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**Lived body-selves in post-polio syndrome:
a narrative analysis**

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UNDER SUBMISSION AT MEDICINE, HEALTH CARE AND
PHILOSOPHY

ABSTRACT

Purpose: This paper aims to understand how people with post-polio syndrome (PPS) experience their body-problems and body-selves.

Method: This study employed narrative interviews with 21 people with PPS. Participants were asked to tell their personal story, describing the impact of the acute polio, the sequelae and later the PPS. Afterwards, a narrative analysis was utilised. Two stories were captured in a vignette and analysed with the use of Arthur Frank's typology of body problems.

Results: The first narrative was characterised by a great need for body-control. In addition, it showed a disassociated body-relatedness, meaning that the body was seen as a more or less separate object from the 'self'. The second narrative was characterised by an associated body relatedness (where the body was seen as part of the 'self') and a dyadic other-relatedness. This implies that the body is seen in a larger social context, where the body does not belong to the person alone.

Conclusions: This study provides value by giving insights into the behaviours, needs, and struggles of people with PPS. Insights into these relational body-selves can support health care professionals to better understand the needs and preferences of people with PPS and the right approach for treatment and support.

Key words: illness experiences, body-problems, narrative analysis, post-polio syndrome

INTRODUCTION

Post-polio syndrome (PPS) is a clinical syndrome of new symptoms, such as increased muscle weakness, pain and fatigue, that can occur in polio survivors decades after the acute disease (1). Over recent decades, many studies have been made into the prevalence of PPS but the numbers are still ambiguous (1-4). Studies in European countries show a range of 31 to 80% prevalence of PPS among polio survivors (1; 4). The majority of studies conducted on PPS focus on the aetiology and physical aspects of the disease (5). Living with a chronic illness such as PPS can have major impact on people's functioning and quality of life in general (6). Physical symptoms can also result in psychological problems, such as depression, anxiety and stress, but also existential challenges relating to one's identity.

Only a small number of studies have explored the personal experiences of people with PPS and its effect on self-identity (5; 7). There has been no research to date that focused on perceptions of the bodies of people of PPS and how the body connects the existential, psychological and physical dimensions of living with PPS. There have been studies that explore the experiences of people with chronic illnesses in general and how they carry their experiences and knowledge "like an invisible rucksack, incorporated within the person, or embodied" (8 quoting Merleau-Ponty (9)). Frank (2013) emphasises the importance of the body and body-experiences in his theories (10). According to Frank, bodies are of great importance as they communicate in their own way, telling their own story. During illness, the story of bodies can change, as it becomes difficult to continue as the body that one used to be.

Frank builds upon Kleinman's (1988) concept of 'body selves', which refers to "how to act as an embodied being" (11). In his theory, Frank distinguishes four problems of embodiment: body-control, body-relatedness, other-relatedness and desire. In each body-problem, the patient experiences 'tensions' between the extremes of the continuum of each problem. For example, the problem of body-control deals with the amount of control one experiences over one's body. This can be a sense of full control or no control at all, and everything in between. According to Frank (2013), each of these problems is a problem of action: *'to act, a body-self must achieve some working resolution to each problem'* (10 p. 29).

In the past, narratives have been used effectively to understand the body problems of people with chronic illness and disabilities (12). This paper explores the meaning of the three narrative types that Frank developed and relates them to the body-problems of people with PPS. These illness narratives include restitution, quest and chaos narratives. The restitution narrative is focused on becoming healthy again. The quest narrative is about a patient who journeys through their illness process and finds or creates meaning.

The third and last narrative developed by Frank, is the chaos narrative, and which involves a story that is incoherent, often unheard, and messy. Frank calls this an anti-narrative, as it is without sequence or reflection (yet). All these types, in a way, are based upon assumptions about the body. For example, the restitution narrative has a rather mechanical view of the body as something to be fixed (10).

This paper aims to understand how people with PPS experience their body-problems and body-selves. Understanding these body-selves of people with PPS, can generate empathic relationships with the storytellers (13). This can help, for instance, health care professionals to build a better relationship with their patients and gain a broader understanding of the care needs of people with PPS. The paper critically discusses Frank's body-types by relating them to the empirical insights into experiences of people living with PPS.

