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Hope and Haunting Images

The Imaginary in Danish Parkinson's Disease Rehabilitation

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Abstract

Much in life is imagined: hoped for, dreamed about, or dreaded, as we engage with potential futures. Parkinson's disease is a progressive and neuro-degenerative disease, currently incurable. During long-term fieldwork among Danish rehabilitees with Parkinson's disease, rehabilitees' mentioning of hope and images of the future gradually inspired attention to an imaginary dimension in rehabilitation. We explore haunting images and hope among rehabilitees as examples of the imaginary in rehabilitation, but also as windows into how rehabilitees orientate themselves towards an uncertain future. We show how rehabilitees' imaginations of the future resemble hauntings instigating an urge to 'do something' to avoid their actualisation; to insist on living in the now, keeping up training, and partaking in clinical trials. This urge translates into rehabilitation practices, where rehabilitees and professionals work with both hope and rehabilitation goals to maximise the present and postpone the future. We emphasise that hope is a complex phenomenon; it is multiple and has a certain elasticity. A person can carry multiple hopes at once; hope can be agentic, co-created and worked with, located, or be an existential stance.

Keywords

Hope, Imagination, Haunting, Rehabilitation, Parkinson's Disease.

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Introduction

> I think hope is always there to at least push it for as far as possible. My neurologist had to make a memo to the employment office. He tells us he'll paint the picture darker than black. As he reads from the memo, [to me, it sounds] something like, 'And after 10 years, you are dead'. My husband and I looked at each other. I thought: 'Okaaay! Ten years! And will life get so tough that you don't . . . ?' But that's in a long time, [medical research] improves all the time, and we *can* do something ourselves. But nevertheless, I do think about this.

Anita's voice fades. She looks downward. Her bleak imagining of the future suddenly contrasts with the bright, inviting flower arrangement at the reception desk of Sano, a specialised rehabilitation centre where Anita awaits her goal-setting meeting. Anita, in her early fifties, was diagnosed with Parkinson's disease (PD) three years earlier. Recounting a consultation at her neurologist's, Anita's imagining involves both a dread that her future life with PD will be tough, but also an embedded hope: the invention of new medicine, and that her own training may help to stall degeneration. Indeed, imaginative lifeworlds and inner dialogues are central subjects for attention in fieldwork among persons confronted with life-threatening diseases that disrupt and bring uncertainty to everyday life (Irving 2017). Hopes, dreams, and dreads may form part of a person's inner dialogue, not necessarily shared with others. In our fieldwork on goal-setting in Danish PD rehabilitation, rehabilitees' imaginations of the future featured goals, hope, and dreads that appeared as specific haunting images.[1] Goal-setting is part of rehabilitation practice, whereby rehabilitees share their rehabilitation goals with professionals to align expectations and set the trajectory of their treatment. A rehabilitation goal can be an activity or a life role that a rehabilitee wishes to be able to do again, like buying groceries or attending family gatherings. In Anita's case, a standard question posed by professionals, 'what are your goals?', requires that she shares her imagination of the future. Goal-setting thus forces the imagined to be made explicit. However, in observations of goal-setting sessions, it became apparent to us that rehabilitees often made subtle references to hope and what we have termed haunting images, which we explore in this article.

The short sentence, 'You have Parkinson's', signifies a dramatic change in one's life. A progressive, neuro-degenerative disease, PD appears as a 'designer disease' (Solimeo 2009, 5), manifesting itself differently in each individual, affecting speech, cognition, and mobility. Persons living with PD must adapt to an evolving situation, as PD's intrusions on the body provoke changes in everyday life and enforce a continuous remaking of daily routines and life plans to fit the

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[1] We use the term 'rehabilitee' as a short term for a user of a rehabilitation service; some research participants objected to being called 'patient'.

current situation. As the disease progresses over time, needs for health and social care change and increase, including the need for rehabilitation. Chronic illness may threaten to unmake the everyday world of persons suffering chronic pain or life-threatening illness (Good 1994). Rehabilitation entails different therapeutic strategies, pursued by rehabilitees and professionals to remake everyday life in the best possible way. With progressive diseases such as PD, rehabilitation may aim to maintain bodily function for as long as possible, by building up strategies that can minimise the extent to which PD affects everyday life. Much clinical rehabilitation literature emphasises specific interventions and the measurement of the effect of these interventions (Kersten, Lundgren-Nielsson and Batcho 2015).

Anthropologists point to other aspects of rehabilitation, describing it as a (self-) transformation process (Tjørnhøj-Thomsen and Hansen 2013), a liminal phase (Zigon 2010), or pointing to its imaginary dimension (Mattingly 1998 , 2010), which is the primary focus of this article. Here, hope and haunting images indicate how research participants orientate to the future; Bryant and Knight (2019) stress the value of more heavily incorporating future orientations (e.g., hope, anticipation) into anthropologists' engagement with time, the past-present-future relation. As compellingly argued by Dekker (2020) in her work on dementia, euthanasia, and anticipation of the future, the future may be unwanted.

In this Research Article, we aim to explore haunting images and hope among rehabilitees as examples of the imaginary in PD rehabilitation, but also as useful windows into how rehabilitees orientate themselves to an uncertain future. We pose that it is relevant to explore both dreads and hope in the context of living with a progressive, degenerative disease. Moreover, there may be practical benefits, since hope can elucidate the kind of choices rehabilitees make during their rehabilitation trajectories. We argue that imaginary processes are part of rehabilitation as, for instance, goal-setting requires imagination. We suggest that in order to bring nuance to our understanding of rehabilitation practices, the imaginary should be studied in greater detail. In this article we focus on haunting images and hope, but we explore goal-setting as an imaginary act elsewhere (Tonnesen, Nielsen, and Andersen 2022). Though our empirical examples are related to PD and embedded in a Danish context, we believe that our results may have wider applicability, not least our conceptualisation of hope, which we argue may take different forms in a person and be co-created between rehabilitees and professionals.

