ORIGINAL ARTICLE

Stopped within a track: embodied experiences of late-stage Parkinson’s disease

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Abstract

Based on a phenomenological understanding of humans as situated and intentional beings, this study explored experience of late-stage Parkinson’s disease. A woman aged 72, in the late stages of Parkinson’s disease, was interviewed regarding her experiences over a five-year period. A phenomenological method was used for scrutinizing tape-recorded and verbatim transcribed interviews. Results reveal that late-stage Parkinson’s disease is manifested as a sense of lost control over daily life and as a life with unpredictable bodily reactions. There was a demand to live within an increasingly rigid, slow rhythm of time, with continuously decreased embodied skillfulness, which caused fragmented mobility patterns. Movements were no longer intentional, i.e. outward; they demanded inward concentration. The intention to move was no longer primary, e.g. to grab a handle, because space is mentally and physically understood. Instead, intention was secondary because movement became primary. This phenomenon changed embodied understanding of relationships with the room, distances, and things. Understanding of distance, e.g. became unclear, and this affected ways in which place and situation were experienced and lived. The results highlight ways that a Parkinson’s sufferer lives and experiences space and time in surroundings and situations; and how the person meets and deals with significant challenges.

Key words: Embodiment, environment, phenomenology, Parkinson’s disease, health, longitudinal

Introduction

Me. A Parkinsonian. Captured in my own skin. Mute. Rigid. Complete chaos. My inner pulse, my rhythm: gone. My inner music: vanished. What’s happened? What’s happening with my body? Where’s the control? The balance? Sometimes my will is paralysed. Impulses must come from the outside. Thoughts and actions are impossible to unite. The powerlessness pains me; everything inside me is at a standstill. All impulses fail to appear. Help! L-dopa is not enough.¹ (Sofia, 1995.)

To provide quality support and care for Parkinson’s disease patients, we need medical knowledge about the disease and knowledge about the individual’s experiences throughout progression of the disease. This includes identifying special demands that the illness places on the individual (Benner & Wrubel, 1989). How else could it be possible to understand the meaning of suffering from a sudden off-condition – when the drug inexplicably stops working – as described by Sofia in the above quotation?

Parkinson’s disease is an incurable neurological disease. During its progression, symptoms become increasingly aggravated (Louis, Tang, Cote, Alfaro, Meija & Marder, 1999). Prescribed medications have a major effect on symptoms and quality of life; with time, they might contribute to complex physical, psychological and neuropsychiatric side effects (Goetz, 2003). Healthcare providers mainly focus on Parkinson’s sufferers’ physical disabilities, although stress is harder for sufferers to deal with (Abudi, Bar-Tal, Ziv & Fish, 1997). Parkinson’s sufferers must perceive themselves through alien body experiences; they must present themselves to others in ways that influence and interrupt personal concerns and habitual ways of living (Habermann, 1999; Sunvisson & Ekman, 2001). This means that
bodily disruption for the afflicted person has a significance that far exceeds dysfunction (Toombs, 1992). Since ways of dealing with illness affects experiences, afflicted persons must have opportunities to talk with healthcare providers about the consequences that their illness has on everyday life (Birgersson & Edberg, 2004; Caap-Ahlgren & Lannerheim, 2002; Habermann, 1996; Marr, 1991).

Care giving includes an act of volition — if there is to be any understanding of the individual’s way of living and experience situations and his or her way of relating to illness and health (Benner, 2001; Tanner Benner, Chesla & Gordon, 1993). So searching for knowledge of meaning-bestowing importance and its inherent meaning about living and experience of illness is essential for developing care and enables caregivers to initiate more support for their patients (Benner & Wrubel, 1989). To contribute to the body of such knowledge, this article explores the lived experience of late-stage Parkinson’s disease.

