews were conducted, including 61 individual interviews (44 with people with PD and 17 with informal caregivers) and 15 joint interviews. The latter involved pre-established dyads, such as conjugal or intergenerational relationships (e.g., a father-daughter and a mother-daughter). Overall, the study involved 91 participants, including 59 people with PD (36 males and 23 females) and 32 informal caregivers (25 females and 7 males).

For reasons of space and clarity, only a brief description of the sample is provided here: the distribution of participants by age groups, gender, and geographic origin respectively for people with PD (Table 1) and for informal caregivers (Table 2). Although additional variables were collected during the research-such as education, marital status, and employment status (current or former)-these are not included in this contribution. Nonetheless, it is important to note that they informed the construction of the analytical categories used in the interpretation of the data.

*Table 1. Distribution of participants with PD by age groups, gender, and geographic origin.*

| Age groups | Gender | Northern Italy | Central Italy | Southern Italy | Islands | Total |
|---|---|---|---|---|---|---|
| <55 | M | 1 | 1 | | 4 | 6 |
| | F | 1 | | 1 | | 2 |
| | Tot | 2 | 1 | 1 | 4 | 8 |
| 55-64 | M | 1 | | | 1 | 2 |
| | F | 3 | | 1 | 2 | 6 |
| | Tot | 4 | | 1 | 3 | 8 |
| 65-74 | M | 10 | 6 | 2 | 2 | 20 |
| | F | 5 | 1 | 2 | | 8 |
| | Tot | 15 | 7 | 4 | 2 | 28 |
| 75+ | M | 5 | 2 | 1 | | 8 |
| | F | 3 | 3 | | 1 | 7 |
| | Tot | 8 | 5 | 1 | 1 | 15 |
| Total | M | 17 | 9 | 3 | 7 | 36 |
| | F | 12 | 4 | 4 | 3 | 23 |
| | Tot | 29 | 13 | 7 | 10 | 59 |

Semi-structured interviews were conducted in mixed mode: 60 in-person and 16 online, depending on the needs of the interviewees. The in-person interviews took place either in venues provided by participating associations or in familiar settings for the participants. While initially not expected, some interviews were conducted in joint form (Morris, 2001), a method sometimes proved to be more natural and effective, offering privileged access to the co-construction of the story in everyday relationships (Bramanti et al., 2023). In joint interviews, the informal caregiver has often held the role of facilitator of dialogue, helping to reduce communication difficulties thus aiding the interaction between the interviewer and the person with PD (Low, 2012). The interview guide was developed using sensitizing concepts (Blumer, 2008), to avoid interpretative constraints and to facilitate the emergence of subjective meanings, while addressing the challenges posed by differing cognitive frameworks (Bichi, 2007).

*Table 2. Distribution of informal caregivers by age groups, gender, and geographic origin.*

| Age groups | Gender | Northern Italy | Central Italy | Southern Italy | Islands | Total |
|---|---|---|---|---|---|---|
| <55 | M |  | 1 |  |  | 1 |
|  | F | 5 | 1 | 1 |  | 7 |
|  | Tot | 5 | 2 | 1 |  | 8 |
| 55-64 | M |  |  |  |  | 0 |
|  | F | 3 |  | 1 |  | 4 |
|  | Tot | 3 |  | 1 |  | 4 |
| 65-74 | M | 2 | 2 |  |  | 4 |
|  | F | 5 | 2 | 1 | 1 | 9 |
|  | Tot | 7 | 4 | 1 | 1 | 13 |
| 75+ | M | 1 |  |  | 1 | 2 |
|  | F | 5 |  |  |  | 5 |
|  | Tot | 6 |  |  | 1 | 7 |
| Total | M | 3 | 3 | 0 | 1 | 7 |
|  | F | 18 | 3 | 3 | 1 | 25 |
|  | Tot | 21 | 6 | 3 | 2 | 32 |

The qualitative analysis, conducted through open coding (Strauss, 1987) using NVivo software, focused on the meanings attributed to the PD and its implications as they emerge from everyday interactions. The experience of PD was interpreted as a social reality that takes shape and evolves through ongoing processes of interaction and interpretation.