In the following, we situate our study within anthropological scholarship on the imaginary, hope, and hauntings. To contextualise the fieldwork, we briefly introduce PD and Danish PD rehabilitation. Using an empirical example, we then show the subtle way in which hope enters goal-setting, and then introduce the haunting images of the future. We show how hope is multiple, and is not defined in the same way by all rehabilitees. We examine ways hope is located, co-created, and changed over time. We conclude that it is multiple and elastic, and that both hope and haunting images relate to an urge to ‘do something’ to postpone degeneration for as long as possible.

The imaginary: Hope, hauntings

Anthropologists have increasingly called for attention to imagination, with the argument that since imagination is part of human life, and ‘so much in life, so many improbable conversations and probable scenarios, are imagined, not concretely real’ (Desjarlais 2018, 86), it should be studied in more depth.

Several studies have focused on imaginary processes or acts in the context of chronic disease. Irving (2017) argues that ‘imaginative life worlds’, e.g., thoughts, fears, and hope, should be incorporated in studies of long-term illness (2017, 70). He studies, among people living with HIV/AIDS in the US, experiences of temporal alteration from imminent death to an imaginable future that materialised with the advent of effective antiretroviral medication. Exploring hope among African-American families whose children suffer from serious chronic medical conditions, Mattingly (2010) also asserts that the study of suffering demands an attention to imagination. Furthermore, in a study on clinical interactions in rehabilitation between occupational therapists and severely injured and disabled patients, Mattingly illustrates how patients with lives disrupted by disease must invent new everyday routines and imagine new lives, and how therapists in goal-setting situations imaginatively tour the future with the patient in order to find a goal to strive for (1998).

Hoping is another way of imagining. In Crapanzano’s *Imaginative Horizons* (2004), he uses a montage of literary and arts references and examples from his fieldwork among the Navajo in the US, whites in apartheid South Africa, and the Hamadsha in Morocco to explore the imaginary and the construction of horizons that ‘determine what we experience and how we interpret what we experience’ (2004, 2). He explores imaginative processes, such as hope, existing in a blurred line between present (the insistent reality of the here and now) and future (an optative space-time of the imaginary). Crapanzano describes hope as ‘an emotionally and morally toned descriptor of an existential stance or attitude’; rather than an undifferentiated experience, hope can be specific and concrete, resembling desire, or vague and abstract, resembling some positive resignation (2003, 26, 27).

Mattingly (2010) finds a paradox of hope in her study about families of children with chronic medical conditions: that even in situations of despair, people still imagine a future—they practise hope, attempting to create lives worth living even when a happy ending seems impossible. Hope lives in a temporal lobby, an imaginative, liminal space marked by temporal uncertainty of waiting ‘for the future itself’ (2010, 14). In relation to PD, Warren and Addison find neuro-curative imaginaries powerful drivers of hope, promoting ‘seductive futures’ of return to a pre-sickness state (2020). In rehabilitation contexts, Hansen and Tjørnhøj (2014) show how Danish cancer rehabilitees practise hope-work by editing time, intensifying attention to everyday life, and setting milestones for future achievements. Among persons disabled by acquired brain damage in Sweden, Antelius (2007) finds that with little hope for a future cure, hope instead resided in the actions and achievements of the present. In other settings, the ‘re’ in ‘rehabilitation’ has also been contested. Such is the case for ex-combatants in a US military hospital who in everyday lives marked by uncertainty, wait around for the next thing to happen (Wool 2017). In ‘collateral afterworlds’, ex-combatants live in ‘the temporality of a difficult present where life is unhinged from the pervasive hope for better tomorrow’ (Wool and Livingston 2017, 2).

In our conceptualisation of hope, we stress its multiplicity—that hope can be agentic, i.e., co-created and worked with, hope can be located, or be an existential stance. Hope can also change over time, and a person might carry a number of different hopes at the same time. We attend to hauntings as images of the future invoked in the context of PD rehabilitation. We were inspired to use the notion of ‘haunting’ by a research participant’s mention of the ‘ghost of the future’ in one of our interviews. Anthropologists have described how images can haunt and affect everyday practices and choices. Desjarlais (2018), for instance, photographed a blind man begging; the photo had him embark on an imaginary journey through interpretations of the photograph, fantasies, and his own visions and hauntings. He found that images circulate in everyday life in diverse forms and intensities and have the capacity to affect and disturb. The power of images also materialises in Gammeltoft’s *Haunting Images* (2014), where images depicting victims of Agent Orange haunt prospective Vietnamese parents and influence their reproductive strategies. In the case of dementia, Dekker (2020) finds that the unwanted future may haunt the present. Hollan (2019) urges researchers to be more precise in their description of haunting: are we talking about ghosts? Or are we using haunting metaphorically, a happening from the past that haunts us in the present? In what follows, we use hauntings in a metaphorical manner, to designate persons being haunted by pervasive thoughts of what the future might bring: a type of dread in the form of images of the future, which appear, disappear, and reappear, impinging on the present, and with a capacity to disturb and instigate action.

Parkinson’s disease and rehabilitation in Denmark

PD causes an array of different symptoms, divided between motor symptoms (reduced movements, rigidity, tremor, speech impairment) and non-motor symptoms (cognitive dysfunction, sleeping disorder, mood disturbance) (Davie 2008). Presently, PD is incurable. Medication, exercise, and in some cases deep brain stimulation (DBS) surgery may ease PD symptoms and postpone degeneration. PD affects everyday life in various ways; shaking affects self-control, shuffling steps affect movement, reduced speech volume affects communication, and slowness affects the very speed of life (Solimeo 2009). An uncertainty pervades life with PD. Uncertainty is an embodied mode of experiencing, as fluctuations (between periods when medication works and doesn’t) make the body unpredictable; medication side effects may create new uncertainties, and uncertainty extends to diagnosis and aetiology (Warren and Manderson 2016, Warren and Ayton 2018). There is, however, a certainty in the uncertainty: degeneration will progress.