**Participant and method**

**Presentation of the participant**

The participant in this study is a Swedish woman who chose to be presented as Sofia. She was diagnosed with Parkinson’s disease 15 years before the study began. Sofia is unmarried; she retired at age 65. When the study began, she was 72 years old. Sofia initiated the current study, because she believes her experiences could contribute to a better understanding of the demands that the illness places on Parkinson’s sufferers. She was living independently in her own house, but by the end of the fifth year of the study period, she moved into a nursing home; then, because her strength was diminishing, we stopped the study. The introduction of Sofia illuminates her fundamental attitude toward her meaning of life and the significant experiences that influenced the important choices she has made in her life.

In Sofia’s reflections about her life, some experiences appear to be very important to her. For example, a sermon that she heard in her teens turned out to be a vitally important experience, which affected the rest of her life:

(At a large gathering) a man was giving a sermon, and he talked about taking care of your neighbour. It was a fantastic sermon. I can still picture it, and it put me on track; after that sermon, I was sure about what kind of person I was and what I had to do. And still, I did not know what to be. But I knew I had a goal in life and a challenge.

After this calling, Sofia’s mission in life has been focused on working among people in distress, and this challenge has taken her to many places in the world. She believes that God has set a goal for her in life. Her challenge is to achieve this goal truthfully, including sensitivity to signs from God and to live a life of serving and guiding others. Sofia’s belief is that God has guided her to the tasks that she was meant to work with. The concrete, developmental and educational experiences that various volunteer organisations have given her have sometimes been life threatening. Others have taxed her health. Her goal was to empower people in distress to improve their life circumstances. She believes that life is a gift that should be nurtured; a gift that she has always speculated about and what it will bring. She remained faithful to her calling when tempted by other choices. She told me:

I had a mission. And maybe that made it hard for me to fight when I got older and thought about getting married and settling down, but I couldn’t betray that call, for all that it was.

**Data collection**

During the five-year study period, I had frequent conversations with Sofia (almost one each month) about her life experiences. In total 12 h of these conversations, relevant for this study, were tape-recorded and conducted consecutively during the five-year period. Sofia decided when she wanted the tape-recorder to be turned on or off and what she wanted to remain on the tape. She has also read the verbatim transcription and this article in a Swedish version.

Sofia talked with me about her life before being diagnosed with the illness and her memories during its development; she narrated the daily experiences in her life with the illness. No particular interview guide was used. Instead, the talks were characterized by an intensive, mutual wish to understand illness experiences. I transcribed the interviews verbatim.

**Data analysis**

Analysis of the interviews follows a phenomenological method developed by Karlsson (1995). Phenomenological research is grounded in the understanding of humans as intentional beings and the phenomenological field concerns the world as meant or intended. It inquires and explicates specific phenomena in the way that they are experienced and described by a narrator. Thus, the phenomenological task is to investigate how a human experiences and constitutes the world as a world.
According to the selected method, the researcher works throughout the analysis process and is focused on the phenomenon being studied. The researcher takes on a phenomenological attitude, i.e. the researcher withholds/suppresses preconceived assumptions about the phenomenon under investigation. Openness to what the text says provides opportunities to investigate various possible meanings (use of free, imaginative variations that facilitates evolution of essences that enable understanding of the original meaning). For such openness for the text, self-understanding about the phenomenon must be continuously questioned and suppressed (bracketed) in the analysis process (Karlsson, 1995).

Following this method, holding on a phenomenological attitude, the text was first carefully read through several times, in its entirety, to get an understanding of the whole and to become sensitive to the given in the text. In a more thoughtful reading, the text was divided into meaning units when a discerned shift in meaning was experienced. Thereafter imbued meaning about the lived experience in each meaning unit – because of the phenomenon under study – was transformed into a descriptive language that highlights each meaning unit’s meaning. To comprehend such a vast collection of data, each year of the five-year study was observed as a separate protocol. Therefore, the transformed meaning units from each protocol were condensed and synthesised into five situated structures. In light of an understanding from all protocols, all the meaning units and transformations of meaning units were considered to discover the solidity for the situated structures and emerged eidetic constituents. In the last step, these eidetic constituents were condensed into a general structure, and all steps, including raw data collection, were considered.