## 4. Results

Results are divided into four sections and trace trajectories of meaning in which the formation of the social identity of people with PD is inseparably intertwined with the social lives of others. Each thematic area reflects interconnected dimensions of identity construction, embodiment, role transformation, and the meaning attributed to diagnosis and disease progression.

### *4.1 Reconfigurations of social identity in PD*

The narratives reveal a tension between the pre-Parkinson's identity and the new identity imposed by the disease, articulated as a status passage (Glaser & Strauss, 2011). This transition entails a redefinition of familial, professional, and relational roles, and is often accompanied by latent forms of stigmatization (Goffman, 2003).

The symptomatic fluctuations of PD compromise stability in social roles, often leading to their abandonment (Perepezko et al., 2019). The absence of objective markers makes the therapeutic management unstable and requires continuous adaptations in the daily routine (Riggare, 2022). Stigma, in fact, emerges from the interaction between social perceptions and unmet expectations, generating misunderstanding, discomfort, and isolation to the point that Maffoni et al. (2017) propose it as a nonmotor symptom of the disease.

During the interviews the meanings attributed to PD emerge through symbolic expressions and evocative images, illustrating what this condition means for those who have been affected and their informal caregivers. PD is more than a clinical label; it acts as an agent of identity transformation, deeply impacting social roles. The narratives reflect a plurality of ways in which the diagnosis is internalized, named, and interpreted, making the disease an integral part of personal identity. People do not merely endure the categorization associated with diagnosis, but actively rework the experience through metaphors, imagery, and biographical references, often tied to their professional background or former social roles. Three main identity patterns emerge: the coexistence of two distinct identities-personal and disease-related; an intermittent identity, seeking to keep Parkinson's disease in the background; and a totalizing identification, where the disease tends to absorb the original identity.

> I live with two kinds of normality [...] some parts are (Name)-Parkinson's. (Full Name) runs fast, (Name)-Parkinson's is dragged along. (I_11_PwPD_M_67).[3]

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[3] Legend: I = Individual interview; J = Joint interview.

> This disease is like a black man, who challenges us to a dual with his black weapon and I need to respond like the knight of light with a sword of light (I_37_PwPD_M_68).
>
> Parkinson's is a lost war [....] you can win some battles but not the war (I_15_Carg_F_75).

### *4.2 Biographical trajectories and identity redefinitions: Parkinson's as a critical transition*

The analysis of the interview highlighted how the experience of PD is deeply rooted in participants' biographical trajectories, particularly within their work and family histories. The diagnosis is not perceived as an isolated event, but as a biographical turning point situated within ongoing transitions, accelerating or distorting their course. In this sense, the disease acts as a catalyst for identity and social redefinition, interfering with personal and collective projects, as well as with the image of itself matured over time.

For young people, PD represents a premature interruption of planning both in work and family life. For most elderly subjects, however, the disease is intertwined with reflections on aging, on dependence and progressive loss of autonomy. In both cases, time – in its double chronological and symbolic meaning – plays a decisive role in the re-signification of the disease, influencing the way it is integrated into the narrative itself.

As Elder (1985, 1998) observed, social transitions contribute to the redefinition of identity and status throughout the life course. In line with this perspective, the interviewees describe their identity as the outcome of an intertwining of working experiences, affective and bodily, which are placed in the time and the space of their biographies. Their narratives reveal an evolving identity, formed in continuity between past and present, and materialized in their current status. In fact, interviewees elaborated their experience of PD through symbolic images reflecting one's professional past. A former electrician, for example, uses the metaphor of the sinusoid:

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First number = Interview number.
PwPD = Person with Parkinson's disease; Carg = Informal caregiver.
M or F = Gender (Male or Female)
Second number = Age at the time of the interview.