In Denmark, Sano rehabilitation centre offers a rehabilitation programme for persons with PD who experience challenges in everyday life such as speech impairments, balance problems, fluctuations, and sometimes hallucinations. Patients are referred to Sano by neurologists or general practitioners, and interest in the rehabilitation programme often exceeds capacity. The programme involves an assessment day, two-week inpatient stay, and two follow-up consultation days. At the beginning of the two-week inpatient stay, each rehabilitee attends a goal-setting session. Rehabilitees work towards their goals together with a nurse, physiotherapist, and occupational therapist in individual consultations and through group training (physical training and sessions with a speech pathologist). There are also educational sessions on subjects like PD, assistive technology, and mindfulness. Approximately 1.5–2 years after completing the initial course, rehabilitees can apply for a boost stay.

PD rehabilitation is part of a Danish health care and social service system based on equal and free access to healthcare and social services, financed by general taxes.[2] The system is regulated by a combination of laws, and professional standards (Mainz, Kristensen and Bartels 2015). Goal-setting is part of professional standards and a constituent element in rehabilitation services. Professionals schedule goal-setting meetings, patient journals reserve a space for goals, and curricula in rehabilitation studies include learning about goal-setting. As rehabilitation goal-setting requires an imaginary process, it follows that goal-setting

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[2] That rehabilitation is free does not necessarily mean that everyone who could benefit from the service attends. Sometimes, neurologists or relatives encourage and help rehabilitees to apply for a PD course. Not all rehabilitees receive this support, while others may not keen to leave home for an extended period of time.

entails a formalised imagination. Hope, on the other hand, is far less explicit in rehabilitation. Hope is not formalised as part of goal-setting, rarely worked with explicitly, and hope is not part of curricula.[3] This may be about to change. According to a recent Danish white paper on rehabilitation (Maribo et al. 2022), professionals should consider a person's needs and hopes when planning rehabilitation interventions.

Methods

Our study entailed multi-sited fieldwork on goal-setting in PD rehabilitation programmes at Sano (2018–20), conducted by the first author. As field notes taken during goal-setting meetings revealed how rehabilitees referred to specific imaginaries and used the notion of *hope*, in a subtle way, at times in semantic vicinity to *goal*, hope became a focus of analysis, as did images of the future. Our decision to examine not just goal-setting but also other forms of future imaginations was driven by curiosity; we wondered if exploring hope and future imaginaries could shed new light on life with PD and PD rehabilitation. The first author entered the field via hospitalisations at Sano with two course groups, each with 10 rehabilitees. She followed these individuals, their hopes and goals, over time and across several spaces (their homes, neurological clinics, physiotherapist clinics, and PD dance), in order to gain an understanding of the paths that these phenomena travel (Marcus 1995, 95–105).

At the initial phase of the fieldwork, the rehabilitees were in their late forties to seventies. Time from diagnosis varied from three to seventeen years. Most of the 20 research participants lived with spouses (two also had children living at home), but three lived on their own. Rehabilitees came from different regions and had diverse occupational backgrounds: blue- and white-collar workers, managers, and work histories that ranged from teaching, healthcare, social services to independent consultancy. Four of the 20 were still working, three of them part-time.

The first author participated in two rehabilitation courses and one boost-stay, 1.5 years after the initial course. During hospitalisations, participant observation involved attending group sessions, a substantial amount of training, shared meals, and socialising at night, and observation of 85 individual consultations, including 30 goal-setting meetings. Some of the goal-setting observations were made later on, as the first author followed the staff during goal-setting days.

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[3] One exception may be psychosocial rehabilitation that uses the concept of recovery which encompasses hope. See for instance the Danish Association of Psychosocial Rehabilitation: https://psykosocialrehabilitering.dk.

The first author interviewed the 20 rehabilitees at least twice, first at Sano and later on in their homes, by phone and at nearby cafés. Spouses sometimes participated in parts of the interviews. Some questions were repeated to detect changes in answers over time, including open-ended questions, such as 'What does hope mean to you?' Several rehabilitees participated in additional interviews, often prompted by observations at neurologist consultations, participation at dance classes for persons with PD, or when specific issues needed clarification. Rehabilitees were followed over time both to allow for ongoing discussions and reflections on the same topic, and to gain an understanding of how the 'design' (or symptoms) of PD changes and affects individuals' lives. Over time, data was gathered in a multi-modal form, through text messages, emails, poems, photos, and phone calls from rehabilitees or their family members.

In this article, we focus primarily on an analysis of the rehabilitees' perspectives, but data derived from observations and interviews with clinicians at Sano, relatives, and neurologists and physiotherapists at local clinics contributed to a broader understanding of the field.[4]

Data derived from informal conversations and unstructured interviews has been coded together with the transcribed interviews, and analysed thematically and chronologically. The analysis developed in an iterative process between a continuous reading and interpretation of data and literature (Hammersley and Atkinson 2007). All names are pseudonyms except Sano. Participants provided written consent to observation and interview.

The goal-setting meeting: What will the future bring?

Back in the lobby at Sano with Anita, rehabilitees performed a six-minute walk test. Staff in matching T-shirts and training shoes smiled to those waiting for a consultation; their energetic strides contrasted with the rehabilitees'. Waiting for her goal-setting meeting to start, Anita pondered on her future work situation. Her office job performance depended on her cognitive skills, but now 'I have to write everything down, and I'm capable of doing only one or two tasks at a time'. Anita's benchmarking (Gubrium, Rittman et al. 2003) was common among rehabilitees who assessed their functional capacities and their probable stage of disease trajectory comparing the assessment to their former level of functioning and with the functioning of fellow PD rehabilitees. Another rehabilitee joined us, waving his weekly course schedule; individual consultations with staff mixed with group

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[4] Eighteen Sano staff members and managers, six relatives, and seven external neurologists and physiotherapists were interviewed as part of the research project.

sessions covering topics such as ‘Motivation and Training’, ‘Learning about PD’, ‘Boxing’, and ‘Parkinson’s and Everyday Life’.

