Sociology and Social Work Review
Volume 8 (Issue 2)/2024 | pp. 87-105

DOI: 10.58179/SSWR8205
https://globalresearchpublishing.com/sswr/

Original Article

Associations: Mirrors for people living with Parkinson's disease

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Abstract
Parkinson's disease, with its profound impact on individuals and communities worldwide, calls for a comprehensive understanding of the social dimensions of the illness. This study explores the pivotal role of associations in influencing coping strategies and shaping identity among individuals living with Parkinson's disease. Through a grounded theory approach, the research examines how participation in associative networks provides a platform for self-expression, mutual support, and engagement, fostering resilience and adaptation. Data were collected via semi-structured interviews with individuals diagnosed with Parkinson's and facilitators actively involved in Italian Parkinson's associations from northern, central, and southern regions of the country. The findings underscore the critical role associations play in addressing the collective needs and aspirations of their members while highlighting significant regional differences in activities, strategies, and support systems. Associations promote solidarity and shared understanding through homophily, offering a sense of belonging and mutual aid. They not only provide access to essential social and healthcare resources but also create spaces where individuals can reflect on their past, navigate the present, and envision a future beyond the limitations of their condition. This dynamic interplay of social engagement and identity transformation underscores the indispensable contribution of associations to the broader care ecosystem and their transformative impact on the lives of people with Parkinson's.

Keywords: social identity; disease management; patient support services; community networks; social interaction.

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Introduction: associations as catalysts for civic engagement and healthcare evolution

Associations, defined as organized collectives pursuing shared goals, emerge as key products of modernization, creating autonomous spaces independent of state and market powers. They act as tools for transcending status inequalities, facilitating new forms of social interaction, and serving as collective agents that, through political participation, empower individuals in conditions of weakness or subordination.

The role of associations is a well-established sociological concept, as Tocqueville's observation (1835-1840), still relevant today, highlights how associationalism represents a liberty of action and a cultural model in which participation is regarded as both a right and a duty of every citizen. This model reinforces values such as liberty, equality, and solidarity, contrasting with the European context, where associations often require state protection to function. In this sense, associations in the present study are considered as collectives formed either through voluntary individual decisions or from top-down initiatives, based on shared or complementary interests that can develop institutionalized forms. Gallino (1978), for instance, defines an association as a stable collective oriented toward achieving common goals unattainable by individuals alone, whether created voluntarily or established from above, with an organizational structure promoting solidarity and cooperation.

This research specifically regards associations as a model of civic participation essential for societal development, adopting an individualistic approach. In this context, the shared interest is identified in the patient role, which seeks solutions to health-related challenges. These needs, viewed as purpose-driven rational actions, drive intentional aggregation and institutionalization of nonprofit groups designed to engage politically with the welfare state.

From the 1970s and 1980s onward, there has been a growing trend of citizen participation in the healthcare sector, expressed politically through the institutionalization and involvement in associations (Maturo 2024). Through these forms of participation, patients, caregivers, and professionals become central actors in the planning, organization, and management of healthcare services. As noted by Graffigna and Barello (2016), this managerial involvement reflects the need for social consensus to implement appropriate and effective policy measures informed by the perspectives of those living with the illness daily.

The partnership between associations and healthcare organizations, in light of the increase in chronic conditions and life expectancy, gives rise to decision-making processes capable of addressing economic and bureaucratic difficulties that hinder access to healthcare. In a healthcare system often characterized by bureaucratic rigidity and technocratic approaches, associations create relational assets that overcome institutional barriers. Associations value citizens as users, patients, and caregivers, allowing for the emergence of needs and preferences that would otherwise remain ignored by managers, healthcare professionals, and policymakers (Giarelli, Lombi and Cervia 2020). Associations do not merely fill the gaps left by the welfare state but redefine public space, contributing to a new civil society characterized by pluralism of social subjectivities (Giarelli, Lombi and Cervia, 2020). At the macro-social level, they actively participate in defining health policy priorities, setting shared goals, and outlining intervention strategies. Therefore, associations serve as a bridge between state institutions and individuals, activating forms of solidarity and promoting social rights to health. Voluntarism is the guiding principle of civil society, and associations are its main collective actors, where commitment and shared responsibility are prerequisites for participation (Dekker and Broek 1998). In modern society, individualism does not hinder volunteering; the reasons for involvement are personal choices, often driven by the need to address individual health needs. The desire to acquire skills and meet personal needs encourages decisions ideally made through debate and exchange of arguments, avoiding hierarchical or economic impositions. Through these dynamics, associations produce private assets for members, solidarity assets such as mutual support, and public assets such as the creation of shared spaces (Dekker and Broek 1998). In fact, these needs emerge primarily where the welfare state does not guarantee the enjoyment of social or health rights, especially for the most vulnerable groups. Associations avoid asymmetrical power relations and foster inclusive decision-making processes, integrating direct experiences and subjective specificities. In this context, they represent an intermediate space between the state and membership groups, acting as intermediaries between formal and informal needs, contributing to social cohesion and improving health (Maturo 2024).