> Throughout the journey, you experience a sinusoid that keeps being a sinusoid. [...] Life with Parkinson's is like a sinusoid. An alternating current. (I_21_PwPD_M_66).

A retired agronomist compares PD to the sensitive mimosa:

> The most representative plant for Parkinson's is the sensitive mimosa [...] Because it is so sensitive that when you touch it, it withdraws, sensitive. It's a plant with beautiful flowers and it is resistant. Beautiful, it can be grown and is resistant to fire (I_3_PwPD_M_64).

The difficulty in recognizing and interpreting the early signs of the disease contributes to diagnostic delay. Prodromal symptoms (Artusi & Lopiano, 2022) are often misattributed to aging-when age permits-or to depressive states. This contributes to a prolonged condition of epistemic uncertainty, which can last for years. In this suspended phase, it is often female informal caregivers who first detect signs of the disease, drawing not only on familial familiarity with Parkinson's but also on prior professional experience: a threshold between suspicion and confirmation that is consumed in everyday life.

> My wife was the first to notice that something had changed. I didn't sleep... I dragged a foot. It started so, in a subtle way (I_7_PwPD_M_30).

> I had had the doubt for years that it was no longer just depression.... My husband in front of the psychiatrist minimized everything, he said 'that was my wife exaggerating. Then the psychiatrist apologized to me' (J_3_Carg_F_73).

The biological malfunction objectively diagnosed – disease (Twaddle, 1979)- represents a "stabbing", a "tile on the head" for those who will have to, from that moment on, negotiate daily activities with the administration of drugs.

The new routine, influenced by pharmacology and physical slowdown, determines profound transformations in one's private life. Mobility problems, falls, communicative and expressive difficulties, disorientation become relational barriers that cause a social identity crisis. The internalization of a "sickness imaginary" (Lombi, 2022a) leads many to conceal the disease, signalling a lack of acceptance of its social impact. When, however, the person manages to integrate the disease into its identity and publicly recognizes its presence, a significant change occurs: the announcement of the disease. This passage marks the first act of acceptance of the social implications of Parkinson's.

> My life is marked by tablets. I seem to be linked to the pills. The alarm clock sounds for the pills. And this annoys me enormously (I_35_PwPD_F_60).
>
> It is especially people with high social status-doctors, lawyers, teachers-who struggle most to accept the disease. They identify with their professional image, and showing vulnerability is more difficult for them. (I_16_Carg_F_51).
>
> I avoided saying it… but because of my inexpressiveness, the so-called stone faced people would notice. So eventually I would say: 'I have Parkinson's', to avoid jokes or awkwardness (I_3_PwPD_M_64).

### *4.3 Relationality with Parkinson's: actors who define Parkinson's in interactions*

The 'Self' in people with PD "is something that has its own development; it does not exist at birth, but it comes rising in the process of experience and social activity, that is, it develops as the result of relationships that the individual has with that process in his totality and with other individuals within it".(Mead, 1966, p.153). Therefore, in the relationship with the other generalized the People with PD internalize meanings, values and norms in that continuous process of socialization. However, this implies that the reflection of the people with PD comes from the attitude of the generalized other, which is nothing more than the attitude of the entire community and consequently it is necessary to consider three actors that emerge strongly as co- construction of the meaning of living with PD: associations, informal caregivers and technology.

The associations are distinguished by their ability to create supportive environments, where participation is autonomous and voluntary. Not only do they respond to the daily needs of the patient and their caregivers but actively commit themselves too raising awareness and promoting research (Parkinson's Europe, 2022, 2025). According to Lombi (2022b), those who have addressed the pandemic by activating personal coping strategies have also been more inclined to join an association, recognizing its value in collective support. However, the path of approach is not linear: in the initial phase, hesitation prevails and the fear of confrontation with more advanced cases; with the progression of the disease, the association becomes a point of reference and source of orientation to inquire and share experiences and often, it is the small daily tips that emerge from comparison between peers to prove decisive; in the advanced phase, despite the growing physical difficulties, many continue to participate and find comfort and a sense of belonging to a rational dimension lived as therapeutic. The associations are therefore configured as “relational mirrors”, in which people with PD recognize and redefine, passing from the initial phase of uncertainty to the awareness of one’s condition, up to the enhancement of a new identity shared with others (Landolfi, 2024).