Ethical considerations

When Sofia initiated this study, ethical permission was asked for and given by the Regional Research Ethic Committee, at Karolinska Institutet, Stockholm, Sweden. Sofia also gave informed consent to this final article.

Results

The lived experience of late-stage of Parkinson’s disease was found to be a striving for involvement while experiencing changes in habitual skilfulness and a changing horizon. Within a changed experience of time and space, there was a striving for embracing personal challenges and adjustment to changed conditions and expression of oneself within an increasing sensitivity for involvement with others and for environmental and emotional influences in a life that was confronted by fragmented, rigid, unreliable embodied skilfulness. This rendered new forms for creating expression and discovering of new worlds (Figure 1). The results are presented below in more detail.

Changing habitual skilfulness

Fragmented embodied skilfulness requires concentration and attention

Rigid embodied skilfulness requires conscious structuring of activities and a living in a slow rhythm of time.

Unreliable embodied skilfulness requires living with doubts about one’s own competence.

Striving for involvement

Internalise conditions influenced by experiences of involvement with others and by environmental and emotional experiences.

Adjust to changing conditions by embracing personal challenges.

A Changing horizon

Creating new forms of expression.

Discovering new worlds.

Figure 1. The general structure of the lived experience of late-stage Parkinson’s disease.
breaks the sequence of movements into mobility details to conduct a fulfilled sequence. Co-ordination of movements demands concentration for execution and maintenance. A few years into the series of interviews, she said:

Cooking is hard work, because I must make so many small, odd decisions. It's nothing that just takes care of itself. Every decision must be forwarded by a decision in my mind.

In activities that require subtlety of movements, she experiences that she must guide her movement with her sight for fulfilment that requires a frequent mental shift of focus from her hands to the material she works with. This leads to fumbling and is very time consuming. She experiences that her guiding-movement ability decreases when she must perform movements hidden from her sight. In an early interview, she said:

To put something into my bag, for example. Now that's troublesome. It's really hard work. Then my sweat flows. And I shake. And when I see that suitcase, it just gets worse.

This necessary mental shift outward — inward — outward, changes her feeling for distance and her feeling of herself in relation to objects and space through misjudgement of distance and changed significance of distance.

With time, her body becomes more in focus: basic tasks and movements become demanding. She must be increasingly concentrated on her actions. Over time, the act of merely keeping her posture straight demands her mental attention. In a late interview, she said:

I act best when I'm present in my thoughts, too. Now I have experiences; there is something that does not hold it all together, keep things in control. It doesn’t all get into the tape, if you understand what I mean. A part becomes blank. It slips. And I cannot afford too many slips during the day. Because when I'm eating, for instance, I must be very concentrated on what I'm doing, otherwise the trout comes in wrong. Terrible. Or when I was sitting here writing like this (she shows how she slid off the sofa). Then I broke two ribs.

In reply to a question as to why it happened, she explained:

Yeah, you know I slide like this sometimes. It also happens when I'm washing up. Suddenly, I find myself half standing up at the sink. And I don't know why it's like this. And it happens when I must stand and wash up and at the same time know where I have all the parts of my body. It isn't easy. Or when I don't understand because this is happening against my will.

Rigid embodied skilfulness requires conscious structuring of activities and living in a slow rhythm of time

As her illness progresses, it is obvious that Sofia must structure her everyday activities. Her decreasing ability to change a decision rapidly forces Sofia to carry out her tasks within static, rigid planning schedules. This tiring, time-consuming way of acting decreases her ability to be attuned to other people. Two years into the interviews, she said:

It's very irritating and slows me down — that I need such a long time to make a decision. I need to know some things in advance, like when someone visiting me suddenly says, ‘Do you want to come along for a ride?’ Then I feel ill. I can't handle such surprises!

On a question as to why she then feels ill, she replied:

Well, it's not that I'm shaking, because I'm used to that, as I shake rather often. But it's psychological, with anxiety and with... I escape into myself in some way. I have no control over my life when these things happen.

Continuing, she said,

Of course, I sometimes get surprises that have no particular effect on me; I don’t know when and why. But I’ve noticed that surprises can turn to chaos for me.