THE POST-POLIO SYNDROME BODY-SELF

Although PPS is not life-threatening, it has a strong influence on people's lives. There is no pharmaceutical treatment specifically for PPS. People with PPS suffer from pain and fatigue and this demands lifestyle changes that concern learning how to manage one's disease. Exercise, the use of mobility aids, and revised activities in daily living are advised. In order to prevent body exhaustion and rapid muscle tiring, people are advised to pace their daily activities (14). Patient education, learning about PPS, is generally considered important for patients. People with PPS also experience psychological symptoms, such as anxiety, depression and chronic stress. People fear a loss of control or becoming dependent on care professionals or informal carers (15). Altogether, PPS has a great impact on people's bodies, minds and lives. There is, however, little research about how people with PPS experience their sense of self and body. In the second half of last century, theories about illness narratives were developed that inform us about how the self is perceived through narratives. Frank developed one such a theory, using the concept of 'body problems'. He distinguishes body problems that inform us, directly or indirectly, about how a person with a chronic illness perceives their 'body-self'. We will now briefly present each body problem.

Body-control

Body-control relates to literal control over the body; being in control of muscles, bladder, sweating, emotions etc. A lack of control can lead to stigmatisation. When becoming ill, some body control is lost. As a result, some people end up in a crisis (often seen by people who lose a lot of body functions such as in amyotrophic lateral sclerosis). These people need control over their body, as it leads to a certain 'predictability' (10). For some

people, the unpredictability is even harder than the physical symptoms themselves. Other people can handle the loss of body-control and the unpredictability quite well, which Frank calls 'contingency'. The continuum of control is often a mixture of a level of predictability and an acceptance of a degree of contingency. How a person responds to a loss of predictability is closely related to the problems described below.

Body-Relatedness

Body-relatedness concerns the way in which people experience their body and can best be summarised in the question: 'Do I *have* a body or *am* I a body?' This question shows that one can experience the body either as an object that you have to deal with, or as a part of the entire, holistic, person. From the holistic perspective, people are in contact with their body, 'listening' to what it has to say (although 'listening' does not seem to be the right word, as this still suggests a dichotomy between the body and the rest of the person, as one can decide not to 'listen' to the body). This is what Frank calls 'associated' body-relatedness ('I am what I eat' Frank, 2013:33). If one sees the body as a separate object, a thing that has to be 'fixed' or with which one has to 'deal' when it becomes ill, it is called a 'dissociated' body-relatedness. Narratives can give insight in whether people experience their body as associated or dissociated.

Other-Relatedness

Other-relatedness is about how people see their body as related to other people, and more specifically other bodies. People can experience a high level of relatedness, for example in feeling common pain (as with peers). The experience of having the disease together as a family or with loved ones is also a way of experiencing other-relatedness. Frank calls this a dyadic, empathic relationship; although the other body is outside your own, there is still a relatedness as both bodies have a relationship with each other. Other people do not feel a shared or common experience; they feel they have to deal with the illness by themselves and that their experience is highly personal and significantly different from that of others. Frank calls this a monadic other-relatedness.

Desire (the body as expressive, performative)

The final body problem described by Frank is the issue of desire. Desire is characterised by its infeasible wishes; there is always the wish to get 'more', whatever 'more' is. If people experience a great deal of productive desire, this is a sign that they still love themselves and their lives; they want to keep on going. The opposite of productive desire is a lack of desire. This is the case when people experience no desire at all, and at its most extreme, no desire to live. People no longer love themselves, or the life they are living. Of course, the productive desire and the lack of desire are, as with the other problems, two extremes on a continuum, and most people experience desire somewhere in between these two extremes.

Altogether, Frank presents four types of body-selves. Figure 1 gives a schematic representation, as made by Montez et al., of the four above-mentioned body problems with the two extremes given for each problem (13).