> I don’t go to associations because, well, I feel a bit more down (I_40_PwPD_F_45).

> It’s good when you meet, [....] you don’t feel alone here(J_14_PwPD_F_64).

> It’s all information, no matter how small, that comes from contact with the people in the association (I_36_PwPD_F_64).

In any case, the role of associations remains crucial in giving voice to people with PD and to informal caregivers, an essential point of reference in daily life. From table 2, it is evident that there is a marked female prevalence in this role: out of 32 informal caregivers involved in the research, 25 are women. Even when the women did not participate directly in the interviews, they are always named as the main figure of support which if on the one hand can generate dependence and can be exhausting, on the other it can be perceived as a threat to identity or as a form of control (Martin, 2024). In addition, the job of female care continues even in the presence of fragility: numerous accounts describe women who, despite being ill, continue to act as caregivers, often with a total lack of support. The illness, in these cases, doesn’t represent a threshold for receiving care, but a condition to manage in silence, while continuing to take care of others

> Apart from having Parkinson’s disease, I had a husband having dialysis and therefore didn’t want to share my illness with anyone, I had to face it on my own [....] not with my children nor with my husband (I_12_PwPD_F_60).

> I neglected my health completely [....] I found myself with hernias, a damaged arm tendon. [....] I realize now, I’m paying a little now for the physical labors I hadn’t felt before (I_15_Carg_F_75).

The COVID-19 pandemic accelerated the adoption of technology among people with PD, at the same time revealing potential and structured limits in the health sector. According to Maturo and Gibin (2022), during the pandemic emergency, many people with chronic pathologies experienced a suspension of care, worsened by cancelled clinical appointments, from the interruption of rehabilitation activities and from the reduction of social contact In this critical scenario, technology has been a key resource: people with PD have made extensive use of digital tools to obtain information, continue rehabilitation at home, and access services (Lombi, 2022b). The testimonies collected reveal different meanings attributed to technology, understood in turn as informational, medical, or motor support. Many respondents indicated the internet as their primary diagnostic tool or for exploring alternative treatments. In both cases, it is mainly women who are more active and open to using technology in the identity-building process (Martin, 2024). Medical devices are considered essential for diagnosis and treatment, while mobility aids support mobility and stability. During lockdown, technology also took on a strong relational value, helping to reduce loneliness and isolation (Cersosimo & Landolfi, 2021), and the digitalization of association activities was appreciated for the emotional support it offered and for creating a symbolically protected space against the stigma associated with the imagery of sickness (Lombi, 2022a).

> So I went on my computer: which illness brings the shrinking of writing? Parkinson’s disease. (I_30_PwPD_F_75).

> The pump has become a part of my life, every day and at any time, the benefits that I obtained are that I don’t take Levodopa pills any longer, they were six, now my stomach can’t take anymore. Levodopa is now in a liquid form, that I take as an infusion (I_6_PwPD_M_79).

> I signed up for a forum online [....] then I met this lady who encouraged me (I_12_PwPD_F_60).

### *4.4 Situated and adaptive coping strategies*

The coping strategies that emerged outline a set of adaptive practices located, in which the process of response to the disease is built in relation to multiple and interdependent variables: the territorial dimension, the relational network, individual biography and gender. Such strategies are not presented as standardized solutions, but as dynamic configurations, modeled by the context of the life of people with PD and their caregivers. The narratives collected show how such strategies range from the reorganization of home environments to the activation of external resources, such as local services and associations. People with PD's coping strategies are configured as complex and stratified responses, influenced by biographical, professional and territorial factors. In particular, the career path emerges as a privileged space for the redefinition of oneself, where the diagnosis often imposes a revision of professional identity and life expectations, in an attempt to contain stress, reduce the cognitive pression and restore an existential balance.

