

Hysteresis – or the mismatch of expectations and possibilities among relatives in a transforming health care system

Smidt, Helle Rønn; Shim, Janet K.; Larsen, Kristian; Hindhede, Anette Lykke

Published in:
Health Sociology Review

DOI (link to publication from Publisher):
[10.1080/14461242.2019.1704425](https://doi.org/10.1080/14461242.2019.1704425)

Creative Commons License
CC BY-NC-ND 4.0

Publication date:
2020

Document Version
Accepted author manuscript, peer reviewed version

[Link to publication from Aalborg University](#)

Citation for published version (APA):
Smidt, H. R., Shim, J. K., Larsen, K., & Hindhede, A. L. (2020). Hysteresis – or the mismatch of expectations and possibilities among relatives in a transforming health care system. *Health Sociology Review*, 29(1), 31-44. <https://doi.org/10.1080/14461242.2019.1704425>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal -

Take down policy

If you believe that this document breaches copyright please contact us at vbn@aub.aau.dk providing details, and we will remove access to the work immediately and investigate your claim.

Hysteresis – or the mismatch of expectations and possibilities among relatives in a transforming health care system.

Authors affiliation and email:

Helle Roenn-Smidt, (Address for correspondence) Department of culture and learning, Aalborg University.
A.C. Meyers Vænge 15. 2450 Copenhagen. Email: Hrsm@hum.aau.dk

Janet K. Shim, Department of Social and Behavioral Sciences, University of California, San Francisco, CA,
Email: janet.Shim@ucsf.edu

Kristian Larsen, University Hospital Center of Health research, Copenhagen, Denmark. Email:
kristian.larsen@regionh.dk

Anette L. Hindhede, Department of culture and learning, Aalborg University, Denmark. Email:
anlh@hum.aau.dk

Accepted author manuscript

Abstract

When a person experiences a severe stroke, their relatives must assume the role of partners in the rehabilitation process. Drawing on Bourdieu's field theory, this study investigates the potential gap between the subjective expectations of relatives in terms of the assistance and care they can offer patients with severe brain injuries and the objective constraints of a healthcare field. Using data from observations, as well as interviews with relatives and official documents, this study shows how some relatives, reliant on their habitus, bring to their collaboration with healthcare professionals an expectation that the healthcare field will be able to take care of their multiple individual needs. However, due to hysteresis - a gap between their dispositions and the objective possibilities of the transformed healthcare field - these relatives are not equipped to recognise, grasp and occupy their new field position. We conclude that Bourdieu's theoretical concept of hysteresis may help us understand how changes in the healthcare field may lead to a mismatch between the field and the habitus manifested in interactions between patients, relatives and healthcare professionals, so that the ill-adjusted habitus of relatives leads to missed chances in relation to the opportunities objectively offered by the field.

Keywords: relatives; expectations; stroke; welfare system; Bourdieu, hysteresis

Introduction

In most parts of the world, it is common practice for people who experience a severe stroke to undergo rehabilitation. In Denmark, this is primarily carried out by the Danish healthcare system, which is funded through taxes as a part of the Danish welfare state. This welfare state is rooted in the Scandinavian social democratic model, which involves extended social citizenship (Esping-Andersen, 1990), so that rehabilitation opportunities are considered to be every citizen's right. However, the welfare state has undergone a transformation over the last 20 years as New Public Management reforms have been implemented, along with a more work-oriented requirement for recipients of health-related benefits (Harsløf, Søjberg Nielsen, & Felling, 2017). Austerity measures and demands for greater efficiency in healthcare delivery have placed increasing strains on healthcare professionals (Nordhaug, 2013) and have transferred more tasks to patients and relatives (Shim, 2010) – tasks for which healthcare professionals were previously responsible.

The changing role of patient and relatives reflects the moral philosophical attitude that every patient is an agent in their own life, and acknowledges the multi-dimensional experiences and choices in health and illness offered people today (Dubbin, Chang, & Shim, 2013). Patient-centred care models place patients at the centre of their own rehabilitation and relatives become important collaborative partners, especially when the patient has a severe brain injury.