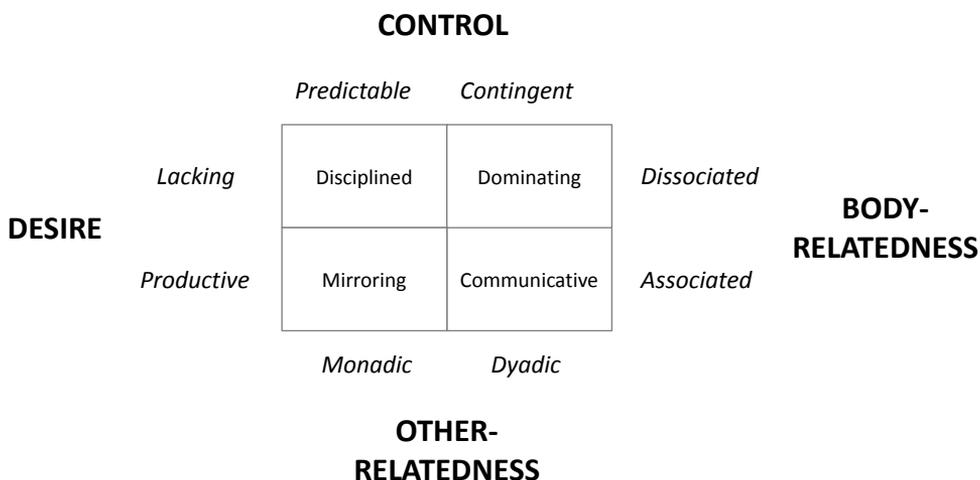


Figure 1: Typology of action problems, action responses, and ideal body types. Based on Montez & Karner (2005).

METHOD

Design

The current study employed narrative interviews, as the researchers were interested in exploring participants' individual stories of their lives with PPS. Participants were asked to tell their personal story, describing the impact of the acute polio, the sequelae and later the PPS. In order to illuminate personal nuances, participants were asked open-ended questions. Afterwards, a narrative analysis was utilised, to provide knowledge of general concepts within the stories.

Participants

The empirical data in this article consists of individual qualitative interviews with 11 women and 10 men with PPS. All participants were between the ages of 54 and 72. The participants were recruited from a larger RCT cohort (2). Participants of the RCT were asked by the coordinator of the RCT if they were willing to be interviewed. 21 participants agreed to an interview and were contacted by MB or KS for an appointment.

Data collection and management

Each participant was involved in an interview of 60 to 90 minutes duration. Interviews were conducted in the participants homes, for privacy and comfort reasons. The interviews were conducted by either MB or KS using an interview guide. This guide consisted of a short introduction to the study and open-ended questions, such as 'can you tell me something about your life after the acute polio?', to initiate the process of storytelling. This afforded sufficient flexibility to further explore relevant themes or statements, while allowing the participants to speak freely and influence the direction of the interview (16). Themes addressed in the interviews include the acute polio, life after the acute polio, the onset of new symptoms, the diagnosis of PPS and life after this diagnosis. The interviews were, with the permission of the participants, audiotaped and transcribed. Each participant was sent a summary of their transcript to check accuracy (member-check) (16). Few participants requested corrections, and these were mostly related to specific facts (such as dates or work history). All names were de-identified to maintain participant anonymity. Ethic approval for the study was granted from the VU Medical Centre.

Analysis

Following an interpretive narrative analysis, the interviews were read several times as a whole, in order to develop familiarity with both their structure and their content. Unlike traditional qualitative methods, the narrative analysis does not fragment the text into discrete categories for coding purposes, but, instead, longer stretches of talk that take the form of narrative were identified (17). The analysis aimed to interpret the ways in which people perceive reality, make sense of their worlds, and perform social actions (18 p.71). This led to the development of the plot and point of convergence and divergence across the narratives (19). To elucidate the broader social significance of these findings, we used Frank's typology of body problems.

The narratives were reconstructed into narrative vignettes. The aim of these vignettes was to provide the reader with a vicarious experience of the lived experience of the respondent. Narrative elements such as time, space, beginning, middle and end were taken into account and the authors created a balance between the themes in the original data (the transcript) and the vignette. MB and MV chose two narratives that represented two different types of stories and emerged from the analysis. Although both narratives had their own individual characteristics, the themes in these narratives have been found in the other interviews as well, and therefore, these two vignettes can be seen as a representation of the general storylines in all interviews in this study.

LIVING WITH POST-POLIO SYNDROME: TWO NARRATIVE VIGNETTES

We will now present and subsequently analyse the two narrative vignettes of people with PPS. Each narrative has its own plot that helps us understand how the patient experiences living with PPS. We selected these two cases because of their depth and variety, and chose two contrasting narratives. The first narrative can be considered a restitution narrative, the second a quest narrative.