Although it is clear that, from a macro perspective, associations play an instrumental role in strengthening the healthcare system and democratic participation, promoting trust and cooperation within the social fabric, the micro perspective offers a complementary view. The latter focuses on how associations respond to the particular needs of individuals. In meeting these specific needs, associations also perform general functions, such as the creation of social networks and the strengthening of a sense of belonging. In light of this, the following research adopts the interpretive framework of Georg Simmel's formal sociology (1908), which views society as a form of association composed of a network of interconnected social circles. From this perspective, the individual simultaneously participates in various associations that intertwine multiple and sometimes contradictory interests. This complex system creates a unique network of affiliations for each individual, making it unlikely that two people share exactly the same combination of relationships.

Our analysis focuses on the interests and individual motivations that contribute to the formation of associations, considering the differences that emerge between collective representations and personal reasons. These differences find an analogy in the reciprocal relationship between individuals, a central element for understanding the functioning of associations, particularly in the context of illness. This approach highlights how associative dynamics are the result of the complex interaction between individual singularities and structural constraint.

Associations as agents to overcome stigma in Parkinson’s Disease

From a sociological perspective, associations for people with Parkinson’s disease serve as generators of social capital, understood as the resources derived from networks of relationships and mutual trust. These connections - both horizontal among patients and caregivers and vertical with healthcare professionals and political institutions - provide critical support in addressing the challenges posed by the disease. The activities organized by associations contribute to building networks of emotional and practical support, alleviating individual isolation, and strengthening the sense of community belonging. Moreover, social participation in the healthcare sector, involving patients, caregivers, professionals, and other actors, positions associations as key players in scientific dissemination, research promotion, power-sharing, and defining ethical priorities. These activities make associations crucial advocates in governance dynamics and health-related decision-making processes. Social capital generated by associations, analyzed from a micro perspective focusing on the individual, aligns with a model that views social networks as essential resources for individuals living with illnesses (Maturo 2024).

In this context, the wealth of relationships fostered by associations highlights central nodes for constructing support networks, which promote emancipation from the disease, increase public knowledge, and create self-help groups. Associations specifically aim to support individuals affected by conditions that interfere with fulfilling social roles and often lead to a progressive withdrawal from public life by those affected and their families (Geerlings et al. 2023).For instance, "Shaking Palsy" or "Paralysis Agitans", first described in 1817 by British physician James Parkinson (Parkinson 2002), reveals a social dimension of sickness whenever the afflicted individual is labeled as unwell in the social sphere (Twaddle 1979). The disease manifests not only as a biological condition but also through interactions and experiences that are inherently social, as the individual continually relates to their social environment (Bury 2005).

Motor symptoms such as dyskinesia, tremors, rigidity, bradykinesia, postural instability, and walking difficulties (Parkinson 2002; Chaudhuri et al. 2011), alongside non-motor symptoms like anosmia, visual disturbances, pain, paresthesia, orthostatic hypotension, depression, anxiety, cognitive decline, sleep disturbances, constipation, and dysphagia, significantly contribute to social isolation. These symptoms not only worsen emotional well-being but also trigger a vicious cycle: depression, reduced social activities, fear of falling, and anxiety feed into one another, further reinforcing social withdrawal behaviors (Ahn, Springer and Gibson 2022). Additionally, language difficulties, fears of making communication errors, anxiety, and depression are among the most frequently associated factors with social withdrawal. Finally, cognitive decline and the increased risk of dementia exacerbate this situation, making isolation even more pronounced (Ahn, Springer and Gibson 2022).

The voluntary and involuntary social withdrawal of people with Parkinson's disease and their family members often stems from the fact that the typical symptoms of Parkinson's disease hinder adherence to shared social norms, leading them to feel shame (Nijhof 1995) and withdraw into private spheres. The symptomatic fluctuations typical of the disease make it difficult to follow social rules. However, shame is not only a consequence of "deviant" behavior but also depends on the social significance of the broken norms, the visibility of these behaviors, and their public labeling as deviance (Nijhof 1995). This dynamic inevitably leads to a confrontation with the issue of stigma (Goffman 1963), which amplifies social isolation and psychological distress.