> I was an entrepreneur [....] I was diagnosed with Parkinson's. Then I sold everything, I bought a house in Sicily, a boat and I started fishing, whilst waiting to die. Then I saw that I didn't die, and I thought 'what do I do, break my balls? What if I live another 30 years, what then?' So, I put myself back out there in the world of careers but completely changing perspective, as an employer (I_3_PwPD_M_64).

Next to the biographical dimension, the territorial context emerges as a crucial factor in accessing services and in the possibility of adopting effective strategies. Availability and economic sustainability of essential resources such as transport and home care strongly affect the daily choices of people with PD and their caregivers. In many areas, structural deficiencies and high costs impose further organizational and economic effort. In this context, the territory can be both a constraint and a resource, especially where there are local associations capable of offering informal support, opportunities for sociability and personal care.

> Also transport, things, there are a lot of problems. Until one passes through. Meaning to accompany him I pay for a person. But if I ask on the side it's because there is no good price. But if I ask the Red Cross, they want 25 euros per trip. But what can you do? Unfortunately, not everybody can afford it (J_7_Carg_F_45).

To summarize, coping strategies cannot be understood apart from the context in which they are developed, they are expressions of continuous negotiation between body, environment, material resources and identity paths. They reflect both the individual and territorial adaptation and social inequalities that profoundly affect the daily experience of the illness.

## 5. Discussion

### *5.1 Identitarian renegotiation: a located process*

Since the first interviews, the awareness of a multiplicity of experiences emerged: each experience with PD is influenced not only by the specific combination of symptoms, age of onset, coping strategies, and treatment responses, but also by biographical trajectories, affective relationships, working conditions, family dynamics, access to services and the availability of social support. The idea that "*Parkinson's does not exist, there are many Parkinson's" (I_36_PwPD_F_64)* and that "*Everyone has their own Parkinson's, each case is different" (I_4_Carg_F_44)* allows for the recognition of this complexity. It challenges a homogeneous view of the disease and highlights the urgency of adopting personalized and context-sensitive approaches. Thus, the people with PD should not be reduced to a set of symptoms, but rather understood as a subject undergoing not only physical, but also social transformation that constitute what can be referred to as the "Parkinson's prism" (Dunlap-Shohl, 2015; see Florijn et al., 2023).

### *5.2 Stigma and self-affirmation*

The identity of people with PD is built through narrative and relational dynamics, often hindered by a stigmatization process. The language used by participants is not technical but rather everyday, emotional, and deeply rooted in the struggle to maintain a recognized presence in familial and social bonds. The disease thus becomes a barrier to social interaction, generating a perceived deviance from social norms and often leading to a forced redefinition of one's position within relational networks. Yet some individuals choose to transform the clinical label into a form of affirmation. Self-descriptions such as "Parkinsonian," which recur in several interviews, reflect the position of Riggare (2022), who reclaims the identity of scholars with Parkinson's as a means of achieving legitimacy and social visibility. In these cases, identity is renegotiated through public affirmation that challenges stereotypes and transforms stigma into recognition, reorienting societal expectations. The identity of people with PD is thus constructed through narrative and relational dynamics that are often obstructed by stigmatizing processes.