Vignette of Mrs. Welling: Ongoing learning and balancing

Learning how to handle her disease and preparing for the future by herself: that is what living with post-polio syndrome seems to be about for Mrs Welling*. As a woman of 71, living alone with her cat and dog, she tells us about her ongoing journey to find balance since she was diagnosed with PPS five years ago. Mrs Welling does not like to complain. She does not want to be a burden to the people who are close to her and prefers to be as self-sufficient as possible.

Mrs Welling suffered from her symptoms for a long time, without knowing or understanding where they came from: extreme fatigue and because of her fatigue, she wasn't able to work for long hours. There were times when everything went well, when she could function properly, but at other times, her pain increased and it became hard for Mrs Welling to keep up with others. 'She didn't know exactly where to go with her symptoms, because 'it could have been everything'. She did not want to enter the medical treadmill again. One day, Mrs Welling stumbled upon an article on post-polio, and she felt a sense of recognition: *"I thought: that's it!"*. As a child, she had polio: *'When I was about two years old, so during the war, 1944, 1945'*, according to the story her father told her. After reading the article, she visited her general practitioner, who she felt always understood her, and indeed he did. He referred her to a rehabilitation specialist, who diagnosed her with PPS. That came as a relief: *"That was a relief. Really, like, I have not imagined things, there is a cause for my stiff, weak and unwilling-muscles"*.

Despite this relief, Mrs Welling experienced great challenges dealing with her disease. She felt she had entered a vacuum. She didn't know what to do and where to find support. She wondered: *'Am I doing it right'?* She had difficulty finding the right balance between rest and activity. *'Then I'd done something and afterwards a felt so miserable that I had to rest for three days'*. She didn't know where to go or who to consult with her questions and complaints, and because of that, she felt very lonely and isolated. The pain in her leg became worse every day.

Almost immediately after she was diagnosed, she started physical training at the Academic Medical Centre in her home town, which ended about four years ago. Since then, for about three years, she received no significant support from professionals. That changed a year ago. Her learning process accelerated then, when she received a referral to a rehabilitation clinic where she underwent several treatments. Since then, she has felt better and her sense of isolation and loneliness subsided: *'Since then, I don't feel isolated anymore and I know now how to handle this [illness]'*. This doesn't imply that Mrs Welling was never tired again, she still crosses her boundaries once every so often: *'I sometimes overstep my boundaries. Sometimes you can't avoid overstepping your physical boundaries. And I pay the price the next day, when I'm in more pain.'*

The last year, at the rehabilitation clinic, her treatments varied from physical therapy, occupational therapy, haptotherapy and she also visited an orthopaedic therapist. Mrs Welling is clear about what she wants and she stressed that is a common trait of people with her disease. For example, Mrs Welling was very clear about where she wanted to exercise: not at the clinic, but at home. From her occupational therapist, she learned how to schedule her days in a balanced way: to prevent too many downs and ups. She really benefited from that: *'Really, that was great, really great'*. Before her visits to the occupational therapist, Mrs Welling didn't know what she was capable and not capable of doing. Now she experiences more balance: *'I don't have these highs and lows anymore, and for me that is fantastic'*.

Mrs Welling handles her disease by herself as much as possible. Sometimes she meets with a fellow-patient and they exchange stories about living with polio and post-polio syndrome. Mainly, though, she does not like to be a burden to the people who are close to her: *'Well, I think post-polio patients are people who will not discuss their problems and so they keep on going and going and they don't want to burden others with 'twaddle', or at least that's how they see it'*. Mrs Welling recognises this: *'My children don't know what is going on or how I feel sometimes. And I don't want them to know. But you can imagine that it is nice when someone, an outsider maybe, knows what's going on, so you can talk about it with someone'*.

Currently, Mrs Welling is no longer supported by professional care. She tells us she now has the knowledge and means, and also some small technologies, to handle her disease in a balanced way. She does, however, still experience pain in her legs that feels like tooth pain. She is unable to walk long distances and cannot ride her bicycle any more. Although she doesn't need assistive devices, she has prepared for her future: *'I have a walker, but that is because someone gave it to me. I will use it if necessary in the future. Because some days I have trouble walking'*. She has become rather inventive about how to cope with daily tasks, like walking her dog: she drives to a place where he can run freely and play with the balls she throws. This makes him run and play, so that she doesn't have to walk a long way.