A nurse invited Anita into a conference room where the physiotherapist and the occupational therapist sat around a table with a laptop. They both smiled at her. ‘We are here to talk about goals,’ the nurse explained. For 30 minutes, the talk oscillated between what was, what is, and what may be, about everyday life, its difficulties and the future, to find Anita’s rehabilitation goals, including a long-term goal. It was here that a notion of hope entered Anita’s vocabulary: ‘I hope to continue to be able to play with my grandchild.’ They discussed changes being made at her workplace to accommodate her cognitive difficulties, and talked about her ‘open home’ with many guests. Anita’s voice trembled slightly: ‘I used to be able to manage it all.’ Upon exit, Anita reflected on setting goals: ‘It’s difficult when you don’t know what the future will bring.’

The unknown future entered Anita’s reflections during the goal-setting session, present through words of hope and an imaginary of a grandmother’s play with her grandchild. In the next sections, we explore the imaginary dimension of rehabilitation, as exemplified by haunting images of the future and hope.

Haunting images of the future

While positive images of the future were invoked in interviews and conversations, such as Anita’s of playing with her grandchild, the imaginary dimension of rehabilitation stands out most clearly in two particular images of the future often mentioned by rehabilitees, *the declining curve* and *becoming a vegetable*[5] [*blive en grøntsag*]. John introduced the curve as we waited for a consultation on assessment day at Sano. Like a Cartesian coordinate system, he drew a straight line in the air, slowly declining, then suddenly pointed all fingers downwards and made an abrupt move to show how the curve would eventually spiral down. ‘The trick with the Parkinson’s curve is to hold it steady for as long as possible. That’s why I do all this training, although I prefer to sit in my nice armchair.’ John glanced at his wife, who rolled her eyes.

Months later, during a home visit, his wife’s rolling eyes and his armchair took on new meanings for us. John’s PD was accompanied by apathy. He struggled, literally and figuratively, to get up from his armchair and do ‘boring exercises, which I do only because I have to’. For John, in his late sixties, his armchair symbolised peace and quiet. For his wife it seemed to signify an enemy from the not-yet, a future where movement ceases and it is impossible for John to get up, their life

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[5] As in English, *becoming a vegetable* is pejorative in Danish, yet widely used when describing debilitating conditions.

changed radically. A persistent viewpoint permeated subsequent interviews with John and other rehabilitees: ending up in an armchair was a quick and sure way to lose the race against the curve. The fear of becoming vegetative loomed large for John, figuring at the end of the spiralling curve. A ‘vegetable’ is a person who is alive, but not really living, a burden to family, unable to take care of oneself. At this point, John talked of himself as already being in a vegetative state. When a nurse asked how he coped with his PD, John sighed:

> There’s a great deal of psychological stuff with all this, things you can’t do anymore, perhaps losing initiative. I actually feel most comfortable when I’m in my armchair . . . Those around me see the advancement, I see it only to a lesser extent. From being in a managerial position to this. But those around me are with me—family, friends.

He pauses and sighs again. ‘I’ve become a vegetable, somehow.’ Getting to know John better, his past experiences and present capabilities, helped us understand why he spoke of a vegetative state. John used to be an excessive talker; his managing job depended on it. He made speeches at private parties, held positions on company boards, and fixed things around the house. Now, John felt PD increasingly intruding on his social identity. John, as many fellow rehabilitees, spoke of haunting images in a temporal dance between present experiences of deterioration (impairments in speech, cognition, gait), past images of what life used to be (leadership, handiness), and future imaginations of a vegetative state.

Being in a vegetative state may be a generalised fear to which many can relate, but in rehabilitees’ narratives the fear particularised in stories of friends and acquaintances. ‘I have several acquaintances whose condition suddenly plummeted, one woman went to the doctor in August, and now shakes like . . . it just shows how fast it can go,’ John said. Christian, in his sixties, said, ‘I joined the PD training with a man who is now in a wheelchair and has to be fed by his wife.’ Emil, a man in his mid-sixties, also invoked the vegetative state: ‘Imagine just sitting there, like a stone, staring, not being able to get out of bed.’ His voice becomes less distinct at this point, but on the recording it sounds as if he continues, ‘And having someone come wipe your ass.’ Diagnosed three years ago, Emil’s PD has progressed rapidly. He shuffles when he walks, and his voice is barely audible. Two years ago he lost his job in logistics. ‘My boss was sad about firing me, but my job depended on my vocal skills.’ His wife nods. She has coffee with us, ready to translate his muffled words. Upon leaving, Emil looks at their car: ‘The first thing I asked after being diagnosed was whether I could continue driving.’ His wife responds, ‘You love driving, but I worry. You tire so easily.’

In response to the way PD disrupts their lives, rehabilitees invoked the declining curve and the vegetative state as imaginaries of the future. Like hauntings, they appear, disappear, and reappear. They represent that-which-may-be-coming-about, as disease worsens. These haunting images of the future also instigate action in the present. As Anita, John, Christian, and Emil explained, they did a lot of training and avoided the armchair in a bid to postpone the declining curve and the vegetable state. To anticipate an unwanted future means to fight it in the present (Dekker 2020). We now turn to another aspect of the imaginary dimension, namely that of hope, which we will argue can be interpreted as a counterforce to the haunting imaginary of a vegetative state.

Hope

Hope was mentioned in goal-setting and at times in group talks among rehabilitees. Rehabilitees' varied articulations of hope revealed the different meanings it carried for them. The following lines are translated from a poetry book *Parkie: Dage og digte* ('Parkie: Days and Poems') by Nørgaard Jørgensen (2020), himself a Danish 'parkie', who writes about living with PD.