### *5.3. Context and co-construction of identity*

The social identity of people with PD is not constructed in isolation; it is shaped and reshaped within relational, material, and symbolic contexts. Among these, digital technologies emerge as co-constructor actors of the disease, as they not only allow the monitoring and personalized management of the symptoms (Arora et al., 2015; Zhan et al., 2016), but transforms the relational modalities between patients, caregivers and health workers (Piras & Miele, 2019). Applications based on videoconference for example, allow the remote evaluation of the voice and the language, noting early signs of the disease (Constantinescu et al., 2010). The patient remains in his domestic environment, while the professional works in his: both connected by technology that transform the symbolic and operational boundaries of the therapeutic relationship (Chen et al., 2014; Zhan et al., 2016). Assistive robotics also play an important role, promoting autonomy through personalized cognitive and social support (Becchimanzi, 2022).

However, the tools intended to facilitate communication can sometimes exacerbate communication barriers. As Prenger et al. (2020) observe, such tools may foster exclusionary and dehumanizing dynamics. When communication fails, the risk that the person with PD internalizes the stigma increases, to the point of isolation and the renunciation of social participation. Yet, precisely in the tension between loss and re-appropriation, a space opens for the identity redefinition. The disease, while breaking the rhythms of everyday life and social participation, can become an opportunity to negotiate your place in the world. People with PD, in daily comparison with communication, mobility and relational difficulties, implement creative adaptation strategies, resistance and self-affirmation. In this process, new forms of visibility emerge – forms that do not hide the disease but instead incorporate it into a shared narrative. These forms enable innovative modes of interaction, capable of challenging stereotypes and restoring social recognition. The goal is not merely to reclaim what has been lost, but to generate new possibilities for expression and belonging, within a framework where identity is not fixed, but continually forged through relationships and life experiences.

## 6. Conclusions

This work investigated the social identity of the people with PD, interpreting the experience of the disease as a transformative and emotionally turbulent event (Hammarlund et al., 2024) able to destabilize the personal and relational balance, disjoining certainties and, at the same time, opening the possibility of renegotiation of oneself (Cersosimo, 2024, p.29). PD in fact, does not manifest only through neurological symptoms, but is configured as a social reality, which redefines roles, relationships and expectations, significantly affecting the construction of identity. The symptoms of PD, when analyzed sociologically, reveal their transformative impact on identity: dysphagia disrupts meal-related rituals and increases self-surveillance (Bartlett et al., 2025); bradykinesia slows everyday interactions; hypomimia impairs emotional communication; freezing undermines confidence in public spaces; micrographia erodes perceived competence and professional identity; and cognitive decline threatens autonomy, exposing individuals to dependency and loss of control over daily life (Hammarlund et al., 2024). Each symptom, therefore, becomes an agent capable of redefining the person in social interactions. The transition from person to person with PD represents a crucial identity junction, which invests not only the individual, but also the relationships. Since the welfare needs of people with PD require structured community support, and as the involvement in social activities strengthens the sense of belonging and identity continuity, it becomes essential to enhance the social dimension of everyday life (Cassidy et al., 2024). This urgency is amplified by epidemiological projections pointing to a sharp global increase in PD cases, particularly in low- and middle-income countries where population ageing exceeds healthcare capacity (Su et al., 2025). It is in this scenario, the concept of complexity (Bichi, 2000) is revealed essential: the life trajectories of people with PD do not follow linear models, but intertwine with multiple universes of meaning, cultural fragments, socio-economic and political conditions and unequal health policies.

Therefore, understanding the shift from person to person with PD means being able to design inclusive policies that respond concretely to vulnerability, policies grounded in people’s capacity to inhabit the world, relate to others, work, and envision a future. The interpretations of PD, as narrated by participants, are not merely a subject of analysis but can become an operational tool. Through these narratives, sociology – within an interdisciplinary perspective – can make visible dimensions of vulnerability often ignored by standardized intervention models, thereby contributing to the development of context-sensitive, life-course-oriented policies. Three main directions emerge from this research as useful frameworks for practical interventions.