*Fictitious name

Analysis of Mrs Welling's problems of embodiment

Mrs Welling experiences the loss of control as difficult; for a long time she looked for the reason she could not function well and why her body didn't want to do what she wanted. The uncertainty about what was wrong with her and the unpredictability of her body was problematic for Mrs Welling, functioning well the one day, and the next day being unable to keep up with others or not being able to control her *stiff, weak and unwilling muscles*. Since the consultation at the rehabilitation clinic a year ago, Mrs Welling feels much more in control of her body and therefore less lonely and isolated. This shows that Mrs Welling is in need of predictability rather than being able to accept the loss of her body-control (contingency).

It is evident that Mrs Welling experiences her body as a separate object, which she has to deal with. The statement '*I know now how to handle this*' shows that she sees her illness and her body as separate from 'herself'. For a long time she did not know how to handle 'it' right, which led to problems such as feelings of loneliness and isolation. Now that she knows how to manage her body she feels better. The word 'handle' in particular clearly indicates that Mrs Welling does not experience her body and illness as part of herself; it is something that has to be managed rather than being a part of her. The fact that she experienced the diagnosis as a great relief and as a reassurance that she was not imagining things, was also important to her. This shows that the label seemed of more importance than the bodily experiences of the symptoms, which fits a more disassociated experience of the body.

Both monadic other-relatedness and dyadic relatedness seem to be found in Mrs Welling's story. She explains that she wants to find out how she can handle the disease by herself, and that she wants to manage the disease by herself, not being a burden to her loved ones; she does not even tell her children how she feels. She describes this as being typical of people with PPS. This suggests a preference not to be too closely related to others, not to be joined by others in her bodily experiences, she prefers to be separate and alone. This is a preference, however, that does not always apply when we look at it from a more existential and experiential perspective. From that perspective, Mrs Welling describes the value of contact with peers every once in a while. This suggests that she does feel a certain kind of relatedness to her peers, and that she is better able to exchange experiences with people with the same sort of experiences, rather than people without similar experiences, such as her loved ones.

Mrs Welling does not seem to experience an extreme lack of, nor productive desire. On the one hand, she described productive desire in explaining that she has found ways to handle her illness and still be able to do the things she wants, such as 'walking' the dog by throwing balls rather than walking long distances. She seems to experience fun in life. She also prepares for the future, already having a walker, although she does feel reluctant to use it, as it is a confirmation of yet another loss of control.

Vignette Mr Petersen: The ongoing fight

"Having Post-polio means fighting" says Mr Petersen, "endlessly fighting". Fighting against his body, against needles, fighting for the right support, fighting against how people view him and fighting against boundaries that he finds difficult to acknowledge. Only when he is at his holiday house does he seem able to let go and accept things: it is only there that he doesn't care about what other people might think of him.*

Very early in his childhood, at the age of 7 months, he was diagnosed with polio. His cousin carried it from his travels to Indonesia and this affected Mr Petersen's arm and leg. His childhood was severely affected by the polio and the disabilities that caused it. He felt he was *'dragged from one therapy to another'*. He had to undergo physical therapy and injections in his back daily and he experienced this as devastating. This resulted in a fear of needles that lasted until he was about 30 years old and a doctor helped him heal from his fear. Because he felt different, Mr Petersen preferred to be just like other children, so he did his very best to belong, by giving just a little more than he felt capable of: *'I bought friends, because I could do things that they could not. I profiled myself, I went to the extreme until it didn't work anymore'*.

Until he was diagnosed, Mr Petersen didn't know about the existence of post-polio syndrome. Being diagnosed felt like a 'recognition': *'then we knew where it came from and then I could start to behave like it. But I didn't. First you need to fall 25 times and only then you learn where your boundaries lie'*. He reports that someone with post-polio syndrome will always cross their boundaries, but *'that is sometimes worth it'*.