What is medically attributed to cellular degeneration in the nervous system that leads to chronic motor control and balance disturbances (Poewe et al. 2017) translates, for people with Parkinson's, into an experience often described as an "atomic bomb" that throws everything into chaos, a metaphor used by individuals with Parkinson's to highlight a profound loss of autonomy and an increased sense of stigmatization (Florijn et al. 2023). The narrative review conducted by Prenger et al. (2020) broadens the understanding of the disease, emphasizing that, in addition to motor and cognitive symptoms, social symptoms impact quality of life in even more significant ways. The authors identify several factors that hinder social interaction and communication, including the bradykinesia of facial muscles, which causes a masking of facial expressions, described as one of the most impactful emotional symptoms for people with Parkinson's (Prenger et al. 2020). Maffoni et al. (2017) highlight how stigma emerges from an exchange of perceptions: patients with

Parkinson's often complain of being misunderstood by others, while at the same time, they perceive the discomfort of those interacting with their physical problems. These misunderstandings arise from interactions that fail to meet social expectations and often lead to withdrawal from the social context (Maffoni et al. 2017). This dynamic makes it urgent to find solutions to prevent stigma from being experienced as an additional "non-motor symptom of Parkinson's disease" (Maffoni et al. 2017: 6).

In light of this, the active participation of people with Parkinson's and their family members in associations is crucial for reducing isolation and social withdrawal. Associations play a fundamental role in public awareness, directly addressing the social stigma associated with the disease. According to Ahn, Springer and Gibson (2022), social activity programs have shown positive effects in maintaining and improving social participation. In fact, these associations, acting as bridges between the healthcare system, families, and the community, represent a transformative force. They combine solidarity, empowerment, and social progress to overcome stigma and prevent social withdrawal. As stated in the Parkinson's Manifesto for Europe (Parkinson's Europe 2022), "Make it easier for people affected by Parkinson's to connect with others in the Parkinson's community to share experiences and knowledge, thereby addressing isolation and providing motivation and inspiration". Associations created for individuals with Parkinson's and their caregivers play a crucial role by providing resources and fostering social connections. During the COVID-19 pandemic, these associations became even more indispensable, addressing the heightened isolation and disruption of care routines experienced by people with Parkinson's. Lombi (2022a) highlights that individuals with established coping strategies often relied on these associations for assistance, further cementing their role as essential support networks.

Improving the quality of life for people with Parkinson's disease (PD) requires coordinated actions by associations in collaboration with the healthcare system. These efforts include organized activities, support services, and the promotion of innovative solutions. Collectively, these initiatives contribute to the process of preserving the self despite, the sickness label, enabling individuals to navigate daily challenges related to their roles and identities within social and personal contexts. In particular, associations support preserving self-strategies, which help individuals with PD maintain their sense of identity through "interacting" and "taking action" (Vann-Ward, Morse and Charmaz 2017). As noted by Vann Ward, Morse and Charmaz (2017) using a constructivist grounded theory approach, preserving self in the context of PD involves two interrelated processes: interacting refers to how individuals redefine their sense of self through relationships with others, transforming their identity via social engagement; while taking action involves constructing a self-identity in relation to others, rooted in the perception of who they were before the diagnosis and who they aspire to be after it. The symptoms of PD often force individuals to confront the inability to perform activities they once considered integral to their identity; therefore, this necessitates a redefinition of self, reconciling their past sense of self with their current capabilities in activities that they now consider fundamental (Vann-Ward, Morse and Charmaz 2017). Through new interactions and adaptive actions, individuals create reimagined identities, allowing them to navigate life with Parkinson's in a meaningful way.

This identity reframing enacted by people with Parkinson's can be interpreted as a challenge to "sickness imagery" (Maturo 2007), both on an individual and institutional level. This capacity for reinterpretation and renegotiation of identity is particularly evident in the work of associations. As noted by Lombi (2022b), associations, as the core of networks of cooperative relationships, address the social aspects of the disease, promoting actions aimed at changing the perception of Parkinson's. Among the primary initiatives are the fight against stigma and support for the recognition of the rights of people with Parkinson's. Through these actions, associations play a crucial role in fostering an alternative and more positive narrative of the condition, helping to create a bridge between the private and public dimensions of the disease.

Research design

Reason and aim of the research

In light of the considerations raised, including the complexity of symptom fluctuations in Parkinson's disease, the difficulties stemming from stigma, and the crucial role of associations in improving quality of life, a key research question emerged: *How does active participation within associations contribute to the intricate process of identity formation among people living with Parkinson's disease?*

This question emerged unexpectedly during the author's doctoral research period, where the significance of associations as mediators between the private experience of the disease and the public experience became apparent, as well as their role as key actors in supporting individuals in the complex process of identity construction and renegotiation. Therefore, the aim of this research is to explore how active involvement in associations contributes to shaping the identities of individuals living with Parkinson's disease. This identity reframing enacted by people with Parkinson's can be interpreted as a challenge to "sickness imagery" (Maturo 2007), both on an individual and institutional level. This capacity for reinterpretation and renegotiation of identity is particularly evident in the work of associations. As noted by Lombi (2022b), associations, as the core of networks of cooperative relationships, address the social aspects of the disease, promoting actions aimed at changing the perception of Parkinson's. Among the primary initiatives are the fight against stigma and support for the recognition of the rights of people with Parkinson's. Through these actions, associations play a crucial role in fostering an alternative and more positive narrative of the condition, helping to create a bridge between the private and public dimensions of the disease.