The discomfort that an unexpected interruption gives Sofia causes feelings of imbalance that can sometimes last for hours. Her reaction when someone disturbs her planning and activities becomes increasingly difficult to manage, and her reactions become increasingly aggravated with time — to the extent that she sometimes becomes locked in herself unreachable to others and without the ability to express herself (c.f. her essay in the introduction).

She experiences an increasing intimate connection between physical mobility and mental ability; slower mobility patterns lead to slower mental ability, and faster mental ability leads to faster mobility patterns. A few years into the study, she said
And then it’s . . . when you move slowly like this, I believe that it takes so much more time to think.

With time, these connections become even more obvious in her narration.

**Unreliable embodied skilfulness requires living with doubts about one’s own competence**

Planned activities involving a certain kind of tempo are often impossible for Sofia to carry out, and she finds projects – which she was able to manage earlier – impossible to manage now because of the change in her stamina and unpredictable body reactions. Sofia’s body becomes the foreground of her actions, and it seems unreliable. Sometimes when trying to achieve planned actions, unexpected reactions from her body sabotage its accomplishment. In these types of situations, she experiences herself as suddenly being mentally blocked, which causes loss of ability actually to perform the act. This physical and mental blockage decreases her ability to think, speak or act. With time, the reaction she experiences from her drugs changes. A few years into the study, she said:

The drug can just lie in my stomach and I don’t know when it will strike my brain. And then I add some more medicine and suddenly, I become so over-mobile that I can’t, I can’t manage. It’s terrible.

Compared to an earlier stage of the disease, she cannot be sure if, or when her functional ability will improve, and she does not know for how long she will have functional ability; and she has no way of knowing what her reaction will be.

**Striving for involvement**

*Internalise conditions influenced by experiences of involvement with others and by environmental and emotional experiences*

During the time that Sofia has lived with her illness, she experiences that feelings, specific environmental conditions and events interact with her illness experience, and these factors tend to either improve or worsen her condition. When emotionally involved in a project, the illness disappears from her mind, and she is captured by feelings of concordance between inner belief and expression. Four years into the study, she said:

When I get a brush in my hand and it’s like this (showing how she trembles), I can calm down a little bit and then start painting. And it does not become smeared. I think that I manage to get my feelings and my thoughts to go out through my arm. I think that’s the way that it works.

At moments such as these, Sofia can be within what she is doing, without needing inward-outward concentration on movement fragments.

In a broad sense, the environment also has importance for Sofia’s feeling of projective skilfulness. In an experienced, favourable environment, Sofia feels that she moves in a familiar, natural way; her body does not call out for attention. During one interview, she said,

It’s fantastic when I walk in the forest. I get quite a different posture, totally relaxed. You should see me when I’m out shopping. People probably think that I’m really drunk. I have no steadiness when I walk.

Sofia’s abilities and limitations for performing her tasks also depend on previous experiences of her present context. Three years into the study, she explained:

For example, the other day, when I met that lady coming from my hairdresser. I felt so lively and healthy as I walked along the street. I thought I walked so well and quite straight. And then I met an elegant lady who said, ‘Oh dear, oh dear, how will this work? Do you think you will find your way home, poor little thing?’ Obviously, she felt sorry for me staggering along; then it really became visible that I had problems with walking straight, but I hadn’t noticed it before she came. And then I couldn’t finish the errands that I had planned.

When I asked Sofia what had happened, she said,

She broke me down. There was no need for more.

However, when experiencing enthusiasm at social gatherings, Sofia can become totally unconscious of her body and feels that her appearance does not show signs of illness.

She notices that if she becomes strongly engaged in something, this is followed by a period of exhaustion, and she then finds it difficult to feel calm and to carry out even basic tasks. With time, Sofia must estimate the price she must pay for the cost of engagement and if it is worth the imbalance and fatigue it causes. The conditions for being together with significant others and participating in various activities is dictated by her estimation of the power that is
required for that particular act. Energy becomes something that is in short supply and must be handled carefully.