Mr Petersen spends his time as a volunteer at a car-repair shop and goes outside for a walk or cycles at least once a day. Once a year he travels to Africa to bring goods to locals, because he feels he wants *'to contribute to humanity'*. He also likes to go to his holiday house with his wife, in another part of the country. During their visits, he can drive freely in his scooter. He doesn't feel judged or looked down upon by people who have known him for years there: *in my hometown, everyone knows me from the fair where I used to work as a child. I was the only one with a disability and everyone was really jealous. I want to keep that pride'*. That is why he doesn't feel comfortable driving his scooter at home. At his holiday house, though, he is not focused on keeping his pride: *'there, it doesn't matter to me at all'*. He says that getting access to these devices was a fight: At the local council, he applied for an electric bicycle, but his request was rejected: *'I was offered a scooter, which is much more expensive, but no electric bike'*. He decided to appeal and in the end, he got the electric bike.

Despite knowing 'why' he has symptoms, it feels as if he has a double disability. To him, it feels as if he has carried something with himself, during his whole life: *'first I am sick, then everything stabilises, now I am worse again...'*. This really bothers him: *'The question is 'why me?'* In times of decline and regression, this questions pops up in his mind. He wonders: *'Where does this end?'* He worries about the progression of his disease, now that his right arm is slowly failing as well. He wonders how long he will be able to drive a car. Usually he has the strength to look for solutions, but now that the strength in his muscles is declining, he wonders how long it will take before he can't do anything anymore. *'If this [right arm] was to really fail, then it [life] will be no longer worthwhile. Then I'll arrange something with a friend of mine who is GP... My wife fully supports this decision'*.

*This is a fictitious name

Analysis of Mr Petersen's problems of embodiment

Mr Petersen experiences a loss of control. He speaks of his 'fight' against this loss, but simultaneously he seems to be able to cope with its unpredictability in a resilient way. Sometimes he goes beyond what he is physically capable of: *First you need to fall 25 times and only then you learn where your boundaries lie*. When a physical therapist tells him there is no treatment available anymore, he fights that and finds a new therapist.

Mr Petersen explains that he feels as if he has carried something with him all his life, and that he felt the urge to prove that he could do anything, physically. This suggests that Mr Petersen is experiencing a close association with his body. In his story, Mr Petersen seems to refer to himself ('I') as a person, not solely his body. We can also deduce his associated body-relatedness from what he did **not** say. He describes the process; 'First I am sick, then everything gets better, now I am worse again'. He could also have said that 'his body' deteriorated again, but instead he reports that 'now I am worse again'. Mr Petersen experiences his illness as a part of himself, of who he is as a person. He talks about the great amount of effort and time it took him to learn how to handle his body. He had to cross countless boundaries: *'I went to the extreme until it didn't work anymore'*. Note that he didn't say 'I took my body to the extreme', which would have implied a disassociation with his body. When Mr Petersen heard about his diagnosis, he finally felt 'seen' and knew he had to adjust. He explains: *'...then I can start to behave like it'*. 'I' refers to himself as a whole person, not just a disassociated body.

Mr Petersen's narrative illustrates a clear example of someone with a dyadic other-relatedness. Mr Petersen is very aware of other persons he 'relates to' (10 p.35); he does not belong to himself alone, but also to his neighbourhood, the people of the fair, the residents of the holiday park. *'In my hometown, everyone knows me from the fair where I used to work as a boy. I was the only one with a disability and everyone was really jealous. I want to keep that pride'* That is why, in his hometown, Mr Petersen doesn't feel comfortable driving his scooter. At his holiday house, though, he is not focused on keeping his pride: *'There, it doesn't interest me at all'*. He also belongs to his marriage and involves his wife in important decisions. This is a clear example of someone who experiences a close relatedness to others in his bodily experiences.

Mr Petersen worries a lot about his life, especially in times of remission, and he wonders: *'Where does this end?'* But the lack of control does not challenge his desire to live. Mr Petersen's story is a story about a strong desire to live, to fight for a life that is as good as possible. It also demonstrates that Mr Petersen is aware of how he expresses his body, to whom and where, and he consciously decides on actions based on that awareness, for example, when he decides to let his pride prevail and not drive a scooter in his hometown.