Methodology

This research uses semi-structured interviews and adopts a qualitative methodological approach based on Grounded Theory (Glaser and Strauss 1967). This methodology allows for an in-depth exploration of active participation processes and their impact on the identity of individuals with Parkinson's disease, providing a thorough understanding of the social and individual dynamics that emerge within associations.

Data collection

Between February and May 2023, semi-structured interviews were conducted by a single researcher. The interviews took place at the offices of associations dedicated to people with Parkinson's disease and their families. The associations played a key role in recruiting participants, disseminating the research objectives, and ensuring anonymity. Through theoretical sampling, the saturation of key categories was ensured, with strategically selected associations reflecting regional diversity across Italy. Seven associations were involved two based in the Piedmont region, and one each in Lombardy, Tuscany, Lazio, Puglia, and Sicily[1].

Sampling

The self-selected sample involved a total of 74 people who gave their consent to participate in the study, but the actual number of interviews conducted were 59. Of these, 44 were individual interviews with people with Parkinson's disease, while 15 involved both the person with Parkinson's and informal caregivers. The caregivers, who played the role of "facilitators" (Low 2012), were crucial in shaping the narrative during interviews, particularly in cases involving individuals in the advanced stages of the disease. As shown in Table 1 a total of 59 people with Parkinson's (36 men and 23 women). As shown in Table 1, a total of 59 participants with Parkinson's disease (36 men and 23 women) were included in the study, distributed across the Italian regions where the involved associations are based. The average age of participants with Parkinson's disease is 67,7 years, with a standard deviation of 10,5 years. Specifically, the average age for male participants with Parkinson's disease is 66,9 years, while for female participants with Parkinson's disease, it is 69.0 years.

Additionally, 15 informal caregivers participated in the interviews, distributed across the regions where the associations operate (Table 2). Their average age is 65 years, with a standard deviation of 11,5 years. The caregiver participants consist of three male participants, with an average age of 72,3 years, and twelve female participants, with an average age of 632 years.

Table 1. Participants with Parkinson's disease included in the study

Region	**PwP (F)**	**PwP (M)**	**Total PwP**
Piemonte	6	12	18
Lombardia	6	5	11
Toscana	2	7	9
Lazio	2	2	4
Puglia	4	3	7
Sicilia	3	7	10
Total	23	36	59

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[1] The following seven Parkinson's associations are gratefully acknowledged for their support: Associazione Amici Parkinsoniani Piemonte, Associazione Parkinson Arezzo: A.P.AR, Associazione Parkinson Insubria sezione Groane Onlus, Associazione Parkinson Puglia OdV, Azione Parkinson Ciociaria, La Parkimaca - Ass. Parkinson Cuneo e le sue valli, and Libera Associazione Parkinsoniani.

Table 2. Informal caregivers participating in interviews with relatives who have Parkinson's disease

Region	Caregivers (F)	Caregivers (M)	Total Caregivers
Piemonte	6	0	6
Lombardia	3	3	6
Toscana	2	0	2
Lazio	0	0	0
Puglia	1	0	1
Sicilia	0	0	0
Total	12	3	15

Data analysis

During the data collection period, the audio recordings of the interviews were transcribed and analyzed comparatively using NVivo software. Identifiable information was removed from the transcripts to ensure anonymity.

The coding process was daily guided by the concept-indicator model (Strauss 1987). Through the interviews and observations, the fundamental elements of Grounded Theory, as defined by Strauss (1987), were identified as empirical indicators.

Specifically, the three concepts identified through conceptual coding were: *Associations' activities*, *Coping strategies adopted by association members*, and *Identity expressions*. These three concepts were developed through the identification of empirical indicators, which were then compared with each other in terms of differences, similarities, and degrees of coherence. This comparison allowed for the refinement of the categories until conceptual saturation was reached.

The conceptual specification of *Associations' Activities* was defined through various indicators such as: motor activities, recreational activities, individual activities, group activities, face-to-face activities, remote activities, types of professionals involved in activities, number of sessions per activity, location of activities, equipment used in activities, use of digital resources, publicity of activities, costs of activities, frequency of activities, participation in activities, average duration of activities, feedback on activities, and accessibility of activity locations.