Adjust to changing conditions by embracing personal challenges

Sofia tries to understand how various dimensions, such as environmental, emotional, physical, and life conditions interrelate to the way her illness is expressed and her capability in dealing with it. With observation and interpretation, she strives to find solutions for ways to recover a balance in her functional ability, in her medical treatment and in her life. This is something that she finds increasingly difficult to reach.

In a never-ending effort to maintain enthusiasm, Sofia forces herself to keep her drive and to take initiative in her life. For Sofia, to have drive means to have focus – to find specific challenges in the changing life conditions that her illness causes and to try to solve them and be open to new opportunities.

Yes, it’s this body that I inhabit, it’s mine, and it’s up to me to keep an eye on it.

She said a few years into the study. In a later interview, she said

I think to be this composed is very important. You must go one step more than usual. I don’t know if I have told you, but I always place my toothbrush and things like that in difficult places. For instance, I must stretch my left hand up into the cabinet in the morning to reach the coffee can. Usually, I know where I keep my toothbrush, but actually, I don’t always know. Sometimes in the evening, I may put it somewhere else because I don’t want to end up doing things in a sleepy, habitual way.

She believes she can achieve a more balanced, smoother mobility pattern if she designs her own medical schedule and reduces the intake of animal protein in her diet. She discovers visualization as a possible way to reduce some symptoms of her illness. She also finds out that in some circumstances she can carry out an intention by transporting mobility problems from one part of her body to another. The following is an early statement:

For example, if I’m in the post office and must sign something, I cannot write. I just can’t. There is no point in trying, I start with big letters and then they become so small and the whole paper becomes entangled. But if I really concentrate on what I’m doing and let my leg go instead of my hand, then I can write.

With time, these strategies become less reliable. With focused, dedicated concentration, Sofia tries to maintain the life that she finds worth living. In her eyes, to give up before all possibilities are tested would give her identity a dimension that stands in sharp contrast to what she feels are essential values in a meaningful life. She explained three years into the study:

I know that there are aids. But I think I’m too young to use them, you see. I will not allow myself to . . . relax so much so that I become dependent, for instance. Then I might sort of become an invalid. And that is not what I want. You see I know that if I tackle the problem, there is hope for a solution. I will not become, I will not become an object for . . . my own self-contempt.

Without care, maintenance and watchfulness on herself and her body, Sofia fears that her access to the world will be closed down. In a later interview, she said,

Yes, that’s what I think I’m afraid of. To become so closed. Because then – I nearly said – then I find no reason for living any longer, I believe.

Sofia experiences the breakdown of her body, and the medical treatment leads to new problems. For Sofia the illness becomes a threat to her meaning of life.

A changing horizon

Creating new forms of expression

What Sofia called a play with Mr. P. coincides with the progression of her illness – as she becomes more aware of new limitations in her life. However, in the later stages of the study, Sofia still has recollections of the skilfulness of her body, as is shown in this quotation.

When I sit down, thinking like this, I believe that there is really nothing in my mind that I cannot manage. But my body reacts in a different way. I think . . . I’m troubled by it. I can make plans and I can think about travel and doing things, I go to the city and . . . So my whole mind is focused on this, to take part in culture and society, making a contribution in some way. But I’ve put my body out of my mind. It isn’t there then. And when I
come back to reality, I must understand that it isn’t actually possible.

Realizing discrepancy between memories of her vital body and her actual body, Sofia continuously searches new ways for remaining faithful to her understanding of what she believes is her mission in life. Together with other Parkinson’s sufferers, she strives to cope with the changed circumstances of her life. She also has discussions with relatives of these other persons — about how life can be living with Parkinson’s disease. She gives lectures to care staff about her illness experiences. Even when living in the nursing home, she tries to be faithful to her life project in her intentions of creating specific meetings for fellow patients who suffer from Parkinson’s disease. She also tries to engage the care staff in the wards and make them aware of how the caring of patients could be improved. Her own impression is that she does not gain any response for her intentions. Then she has no ability to hold onto her mission in life.