> That it only gets worse in this life of mine
> Is hard to get used to—to just get in line.
> You always hope they invent a pill
> Which with time stops the crawl uphill;
> That the cure is not in some far-fetched lane
> But appears in time to save my brain.[6]

The poem, and many other works of literature or art, was referenced often by interviewees when talking about hope. As if the individual's own words did not always suffice. Research participants referred to hope in multiple ways: embodied and spatial terms (outside you: hope as more than what can be carried by an individual, in a spiritual sense; inside you: hope is carried close to your heart because of its importance, hope is a feeling), or as encompassing everything, a vision, and often also intertwined with hopelessness. A rehabilitee, Lilly, in her seventies, spoke highly of Jørgensen's poetry during her boost stay at Sano. 'I feel he is writing about my life,' she stated in a group discussion, 'those long nights with little sleep, and the depressive periods'. The book of his poems wandered from room to room and stirred debate. Some rehabilitees recognised their own thoughts and feelings in the poems. John, however, who also participated in the boost stay, said, 'I prefer not to dwell on the dark hopelessness. Life must be lived *now*.' Other participants nodded in assent. The discussion touched on the essence of hope

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[6] In Danish: At det kun bliver værre resten af livet / er svært at vænne sig til og tage for givet. Man håber jo altid, at de opfinder en pille / som hen ad vejen får alt til at spille kuren den ikke ligger langt ude i det fjerne / at den kommer tidsnok til at redde min hjerne (Nørgaard Jørgensen 2020, 65). Translation to English by the authors, with consent from the poet.

and on what hope may do or bring, and proved conducive to understanding how hope does not convey the same meaning to all the rehabilitees. The first of a few illustrative examples follows, stemming from the discussion.

Ian pulls up his shirt to show a tattoo of the chemical sign for dopamine: 'This is my hope,' he declares. Dopamine functions as a neurotransmitter, but PD is associated with progressive loss of dopaminergic neurons. Diagnosed with PD in his thirties, almost two decades ago, his condition is deteriorating. Few options are left for treatment. 'I speculate', he says, 'what is the next step . . . Hope . . . everybody, mind my words, EVERYBODY has hope.' A bit later, he quietly adds, 'I have seen those who lost hope and that's not nice.'

Ian referred to hope as essential when living with a degenerative disease. For Ian, losing hope is losing life, thus resembling the 'paradox of hope' (Mattingly 2010), hope in what seems a hopeless situation. Reminded that he missed out on a gym session, Ian nodded, 'I was low on medicine—then I freeze completely.' When the medication kicks in, he can move and work. Ian runs a small business, compatible with the fluctuations of the disease. He found it important to keep going and keep hoping, not least for his children (now in their twenties). 'My kids still need me,' he said.

Another discussion about hope was among three men, all retired and in their mid-sixties to early seventies, sitting in a living room area at Sano one late afternoon:

Emil: Of course I have hope, at least that it gets no worse.

Morten: I'm not crazy about that word, 'hope', it's as if you let others take over. What I have learned from living with this disease for five years is that you cannot rely on neurologists or medication to change anything. It's up to me [. . .] Some hope that Jesus or others will come and do it for them I think it's better to say, 'What can I do?'

Emil: I just hope to be able to drive to Southern Europe with my wife next summer. But I don't know how my condition will be by then.

Morten: It may be harsh to say, but I believe you've got to take control yourself, not fold your hands and say, 'I hope things will turn better.'

Emil: What I can do, I do. We wouldn't be here, you know, if we weren't motivated to act.

Jorgen: To me, hope is like an ostrich policy, saying that things will probably work out. I'm practically orientated I know it will not improve, so I have to hinder deterioration.

While Emil saw no contradiction between hope and his own agency, Morten and Jorgen saw hope as devoid of self-agency, and thus expressed scepticism about using the word ‘hope’ in relation to PD. Anne, in her fifties, reflected:

> I think hope signifies something you are not sure about. I prefer ‘belief in’, I believe in the things I do [. . .]. I believe I am doing well after eight years with PD because I made PD my new job: to stay active, live a good life NOW and for as long as possible with my family. I’d like my kids to think back—‘though Mum became ill, had a great career and became someone else, she was still there for us [. . .]’—that they will never see me as a vegetable, in the bedroom, crying.

In accentuating ‘belief in’, Anne probably agreed with Kierkegaard, who cautioned against setting out to sea with only hope as ‘an untrustworthy shipmaster’ (Crapanzano 2004, 116). Other research participants linked hope with their age and realism. For Mary, in her seventies, ‘hope may diminish with age, as you simply have fewer years ahead of you.’ Elizabeth, the same age, took a similar pragmatic stance, when interviewed in her rose garden:

> Hope—that’s many things. I’m terribly realistic, so hope . . . well, you can hope for hope. But I don’t really believe in it *. . .* No! That was when you were younger. Though I do hope that we can stay in this house for many years.

While this article was being finalised, Elizabeth phoned. Things were not going well. She and her husband had left their home and rose garden and now lived in a house that was more suitable for her needs. She was in pain but unsure whether it was related to PD. Upon hearing about this article, she said, ‘If you lose hope and your sense of humour, you might as well switch off the light.’ Elizabeth’s age combined with her PD led her not to believe in hope. Still, she expressed a specific hope to remain in their house. A year later, in pain, having moved and downscaled activities considerably, her hope to stay in her house had been defeated, but she then expressed an existential hope, to ‘keep the lights on’. Elizabeth’s words serve as a reminder that individuals often operate with a multiplicity of hope (see Jansen 2016, 459 for similar point), but also that hope can change over time and space, exposing a certain plasticity. This is illustrative of what Jensen (2016) refers to as transformative practices of hope, writing about relatives of organ donors shifting their hopes from survival, to death, to survival of the organ recipient.