The concept of *Coping Strategies Adopted by Association Members* was considered saturated through indicators such as: accounts of problems and how they were addressed, experiences of stigma, physical difficulties encountered, requested assistance, the role of caregivers in supporting daily life, frequency of sharing personal experiences, use of techniques to cope with symptoms, use of medications to address symptoms, use of resources, adoption of unconventional strategies to face daily challenges, participation in activities to develop new skills, participation of caregivers in activities aimed at defining coping strategies.

Finally, the saturation of the concept *Identity Expressions* was reached through indicators such as: use of metaphors, images, and photographs, linguistic choices, modes of presenting oneself during the interview, presence or absence of companions, narratives of the moment of diagnosis, difficulties experienced during the interview, statements about future perspectives, and willingness to participate in the association.

The process of conceptual coding represented the first step in identifying the core categories (Strauss 1987) and their related subcategories. During the analysis, it was deemed appropriate to adopt the same names of the concepts as core categories. This result did not stem from a guided approach, but from the fact that the concepts emerged spontaneously during the research, initially conducted for other purposes, fully adhering to the principles of Grounded Theory.

Results

The following table (Table 3) presents the main categories and their related subcategories to be explained

Table 3. Categories and subcategories

Associations' activities	**Territorial approaches to rehabilitation**
	Progressive adaptability of activities
	Compensatory activities
Coping strategies adopted by association members	Medical provider selection
	Preparatory practices
	Dealing with stigma
Identity expressions	Parkinson as an unwelcome guest
	Parkinson's is a cohabitant
	Parkinson's as a dominant identity

Associations' Activities

From the words of the interviewees, a variety of activities within the associations emerged, ranging from medical interventions to recreational initiatives. Medical activities include rehabilitation sessions, medical visits, and speech therapy. In parallel, recreational activities are organized that not only provide entertainment but are also functional in managing Parkinson's symptoms. Among these, dancing, particularly tango therapy, and practices such as Tai Chi, which promote movement and physical well-being, stand out. Recreational activities, such as organized trips and online meetings for discussions and leisure, complete the offerings. More specific initiatives include the use of psychologists, self-help meetings, and promotional activities. The latter may involve the use of applications or tools useful for participants, highlighting the commitment of associations in supporting members through innovative resources.

Territorial approaches to rehabilitation

It emerged that all the associations share the commitment to organizing rehabilitative activities; however, these activities vary significantly from region to region, reflecting geographic, cultural, and logistical factors. For example, Nordic walking is particularly popular in mountainous regions like Piedmont, where the terrain lends itself to this practice. Conversely, swimming is more widespread in coastal areas such as Sicily, where the availability of aquatic facilities facilitates access to such activities.

These differences highlight the adaptability of associations in shaping their offerings based on regional contexts. In areas where territorial compliance is a challenge, rehabilitative activities are often carried out within association premises, adapted with the aid of specific tools. During the COVID-19 pandemic, many of these activities were transferred online, ensuring continuity even under extraordinary conditions.
As one interviewee stated:

In the sense of sailing, canoeing, all sporting activities for young Parkinsonians. (P_23_M_64)[2]

It has been a very nice experience with the young people, especially because even today, once a week, I continue to do Nordic walking with them. I am still part of a great group (P_36_F_64)

Progressive adaptability of activities

The activities proposed by the associations reveal their ability to progressively adapt to the different stages of Parkinson's disease. The diagnostic criteria of the International Parkinson and Movement Disorders Society (MDS) divide the disease into three main stages: prodromic, early, and advanced (Artusi and Lopiano 2022). The prodromic phase, characterized by the onset of early motor and non-motor symptoms until diagnosis, is generally not associated with participation in associations. In this phase, the disease is perceived as a concerning but still undefined condition, prompting individuals to seek answers primarily in the medical context, often referred to as illness (Twaddle 1979: 18) In the early phase, which extends from the onset of motor symptoms to the onset of motor fluctuations (Artusi and Lopiano 2022), many people avoid joining associations. This behavior is often related to the fear of facing individuals in more advanced stages of the disease, a reflection of a possible future that evokes fear. As reported by an interviewee:

At the beginning, I was a bit hesitant, because you know, I was 28 years old, and I knew there were much older people than me, with definitely more serious problems. Fortunately, I don't have major issues right now, but at the start, I didn't want to get involved in this environment. Also, because then people talk: 'I'm like this, you're like that.' In fact, for the first few times, I tried not to join a group, not to get included in any group. (P_7_M_30)