Discovering new worlds

Sofia’s increasing fragility causes her to experience her narrow world more intensely. In a late interview, she expressed this reflection:

Earlier, you lived an unlimited life; you thought you would live forever. And you don’t anymore. Not me, anyway. I’m always conscious about limits. And then it becomes very… Now I must find the right words. It’s hard to describe… that I think people look at things in a narrow-minded way. Maybe I see things a little bit deeper. I see other dimensions. And then… a lot of things aren’t that important any more.

She experiences her body as rapidly ageing, making her conscious about death, and she lives with a strong consciousness of the finiteness of life. Her world is dwindling and as the illness progresses, a new concentration and density develops; future visions become limited to her life here and now as illustrated by this statement:

Now, my world has shrunk, and my perspective has gotten a little bit deeper. I don’t have to go so far away for experiences anymore. I mean my life and my world: it was the world, because I worked with people in so many parts of the world. So it’s as though there has been a new opening — you know those cabinets that you can open and there are new pictures and new pictures? It’s like that.

These experiences contributed to a transformation of the way she lived and experienced time and space.

The meaning of late-stage Parkinson’s disease

Sofia’s narratives cover a five-year period. During this time, her experiences of her illness returned in different shapes during its development, and they influenced how she could live out her interests. As her illness forced her to change the way in which she managed, it also changed her way of living during this time. Besides this, Sofia’s appearance and self-image as an active, engaged human being, altered with her decreasing strength.

For Sofia, the nature of the meeting became extremely important for her experience of involvement and ability to perform and complete her intentions. If the conditions of her encounter were good, then Sofia could exceed the limits that her illness placed on her. If conditions were unfavourable, then her illness took over.

With development of her illness, Sofia’s outlook changed (on the essentials of life), and she gave them other meanings. Her activities and engagements took on new expressions and provided other qualities, while her beliefs in life remained important as a core in her engagements. These experiences helped create Sofia: she learnt that her life became interwoven with her illness in her strivings for expression of her way of being. Even in her life at the nursing home, where her opportunities were so limited, this striving was still important to her.

For Sofia, her illness also encouraged a new relationship to the things in the room. For her, the things were no longer ready-at-hand. By using concentration, they were something that Sofia must consciously force her hand to grasp and move her body toward. With this introverted concentration, her feeling for the room and her relation to things became vague, and the inborn rhythm of her body — in its motoric intention — was weakened. Her tempo became static and difficult to adjust to unexpected demands. She was only able to move and create in a smooth way when she felt involved and engaged.

The experience of her decreased bodily capacity brought about a different meaning of space for her, compared to the experience that most people have when conditions change (c.f. Toombs, 2001) and in a certain way that was related to the specific conditions of her illness. Space challenged the lived body — as a reality and possibility for action — in a new way. According to Merleau-Ponty (1962), the lived body is the medium through which we become engaged in and make demands on the world. Events and significant emotional experiences, disabilities and illnesses become experiences that are
embedded and merged with earlier experiences to a change in engagement, ability, and demands. With changed, merged conditions, Sofia inhabited space in a new way. Sofia’s illness limited her ability to broaden her horizontal space. She could no longer travel, as she would like to, because the world was not as available to her as it was before. With this shrinking of space, her experience of this narrow world became condensed in her experience of things that previously had not caught her attention. For example, when she had the energy and capabilities, she was involved in larger “external” projects — the wide world. Home was a place to eat, sleep and meet people. As she increasingly required more peace and quiet, she started to notice the birds outside her windows and the changing of the seasons. These things captured her attention when larger project no longer occupied her.

Sofia’s changed living conditions and way of life illustrate how her experience of space and her relationship to things are connected with a new experience of time (and thus a new relationship to time). Merleau-Ponty stresses that “Time is… not a real process, an actual succession that I am content to record. It arises from my relation to things.” (Merleau-Ponty, 1962, p. 412, italic in original). The tempo of the lived body creates time, and in Sofia’s slow action, she dwelled in everyday tasks. If she was not interrupted in the rhythm of her actions, she could create and carry out her projects. For Sofia, to be suddenly interrupted meant a confrontation between her lived time and another person’s flow of time: her own rhythmical being lost its driving force. This is evident when someone disturbed her and when medication did not relieve her symptoms. Both types of interruptions influenced her experience of time and deprived her of abilities to deal with and manage things.