Emil’s hope for a summer vacation with his wife exposed a social dimension of hope, echoing Anita’s hope to fulfil her role as grandmother. Hope, though often placed in the individual, cannot ‘be removed from social engagement and implication’ (Crapanzano 2004, 123). This includes the hope of not becoming a burden to one’s family. Dennis expressed it similarly in an interview: ‘hope is to stretch it as far as possible. That you die before you end up a vegetable. There's a hope for that.'

As shown above, rehabilitees interpreted the notion of hope differently: from escapist 'ostrich policy', to essential to life, to marginal with regards to PD. That hope provokes diverse associations may not surprise, but nevertheless accentuates the importance of not assuming that research participants share a single interpretation of hope. Themes of agency, age, and realism emerged in conversations about hope, revealing how rehabilitees saw hope through different lenses. Some expressed a discord between agency and hope, which highlighted the importance rehabilitees put on self-agency, the capacity to act. This correlates with Whyte's findings regarding misfortune and how people in Uganda deal with uncertainties of life, such as illness and death: 'In matters of suffering, undertaking was as important as undergoing' (Whyte 2005, 246). Under a cloud of uncertainty, people still act (Mattingly 2010, Hansen and Tjørnhøj-Thomsen 2014), or to quote Anita, 'do something'.

Locating hope

Rehabilitees who want to keep their bodies and voices agile must indeed 'do something'. All participated in PD training once or twice a week, and several were active in PD dance, fitness, yoga, or sang in choirs. We argue that rehabilitees locate hope in PD training. In the following field notes from three consecutive course days at Sano, we show how 'doing something' unfolds in a rehabilitation context.

Thursday

In a mix of singing, miming, and saying 'aaaaaaaaaaa' until the sound resembled Mongolian throat singing, a speech therapist educates us on how PD may affect voice, word-finding and mimicry, and gives advice on voice training. Her questions prompt thoughts about communication difficulties:

> *Elizabeth: Sometimes words stay inside my mouth, like a bubble, refusing to leave. Many [people] don't hear me out. At times, I wonder if it's worth participating in a conversation.*
>
> *Robert: In discussions, I have to answer straight away and with a few simple sentences. That's all I can handle.*

Friday

Loud music in the hallway indicates morning gym session. Anita follows the physiotherapist's commands, well tuned to the music. John tries to follow suit, but his stiff movement inhibits his rhythm. Others hold onto chairs for balance. At the 'Motivation and Training' afternoon session, a physiotherapist shows slides on a screen. One slide is about the purpose of training, which according to my field notes is to maintain body functioning, prevent complications, and compensate for lost functions, with 150 minutes of weekly training recommended.

It takes considerable work to try to postpone the future degeneration, and when I later go through my field notes, a question arises: When activity decreases or ceases with PD progression, as happened to Elizabeth, is this the moment when the plasticity or multiplicity of hope becomes apparent?

Saturday

The corridors are silent: no sound of busy steps from staff, no tests in the lobby. Rehabilitees in their sixties and seventies sit in the quiet living room. Their questions about this study lead to the following exchange:

Robert: Hope is to be able to postpone the inevitable for some years. That's what training aims at—that you buy some years at a reasonable level, then down it goes, we all know that, but pushing it for as long as possible is what counts.

Bente: Be independent for as long as possible, right? Take care of your own hygiene and stuff like that. You gave me hope, Robert. You do okay after your surgery [DBS]. Hope is about finding a new medication, perhaps even a cure.

Ditte: Don't forget that hope is also that our training yields results.

Robert: Hope is kind of a vision. It is everything. If you don't have hope, you have nothing. The goal supports the vision, or the hope.

Bente: We carry hope within us, luckily, because if we lose hope . . . there are days when you think that nothing really matters.

The dialogue captures how rehabilitees seem to locate hope in training, medical achievements, and in others, as 'repositories of hope' (Kleist 2016). The idea that persistent training can postpone 'the inevitable' was common among rehabilitees. Christian hoped 'that training will hold it back [. . .]. I started jogging when diagnosed. I've been able to hold it back for four years. Now I cannot jog anymore. My goals concern how I can maintain physical exercising.' Although Anita knows PD is incurable, 'you still hope that what you do can change something or at least push it further ahead.’ Both Christian and Anita expressed a certain acceptance that degeneration was occurring, but accommodated training to their present functioning and to good days and bad days.

Rehabilitees’ hope in medical research surfaced in different ways. Some rehabilitees kept a keen eye on research findings. Several were active participants in ongoing research programmes, by which medical research transformed from a mere location of hope to its embodiment, with rehabilitees’ own bodies as a medium. Anita invested medical research with almost magical powers for instance: ‘When you listen to research, then for now there is no hope for a cure. But as my neurologist says, we can hope they find something to stall the progress so it doesn’t get any worse. You may say that’s where the hope is: that somebody will find the philosopher’s stone.’

Some rehabilitees, reluctant to believe in a cure arriving in time for themselves, expressed an extended hope for the next generation of people with PD. The neuro-curative imaginaries as drivers of hope (Warren and Addison 2020) thus took a generational turn. Chris, in his early sixties, explained, ‘You hope that someone could make it [one’s own PD] disappear. Even though you know that this will not happen. But perhaps others, in the future, can be cured.’ To locate hope in others, a personified hope, was directed toward fellow ‘parkies’ who did well against the odds, and professionals who instilled hope (del Vecchio Good, Good et al. 1990), or constructed hope (Warren and Manderson 2008), or ‘sprinkled white magic’, as a neurologist in our study said, adding that there is a huge placebo effect in hope. While all professionals interviewed stressed that they are careful not to give false hope, Sano professionals also emphasised the importance of not taking away hope. In a group interview, a nurse explained:

> We shouldn’t take away hope. If we support them in their hopes for the future, it’s easier for them to achieve their goals. If we question whether it’s realistic, it becomes more difficult for them. So to change things for the better, increase quality of life—well, that really depends on hope, right?