As the disease progresses to an intermediate phase, characterized by motor fluctuations, associations become an essential point of reference. They offer information, peer support opportunities, and practical help to cope with daily difficulties. One interviewee shared:

I have a lot of swallowing problems, like how to swallow a pill without struggling, or issues with my feet. These are all bits of information, even though small, that come from contact with people in the associations. (P_36_F_64)

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[2] Each excerpt is accompanied by an anonymous identifier in parentheses, indicating whether the participant is a person with Parkinson's disease (P) or a caregiver (C). The identifier also includes the interview number, the participant's gender, and their age

Finally, in the advanced stage, when therapeutic responses no longer provide adequate functional compensation and severe motor, cognitive, and psychological complications arise (Artusi and Lopiano 2022), associations, beyond sporadic attendance expectations, become a refuge - a place where members can share experiences, feelings, and receive emotional support, as highlighted by a participant:

For example, when I go to the association, I walk in and it's as if I were another person because I feel good. I really feel good with those people. When I go home, I feel more supported and satisfied. (P_43_F_73)

Compensatory activities

Associations prove to be crucial in filling the gaps left by healthcare and social support systems, especially in less-served areas. Through a series of compensatory activities, they respond to critical socio-assistance needs, providing resources and opportunities that would otherwise be inaccessible to people with Parkinson's disease (PD) and their caregivers. These activities aim not only to integrate local services but also to create a support network that fosters the sharing of experiences and knowledge, thus expanding access to information and resources essential for the well-being of the members. Moreover, for both people with Parkinson's and many family members, involvement in associations represents significant emotional and practical support, offering opportunities for connection, socialization, and the sharing of experiences that contribute to their overall balance (Fekonja, Irgolič, and Vrbnjak 2024). As an interviewee emphasized:

And then we're organizing a series of activities that take us all over Italy. That's where our association started. Now we're trying to restart, and we're doing an online course in person together with a neurologist and a psychologist. 12 seminars, one a week, to increase Parkinson's awareness. (P_17_M_72)

I started last year. I've known for two and a half years that I have this disease. There's a lady I know who had her husband, so I came along too, and I feel good here. The teachers and the people are really, really good. The teachers are really great, the psychologist, who is a young woman, is very good, but also the other two are great. But especially this psychologist. (P_26_F_73)

Coping strategies adopted by association members

Another dimension that emerged from the interviews concerns the role of the association in socializing members and providing coping strategies to address the daily challenges of the disease. These strategies represent both practical and psychological support for managing symptoms, improving therapeutic adherence, and planning for the future.

Medical provider selection

Coping strategies for dealing with the symptoms of the disease primarily involve a specific medical provider selection, which is expected to be the same doctor followed by other association members. This desire to have the same doctor is often linked to the need to feel part of a community of patients facing the same condition, sharing experiences and therapeutic solutions. For many members, being followed by the same doctor who treats other association patients not only ensures therapeutic continuity but also creates a sense of cohesion and mutual support. In this case, the doctor becomes a common reference point, not only for their professional competence but also for the bond they establish with the group of patients who have chosen to follow them. This shared choice of a doctor among association members also offers practical benefits: patients feel more secure and reassured knowing that the doctor has a broad understanding of the disease and its implications for a larger community. Sharing a therapeutic journey with others makes the treatment less solitary and more easily accepted. As one interviewee shared:

I started asking for help from the association. The questions everyone asks: Who do I go to? Which doctor? What is the approach? (P_45_F_60)

In November, we do what many others in the area do: we hold Parkinson's Day. The association provides its facilities and neurologists who share the latest updates and try to inform us about the most recent developments in the field. (C_10_F_44)

Preparatory practices

Another crucial aspect of coping strategies involves preparatory practices. People with Parkinson's and their caregivers adopt proactive measures to manage future activities, aware that the disease's symptoms and the effects of medications can be unpredictable (Abendroth, Lutz and Young 2012). These practices include scheduling medication intake, modifying the home environment to make it more accessible, and mentally and physically preparing to face potential obstacles, such as mobility issues or fatigue. The association plays a key role in this context by connecting individuals at different stages of the disease, fostering the exchange and sharing of experiences. This exchange enables members to prepare for future symptoms or medical, work-related, and relational decisions, drawing inspiration from others' experiences. As one member highlighted:

There are people who, unfortunately for them, have suffered from this disease for many years. I go to ask them: How do you manage to do this, from the very first years until now? How has your perspective or life changed, the symptoms? (P_31_M_67)