Sofia’s experience of time also has another dimension. In her experience of herself, she became confronted with her “rapidly ageing” body. Brough (2001), p. 42) explains that time is embedded, as time is engraved in things around us, in our own ageing faces or those of others, and so on. Through these signs, time becomes visibly connected with space, as time engraved in our bodies make lived time visible (Abram, 1997, pp. 201–217). Confrontations with thoughts about her death and the unknown path toward it threw Sofia into overwhelming fatigue. Sofia’s thoughts about her rapid ageing and the development of her disease guided her to a deeper understanding of her life and its meaning. This understanding transformed earlier values and influenced her view of others.

Discussion

The Parkinson’s disease complaints in Sofia’s narration are easy to recognize: visuo-spatial deficit, postural instability, hypokinesia, rigidity, tremor, physical and mental on-off signs, decreased simultaneous capacity, bradyphrenia and increased sensitivity for stressful situations. From this perspective, current results confirm other findings (c.f. Jankovic, 1987; Louis et al., 1999). The important finding is the illumination of how Sofia incorporated these symptoms in her life world. She did not experience them as singular entities. Rather, they were embodied in her being and experienced as a way of encountering her world. Also important is the intimate connection between Sofia’s experience of environmental and social influences and the possibilities she had for expressing herself and her ability to perform tasks. In addition, her medications did not always work the way she needed them to work for her in given situations such was when she felt uneasy. Accordingly, the medications extended far beyond their target, the biological body (c.f. Habermann, 1999).

Another very important result is the ways in which Sofia strove to find a means of holding onto her basic attitude concerning the meaning of life and to face significant challenges that she believed were expected of her in life. With changed life conditions and new experiences, her expressions became visible in various ways. Her outlook on life remained the same within her changing life, while she experienced that her interpretation and understanding of important issues became deeper and more insightful. Consequently, Sofia’s way of coming to terms with her illness and symptoms were in relation to her cultural meanings and concerns, embodiment, situation and temporality. These findings are aligned with other studies that focus on the lived experience of Parkinson’s disease, and they emphasise the importance of giving advice and treatment, by accounting for the individual’s way of living through illness experiences (Caap-Ahlgren & Lannerheim, 2002; Habermann, 1996; Sunvisson & Ekman, 2001).

With this in mind, Sofia teaches us that the focus in healthcare should be to help patients to elicit potential situations that would solicit a reintegrated healthy understanding of the self in the situation. Absence of such support leaves the individual alone with the difficult task of trying to work out ways of coming to terms with all the challenges that illness brings about.

Being afflicted with Parkinson’s disease is to live with a neurological disorder associated with medications that patients and caregivers must know a lot about. As the lived body is an intertwining of
intentionality and materiality (Merleau-Ponty, 1962, pp. 130–155), notions of disease should involve existential and biological concepts related to care and treatment (Leder, 1998, Svenaeus, 1999). Thus, caregivers must find out how patients understand illness-related interruptions and effects from medication on their everyday lives. Neurological and neuropsychiatric knowledge about Parkinson's must then be used and discussed with patients in a way that makes it comprehensive and meaningful for each person. Since illness is an embodied experience, caregivers also must understand how engagement, situation and surroundings influence a person's illness experience and ability for expressions. In addition, they must be sensitively open-minded in meetings with each person and attuned to the person's rhythm of time. In every meeting, caregivers must reflect on what influences the chosen place for communications and own body rhythm might have for the person's experience of interruption or involvement. Together, this will provide opportunities for meeting the great challenge in healthcare: giving people who suffer from illness optimal medical treatment and helping them acquire experiences of health and well-being – even when suffering from an incurable illness.

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Note

1. L-dopa is the chemical substance in the most important drug for Parkinson’s sufferers.

References