A physiotherapist responded, with a pensive look, ‘Sometimes we may co-create hope. [If a rehabilitee’s level of functioning is deteriorating,] then we work with hope, working towards better gait, turning up voice volume. In such instances, you work consciously with hope.’

Training, medical research, and others exemplify locations of hope with the potential for PD rehabilitees to mobilise agency. Hope located in training may lead to rehabilitees doing (more) training. Hope in medical research may lead rehabilitees to sign up for medical trials or supporting donations towards medical research. Hope in others may lead to seeking advice or inspiration from hope givers.

However, locations of hope can transform to locations of hopelessness too. Falls or apathy may inhibit one's capacity or drive to keep up with training. Medical trials may fail. Seeing others in worsened conditions may yield hopelessness. Although most rehabilitees expressed gratitude about joining a group of people 'in the same boat', some found that seeing others in worse condition than how they perceived themselves reminded them of their own possible future condition. Rehabilitees stressed the importance of training, but many struggled with keeping up with it. Apathy, a known symptom of PD, signifies the opposite of being active (Kudlicka, Hindle et al. 2018). The balance between not giving false hope *and* not taking hope away may indicate that professionals view hope as potentially both productive and counterproductive in health interventions. Hope and hopelessness seem never to divorce (Crapanzano 2004). John captured this opposing relationship, looking apologetic when he answered a question about hope: 'Actually, it's hopeless. There are only means to reduce symptoms, not to cure. You have to live in the now. I just hope I will not turn into a complete idiot.'

Hope-work and the co-creation of hope

Fieldwork in rehabilitation sessions revealed that hope is co-created and involves what we term 'hope-work'. On a warm summer day in the parking lot at Sano, Emil and the occupational therapist try out different types of transfer boards for his car. They work together to fit the boards, while Emil, with stiff movements, gets in and out of the car. They discuss which boards work best.

This scene seemed like just another consultation, a concrete activity where a professional works together with a rehabilitee towards a rehabilitation goal. In this case, Emil's goal is to be able to enter and exit the car. However, given Emil's hope to drive south for summer vacation with his wife, the scene also involves hope-work in collaboration between Emil and the occupational therapist. Being able to enter and exit the car is a prerequisite to actualise his hope.

On another occasion, a nurse asks how Anita copes with living with PD. With a few tears rolling down her cheeks, Anita responds that she just hopes to be able to take care of her grandchild. She refers to other rehabilitees—when would she too have shuffling steps and fading voice? The nurse reassures her that PD progresses differently from one person to another. Anita says, 'My shaking should indicate a milder trajectory.' The nurse nods. 'I heard that too.'

This scene is not just an example of pursuing Anita's goal about coping and learning to live with PD: the nurse's small assurances also reveal a co-creation of hope. A milder trajectory could indicate a better chance of maintaining Anita's level of function, so that she might possibly continue caring for her grandchild. The 'I heard that too' illustrates how the nurse balanced hope, making sure not to take it away, but at the same time avoid giving false hope by not offering firmer certainty.

On the bicycle lane outside Sano, Christian walks with rather fast strides together with his physiotherapist, who observes his gait closely. The two of them discuss prospects of Christian being able to jog again and possible alternatives to jogging. His goal is to maintain his training regime. His hope is 'that training will hold it back', which transforms a practical consultation working towards his goal to also involve hope-work between health professional and rehabilitee.

These empirical examples show how rehabilitees and professionals worked with both rehabilitation goals and hope to maximise what brings meaning to the rehabilitee's life, which could be as mundane as maintaining skills of getting in and out of the car, being able to care for one's grandchildren, or maintain a training regime to postpone PD degeneration.

In concrete situations, in the parking lot, consultation room, and bicycle lane, rehabilitees and professionals would probably not describe what is going on as hope-creation or hope-work. To interpret these activities as hope-work, as the co-creation of hope, necessitates knowledge or acknowledgement about the rehabilitees' hopes (see also Mattingly 2010). Hope emerged as a dimension in rehabilitation through words and concrete activities. Nonetheless, a thin line separated hope-work from hopelessness. Living with a progressive degenerative disease means that uncertainty about the progression and the future pervades everyday life. Hope to postpone the future of degeneration can be replaced by hopelessness when realising that one's dread for the future has become reality. This was the case for Bente, who hoped to stay independent for as long as possible. One day, she entered the gym, full of sweaty rehabilitees, and looked around, tears streaming down her cheeks. She said to the physiotherapist, 'I just realised how many things I cannot do anymore.'

Concluding discussion

We set out from the assumption that imagination forms part of our inner lives and interpersonal relationships, and can materialise as hope and haunting images. Our aim in this article was to explore haunting images and hope among PD rehabilitees at a Danish clinic to cast light on an imaginary dimension of rehabilitation, and to explore how rehabilitees orientate towards uncertain futures. We chose to focus on the subtle presence of these particular materialisations of imagination in goal-setting sessions, one of the specific activities in PD rehabilitation.

Our study offers an ethnographic account of life with PD and participation in PD rehabilitation. We found that, living with certainty that one's condition will deteriorate, mixed with uncertainty as to when, how fast, or how badly, rehabilitees do not (only) wait and undergo, they try to 'do something'. The future was imagined by research participants in terms of the 'declining curve' or 'becoming a vegetable'. We argue that these are haunting images, bridging the present to an unwanted future of degeneration and reinforcing the sense of discontinuity of life at the hands of the disease. The imaginaries from the future haunt in the present; they emerge as forceful imaginations, which rehabilitees act upon to avoid their actualisation.