Dealing with Stigma

People who participate in the associations, or at least according to their explicit goals, develop strategies to cope with the stigma associated with the disease. For example, using self-deprecating humor as a resilience tool and acquiring knowledge to be prepared are important coping methods. In this context, peer support groups are created, where the term "peer" refers to people with the same condition of illness. These groups allow members to share experiences and challenges, reducing the sense of isolation and excessive attention to one's health status. Such initiatives aim to decrease the shame related to the disease. This is one of the central objectives of the associations, although the collected data shows that the real dynamics are more complex. The interviews reveal that denial or concealment of the disease is more widespread among individuals with higher social status. However, when these individuals become aware of the social implications of the disease, often due to the work done by the associations to change public perceptions, they are more willing to discuss it openly. This shift, from denial to sharing, represents a significant step towards accepting one's condition. As an interviewee noted:

We've attended several courses and socialized, especially by being together, because the association alone cannot do anything. It can't solve the problems of all of us affected by the disease. But the fact of meeting is very important because, in addition to knowing that other people are like us , you don't feel isolated. You don't feel like the only person who's had this misfortune because having diseases is always a misfortune. (P_54_M_81)

Identity expression

The data analysis also reveals that there is no single definition of Parkinson's disease. It manifests in various forms, with differing combinations of symptoms, age at diagnosis, management strategies, pharmacological treatments, and symptom intensity. For instance, there are significant differences in the frequency and severity of freezing episodes, as well as in how patients experience and define their identity in relation to the disease.

The identity definition of people with Parkinson's is articulated in three main interpretive modes, expressed through symbols or evocative phrases that represent what the disease means to those affected:

Parkinson as an unwelcome guest

In this case, Parkinson's is seen as an unwelcome visitor that arrives unexpectedly, prompting those affected to hide or ignore it as much as possible. This approach often leads to efforts to mask or minimize the symptoms. As one interviewee shared:

The monster wanted me, I don't know why it wanted me. (P_1_F_60)

Parkinson is an enemy to fight. (P_38_M_74)

Parkinson as a cohabitant, a roommate

Here, the person's identity and Parkinson's identity coexist within the same body as two separate entities. This dynamic is characteristic of individuals who have come to terms with the disease and acknowledge its permanent presence in their lives. Rather than trying to hide or resist Parkinson's, they accept it as an integral part of their identity and strive to coexist harmoniously with its effects.
One participant said:

Well, I mean well with Parkinson's, because it's no longer like when you didn't have Parkinson's. Feeling well means feeling well with Parkinson's. (P_59_M_75)

Parky, sometimes I scold him and then he scolds me too. Now it's become a sort of game between me and him. It's like having a third brother you can't get rid of, like a Siamese twin. (P_15_M_70)

Parkinson as a dominant identity

Finally, there are individuals who perceive the disease as a dominant part of their identity. In these cases, the disease overshadows their sense of self, becoming the defining feature of who they are and how they are perceived by others. These individuals often introduce themselves by saying *Hi, I'm ___ and I have Parkinson's,* making it a central part of their identity.

As one interviewee expressed:

I was telling you that I have Parkinson's. I've known Mr. Parkinson for a lifetime. (P_17_M_73)

I am ___ and I have Parkinson's.(P_5_M_53)

Discussion

Living with Parkinson's disease profoundly affects social roles, including relationships, family dynamics, and professional life. Symptom fluctuations often disrupt daily routines, leading to withdrawal from roles and altering social interactions (Perepezko et al. 2019). Marital relationships, in particular, may see both positive and negative changes: strengthened mutual commitment for some couples, but also increased responsibilities for the partner, shifts in intimacy, reduced shared activities, and financial strain (Perepezko et al. 2019). These challenges arise as the emotional and physical burdens of being an informal caregiver take their toll (Geerlings et al. 2023).Family roles are similarly reshaped, with the initial communication of the diagnosis playing a key role in fostering acceptance or rejection, impacting coping strategies within the family (Perepezko et al. 2019). Similarly, professional roles are often significantly redefined, with individuals experiencing a reduction in work-related activities. This decline persists despite medical interventions such as pharmacological treatments or deep brain stimulation. The loss of occupational roles contributes to social disconnection, as individuals with Parkinson's tend to organize fewer outings with friends and participate less in recreational activities, favoring solitary and sedentary pastimes.

The variability of Parkinson's symptoms adds further complexity. Without reliable biomarkers, individuals experience significant day-to-day and even hour-to-hour differences in symptom expression and responsiveness to treatment, requiring meticulous planning around medication schedules to manage symptom fluctuations (Riggare 2022). This unpredictability exacerbates the challenges of sustaining social roles and relationships, underscoring the profound impact of Parkinson's on both individual and collective well-being.