DISCUSSION

Through the presentation and analysis of the two vignettes, we have presented a narrative analysis of the body-selves of people with post-polio syndrome. People with post-polio syndrome share their experiences of living with their illness and the impact on their sense of self and body. Their narratives provide us with illustrations of the lived body-problems they experience, and from that, we can deduce how they perceive their 'body-selves'. The first narrative was a restitution narrative, which was characterised by a great need for body-control. The narrative also showed a disassociated body-relatedness, meaning that the body was seen as a more or less separate object from the 'self'. The second narrative was more of a chaos narrative, without a clear vision of where it all would end. This narrative was characterised by an associated body-relatedness (where the body was seen as part of the 'self') and a dyadic other-relatedness. This implies that the body is seen in a larger social context, where the body does not belong to the person alone; he was aware of the other persons to whom he is related. We will use this discussion to reflect upon the practical relevance of the body-problems presented.

When looking critically at the typology of Frank's body problems, one can conclude that the given typology does not mirror the lived experiences of people with PPS. We see this, first of all, when we look at the concept of 'other-relatedness.' Based on our results we would argue for a more context-related perspective of the 'other-relatedness' than Frank proposed. In the theoretical continuum of, on the one side, dyadic, and on the other side, monadic, types, other-relatedness does not so much involve how one generally feels related to 'others', but is closely intertwined with *what* particular others are involved in *which* situations. This would plea for 'situational other-relatedness'. A second shortcoming of Frank's model is that Frank's typology emerged from looking at *action* problems and the responses of people with a chronic illness. The *lived* experience perspective of people with PPS points to other problems that are body-related, but not related to action. For example the experience of 'being with pain'.

As with all models, however, we realise that Frank's model of body problems is inevitably a simplification of reality and therefore we cannot ask it to mirror the real world. It seems more meaningful to look at it from a performative perspective, by asking ourselves how this model can be helpful for health care practice. In recent decades, patient-centred or patient-led care has become increasingly important in western health care (20). The aim of this care is to give patients more 'choice and voice' in their own health care. This should be done by, amongst other things, "respecting people for their knowledge and understanding of their own experience, their own clinical condition, their experience of the illness and how it impacts on their live" (20; 21). Dahlberg et al. argue that a good practical execution of this can be rather difficult, and runs the risk of resulting in

economic or political driven health care instead of care that accommodates the agency and vulnerability of patients (20). In order to create meaningful patient-centered care (or, as Dahlberg et al. call it, 'lifeworld-led care'), health care professionals need to really take a patient's illness experiences into account and see patients as "storied beings" (20 p. 270).

Frank's body problem typology is built on philosophical concepts and at the core is epistemological: it is focused on how to *know* body problems. The concept of body-relatedness, although using other words, has been discussed by the phenomenologist Husserl in the 1950s and has often been used ever since (22; 23). In this theory, a distinction is made between the body as a 'Körper' (an object) and the body as a 'Leib' (a subject). In abstraction, "...there is a subject: a 'you,' posited separate from another entity, 'the body'. The relationship seems to be about possession: you, the subject, have or own an object, the body" (24 p. 40). In addition, when we move to ontology, Heidegger, with his notion of Dasein, being-in-the-world, went beyond the dichotomy of the body as an object and subject and moved toward the body as the place where "we", or our relational selves, dwell (25). Seen from this relational ontology, we could perceive people with PPS as continuously being in a living relationship with their bodies. Frank's model describes relationality and self/other as epistemological axes (ways of knowing the body problems) and from this we could argue for a relational paradigm and then develop a model of body problems. The typology of Frank thus gives insight into the importance of the difference of Körper and Leib (or as he calls it associated or disassociated bodies); prior to paying attention to the body, health care professionals should become aware of *how* patients experience their lived body from a relational perspective on body-selves. Patients who talk in a dissociated manner about their body might need a different approach (based more on how to handle the body) than patients who talk about their body in an associated manner (more holistic based care).

We believe that Frank's typology of body problems can help health care professionals to see patients as storied, embodied beings. It is applicable for health care professionals precisely because of the discussed simplification of this model; it points out four important themes that affect the illness experiences of patients and describes how these experiences can be affected. The analysis given in this paper can be used as an example, or even a guide to help health care professionals give meaning to the patient stories they are confronted with in practice. Although this might be a difficult task, we believe that this paper provides some first tools to do so.

In summary, insights into relational body-selves can support health care professionals to better understand the needs and preferences of people with PPS and the right approach to treatment and support. A patient who experiences a lack of (bodily) control may need different treatment and care than a patient who experiences a lack of desire to live. Insight into the body-selves supports health care professionals in deciding whether to refer someone to an occupational therapist or to a psychologist.

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