First, the identity renegotiation process is deeply situated. Being a person with Parkinson’s is radically different depending on whether one is a man or a woman, young or old, living in the North or South, an agronomist, a hairdresser, or a factory worker etc.. This demands personalized and context-sensitive responses. Inclusive policies must therefore account for the social variables that become especially evident when viewed through the lens of sociological intersectionality: social factors are not merely control variables but structures that deeply shape the Parkinson's experience (Adkins-Jackson et al., 2024).

Secondly, the research shows that the social identity of people with PD is not a fixed attribute but is continuously negotiated through social interactions. It is precisely within these interactions that identity can be either stigmatized or, conversely, publicly affirmed and reclaimed. Saying "I have Parkinson's" or identifying as a "Parkinsonian" can represent an act of vulnerability that exposes individuals to stigma, but it can also offer others a framework for understanding the intentions behind their actions, preventing misinterpretation and mislabelling. For this reason, social identity cannot be considered secondary to clinical management; rather, it must be recognized as a therapeutic resource in itself. As Soundy et al. (2014) argued, social identity is a key factor influencing individual well-being. Understanding and supporting patients' social identities allows for care that does not simply aim at functional restoration, but sustains the self across the challenges of illness. Health interventions that fail to consider identity risk becoming ineffective or even harmful. One example from the research illustrates this point clearly: pharmacological management, often seen as a purely clinical task, is closely linked to personal biography and social context. A 50-year-old woman with a background in marketing adjusted her medication not only based on physical symptoms but also in preparation for the semi-structured interview. She perceived the interview as a chance to express her professional identity, communication skills, and personal agency. What seemed like a clinical adjustment was, in fact, a deliberate act of identity positioning – affecting her sense of autonomy, quality of life, and social recognition. Similar coping strategies observed in other cases highlight how illness management is shaped not only by biological needs but also by the ways individuals define and assert themselves socially.

Therefore, it is necessary an approach that goes beyond the symptomatic dimensions and recognizes the identity as a therapeutic resource. The social identity of the person with PD constitutes the fulcrum from which to design truly adaptive, sustainable social-health interventions and oriented to the redefinition of oneself. In fact, to consider identity transformation as a central element of the experience of the disease also means contributing to the improvement of the quality of life of the person with PD , which is influenced not only by the symptoms but, above all, by psycho-social and existential dimensions including identity, understood as a social and personal representation of one's self and capable of mediating between bodily experience and social recognition (van Munster et al., 2024). As noted by Daemen et al. (2025), people with PD express a strong need early access to resources for self-management, fundamental for psycho-emotional well-being, identity continuity upkeep of autonomy. However, so that the support must not translate into social control, it is essential to avoid dynamics that feed dependence and delegitimization of self-efficiency. As Martin (2024), warns, assistance risks becoming expensive, exhausting and disabling if it does not enhance the individual's resources and his right to self-determination. The role of professionals is not to replace, but to empower individuals by creating environments that preserve their agency.

Finally, when implementing interventions, it is essential to recognize that the social identity of the person with Parkinson's is not a secondary consequence of the diagnosis, but a structural component of their lived experience. Nowadays it must also be acknowledged as such by those involved in the design of technologies. This highlights the need for the interpretation of lived experience to become a guiding criterion in design processes. Technologies such as apps, digital devices, and platforms should not be limited to meeting standardized needs. Instead, they must be capable of incorporating context, subjectivity, the evolving nature of identity, life trajectories, and relational bonds. To achieve this, they cannot operate in isolation. They should function in synergy with patient associations and informal caregivers, both of whom inhabit and understand the same everyday environments of people with Parkinson's.

In conclusion, this qualitative research, by addressing the interdependence between the vulnerable bodies of people with PD and their social identities, suggests that the knowledge gathered can be transformed into tools for action. Specifically, these insights can inform the creation of narrative, educational, and institutional frameworks that place lived experiences, individual resources, social contexts, life courses, and relationships at the centre. It is not the person with Parkinson's who must adapt to society.

It is society that, when equipped with the appropriate tools provided by research, can learn to recognize, accommodate, and support vulnerable identities.

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