Drawing from the principles of interactionism, it's clear that Parkinson's associations are not merely support networks but also pivotal arenas for social interaction and identity formation (Strauss 1959). These *association mirrors* reflect the broader processes described by Strauss (1959) highlighting the role of face-to-face interactions in the constant evaluation of oneself and others. Through such interactions, individuals undergo a dual process of self-assessment and other-assessment, reshaping their identities in the presence of peers, as they present themselves both to others and to themselves, mirroring the judgments exchanged within the group (Strauss 1959).

Thus, the interpretation of the association can be seen as a mirror that, through the combination of these categories, can take on three different types, which vary depending on the stage of the disease the member of the association is in: early, middle, or advanced: Premonitory Mirror, Reflective Mirror, Retrospective Mirror.

Premonitory Mirror

This type is primarily interpreted by those in the initial stage of the disease. These members see the activities carried out by the associations as not aligning with their current condition, often participating with reluctance. Not yet familiar with coping strategies, they view Parkinson's as something to be concealed or masked. In this context, associations are perceived as premonitions of a future reality to which they do not yet feel they belong.

Reflective Mirror

This type of association involves members who have had the diagnosis for some time and have become accustomed to living with the disease. Employing similar coping strategies, they engage in activities deemed beneficial for their condition. They perceive the association as a mirror reflecting their identity, seeking to understand their situation and symptoms through comparison with others. Notably, they observe members in advanced stages to prepare for the progression of their own condition.

Retrospective Mirror

This portrayal presents the association as a commemorative mirror, reflecting memory and experience. It involves *veterans* of coping strategies who deeply identify Parkinson's with their own identity. These members often introduce themselves by saying, "I have been Parkinsonian since…", using the activities organized by the association to reflect on who is the "sickest of them all", or at least sicker than themselves. They engage in activities their condition allows and strive to share their experiences with other members.

This interpretation of associations as mirrors through which members reflect and redefine their identities highlight the importance of these spaces not just as places for practical support, but as dynamic social ecosystems. Associations for individuals with Parkinson's provide more than practical support; they function as dynamic social ecosystems where identities are continually reshaped through interaction, mirroring, and reflection. By fostering recognition, empathy, and shared understanding, these associations offer an invaluable microcosm for navigating the complexities of modern life with a chronic disease. Moreover, associations contribute to preserving roles and identities, which are often challenged by the limitations imposed by motor and cognitive symptoms of Parkinson's disease. These symptoms challenge self-image and disrupt socially constructed notions of femininity and masculinity linked to chronic illness (Fleming, Tolson and Schartau 2004; Simonetto and Tucsok 2023). By acting as mirrors, associations play a key role in helping people with Parkinson reconstruct broader social identities.

Conclusion

In conclusion, this study reflects on how membership in associations serves as an encounter with others, where individuals with Parkinson's can reflect on their past, contemplate the present, and envision the future, significantly influencing their journey of adaptation and acceptance of the disease. Associations provide individuals with the opportunity to maintain their connection to the social fabric, even when their health is compromised by the progression of the disease (Kawachi and Berchman 2014) .

This dynamic aligns with Simmel's concept of reciprocity (1908), which underscores the interconnected nature of social life. Just as societal cohesion is sustained through the mutual exchange of influences among individuals, associations serve as microcosms of this relational dynamic. They facilitate a continuous interplay of shared interests - whether practical or ideal, transient or enduring, conscious or unconscious - through which individuals find unity and purpose. In doing so, associations not only support their members but also reflect the broader processes of social integration and mutual influence that characterize society as a whole.

Through this lens, associations emerge as spaces where social ties are fostered and redefined, enabling individuals with Parkinson's to navigate their challenges while remaining active participants in the collective social experience.

Limitation

Limitations in this research may be related to sample characteristics, research setting, and researcher bias. The sample was relatively small, and all participants were members of organizations providing support to individuals with Parkinson’s disease. This concentration of participants may limit the generalizability of the findings, as their experiences may not fully represent the broader population of individuals with Parkinson’s, especially those who do not engage with such associations. Furthermore, while the research setting was isolated from external influences, it may have inadvertently hindered participants from expressing negative opinions about their membership, potentially due to social dynamics within the group. Lastly, as the study was conducted by a single researcher, the lack of multiple perspectives limited the triangulation of the analysis, which could have increased the risk of interpretive bias and reduced the overall validity of the finding.

Acknowledgments

This research would not have been possible without the essential collaboration of the Parkinson’s associations, which acted as key mediators in the recruitment process and as valuable sources of knowledge.

Declaration of conflicting interests

There are no conflicts of interest to disclose regarding the research, authorship, or publication of this article. All aspects of the study were conducted independently, without any influence or bias from external parties.

Funding

This work did not receive any specific grant, financial support, or funding from public, commercial, or not-for-profit entities. The research, authorship, and publication of this article were carried out entirely without external financial contributions.

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Received 22 June 2024, accepted 27 December 2024