Delving into hope, through an empirical exploration, exposed a complex phenomenon. Hope appeared multiple, both in the ways research participants interpreted it and referred to it in embodied and spatial terms (outside you, inside you, a feeling). Some saw hope as a necessity to life, whilst others interpreted it as devoid of self-agency, and dismissed it in relation to PD. That hope carried no uniform meaning to research participants serves as a reminder that studies of hope should not assume a singular interpretation of hope. Further, hope appeared in multi-modes (Webb 2007), as research participants spoke about hope on a continuum, from abstract hope (life necessitates hope) to more specific hopes such as getting in and out of a car to be able to go on vacation, playing with a grandchild, or keeping up a training regime to postpone degeneration. Thus, in our study, hope was not an undifferentiated experience. Neither was hope singular. Over time, rehabilitees referred to a multiplicity of hopes, and hope came to take many forms within an individual (see Zigon 2009), including transforming over time, revealing a certain plasticity.

Our analysis illuminates social and scalar dimensions to hope. PD-related hopes are often associated with personal or social hopes that one's role in life may prevail. These hopes were situated, contextualised within specific life-situations (see also Jansen 2016, Kleist 2016). Rehabilitees also connected medical hope with their avid attention to concrete clinical trials taking place in other parts of the world, forming a political economy of hope (del Vecchio Good, Good et al. 1990), and to not just family but also distal relations such as the next generation of persons with PD, exposing scalar dimensions of hope (Moore 2011).

For Crapanzano (2003), hope describes an existential stance or attitude, whereas Mattingly prefers to 'speak of hope as practice, rather than simply an emotion or a cultural attitude' (2010, 6). In this study, hope appeared both as an existential stance (hope as everything, hope keeps the light on, losing hope is losing life), but also in a specific form (hope to go on summer vacation) and in a more agentic form, as practised and co-created, and as located in something or someone (training, medical research, and others), with potential to instigate agency. Further, some rehabilitees expressed a hope to die before serious degeneration sets in. They found death preferable to ending up a vegetative state. This may not be unusual when faced with unwanted futures. However, as observed in the field of dementia, boundaries of life worth living kept shifting (Dekker 2020). Can hope be defeated, get lost to us, when the unwanted future closes in? Maybe. If one oscillates between hope and hopelessness, when the latter seems to gain terrain, then perhaps at some stage some acceptance of 'it is what it is' takes the floor. Or if, as we have shown, a person can carry multiple hopes at any given time, it could be that as one hope subsides, another comes to light.

Probing into hope gave insights into the significance of agency—taking an active stance against hauntings of a future vegetative, motionless state. This illustrates Desjarlais' point that imaginaries have the capacity to affect and disturb (2018, 174). The haunting images pervaded rehabilitees' narratives and the hope they expressed, where hope seemingly transformed into an antidote to the haunting imaginaries. As such, hope became a counterforce to the vegetative state: hoping to die before reaching that state, hoping for a cure, or hoping to be able to fulfil one's social roles in life. We argue that the way rehabilitees located hope in training, medical achievements, and others offers the possibility of 'doing something'. Or simply living in the now, thus maximising the present. Another insight was that 'hope', as compared to 'goal', touched another nerve, opening for more profound reflections on life and death.

In their studies about ex-combatants and persons with acquired brain damage Wool (2017) and Antelius (2007) find a certain stuck-ness in the present, a 'collateral afterworld' (Wool and Livingston 2017, 2) among rehabilitees with no or little hopeful imaginary for the future. However, we find it more appropriate to talk of a beforeworld. We found among rehabilitees a desire to 'do something' to prolong the present, that is, the world *before* serious PD progression and degeneration.

Furthermore, we found that rehabilitees and professionals co-created hope, or worked with hope, as also found by Hansen and Tjørnhøj-Thomsen (2014) and Mattingly (2010). Many rehabilitees located hope in PD training, and all but one rehabilitee had goals related to physical activities. This indicates that rehabilitation goals could appear as stepping stones towards hope. Rehabilitation goals reflected impairments which influenced everyday life, but may also represent an active, temporal agency, something which can be done in the now. Goals may therefore—with hope—pose as mediums to postpone the actualisation of the haunting images, or work as antidotes to the imaginary of the declining curve and the vegetative state. However, apathy and fluctuations in PD may counteract the urge to 'do something'. A thin line separated rehabilitees' hope from hopelessness.

Maybe it is this thin line that professionals refer to, when expressing cautiousness about giving false hope. It is along this line, between hope and hopelessness, that goal-setting is enacted.

We believe our exploration of hope when living with a progressive disease—how and where hope can be found when anticipating degeneration—has relevance in other areas of rehabilitation and beyond the anthropological literature on neurodegenerative disease. We contribute to studies of rehabilitation with anthropological insights of the imaginary, incorporating both hope and dread in the form of hauntings. While we agree with Mattingly (2010) that one must look to personal and family lives to discover facets of hope, we will emphasise a methodological point: asking research participants of *their* definition of hope can illuminate essential aspects of the concept: in our case, the different, multi-layered perceptions of hope. The link we make between hope and goal-setting may be valuable to rehabilitation studies in general, and deserves more exploration in future studies.

While goal-setting makes imagination explicit, public, and shared, hope appears less explicit, more private, and not necessarily shared. We conclude that in our study, hope and haunting images of the future formed part of an imaginary dimension of PD rehabilitation. Exploring inner life worlds exposed both ‘darker’ sides of living with PD, the dreads exemplified by the declining curve and the vegetative state but also a realisation of where hope may be located and enacted. Crapanzano (2004) points to the ambiguity invested in imagination as it serves action, though not yet realised. Here, hope and images of the future had the potential to influence rehabilitation activities and serve action. Therefore clinical rehabilitation services, often focused on tangible, measurable activities, might gain from directing more attention towards the imaginary and acknowledging the intertwinement of and continuous interaction between hope and hopelessness when setting goals with persons facing unwanted futures.

Authorship statement

Merete Tonnesen is the primary author, and the article is based on her fieldwork. She conducted data analysis, and did most of the editing of the article. Development of the argument was done in collaboration between both authors. Both authors contributed to the article and approved the submitted version.

Ethics statement

Ethical approval for the research project was granted by Central Denmark Region (1-16-02-15-19). The participants provided their written informed consent to participate in this study.

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