The aim of this article is to investigate the relations between relatives and healthcare professionals in the context of transformations in the delivery of healthcare. This subject is highly relevant because there is a growing interest in collaboration with relatives with regard to rehabilitation, and several studies show that collaboration entails greater satisfaction for patients and relatives, as well as greater trust in the provider (Altin and Stock, 2016; Gabay, 2015). Several studies argue for the increasing involvement of relatives (e.g. Guldager et al, 2018), suggesting new strategies for collaboration. However, these processes of change, involving new norms for the roles

of patients, relatives and healthcare professionals, may be considered a challenge for some relatives, particularly for those who may not have the competences needed to fulfil their new role.

We therefore sought to investigate the relationship between relatives and healthcare professionals in the specific context of rehabilitation after a stroke. Our research question is: How do relatives of stroke patients act in relation to the care of their family member in the context of a transformed healthcare field?

Theoretical approach

In order to answer our research question, we drew on Bourdieu's theoretical concepts of habitus, capital, and field. Bourdieu's empirical work provides clear examples of how to investigate a social space of action as the focal point of an analysis (Collyer, 2018). His theoretical work builds on the construction of a way of doing social science research without having to choose between a focus on the individual and a focus on society, a subject or an object. Instead, he argues that the social world exists in relations (Vandenberghe, 1999).

Bourdieu expands Marx's notions of the exchange of mercantile capital with the objective of maximising profit to include other forms of resources and power that actors may have at their disposal, particularly those of a cultural nature. He envisages these as various types of capital, such as social, cultural and symbolic capital (Bourdieu, 1985). Capital is produced within fields and exists only in relation to the specific field (Bourdieu and Wacquant, 1992). The field, therefore, becomes a site of struggles and diverse forces, as individuals and groups seek to leverage capital in relation to what is valued and legitimate at any particular time.

The relations in the field constitute the beliefs and values in the field, and the agents' dispositions allow some of them, according to their habitus, to have a feel for the 'game', while others find it more difficult (Bourdieu 1990, p.66). Habitus is:

'... a system of lasting and transposable dispositions which, integrating past experiences, functions at every moment as a *matrix of perceptions, appreciations, and actions*, and makes possible the achievement of infinitely diversified tasks, thanks to analogical transfers of schemes [acquired in prior practice]'. (Bourdieu, 1977: 82-83).

'When habitus encounters a social world of which it is the product, it is like a "fish in water" . . . it takes the world about itself for granted'. (Bourdieu and Wacquant, 1992: 127), meaning that structures work in a deeper, practical and often pre-reflexive way, through which the agent develops a sense of the field, that is, what to expect and how to interact and gain acceptance and benefits in that specific field.

However one's sense of the field is not always stable and enduring. Bourdieu introduced the theoretical notion of hysteresis, to describe a condition in which there is a disruption between the habitus and the field: 'The hysteresis of habitus, which is inherent in the social conditions of the reproduction of the structures in habitus, is doubtless one of the foundations of the structural lag between opportunities and the dispositions to grasp them which is the cause of missed opportunities ...'. (Bourdieu 1977: 83).

In this paper, we investigate if and how hysteresis can be used as a framework to better comprehend the process of transformation in the healthcare field, in which disruption might occur in relation to the habitus of relatives and their ability to act (in cases where the habitus has been shaped by the former conditions in the field) (Hardy, 2014; McDonough & Polzer, 2012). We commence by describing the Danish welfare state and the changes it has undergone over the last decades, in order to situate our study within a transformed healthcare field.

The Danish welfare state

In Denmark, the welfare state was primarily consolidated between 1956 and 1970, when women entered the labour market and, consequently, the welfare state was transformed and expanded. The care of the elderly and the infirm became a matter for the state (Petersen, Petersen, & Christiansen, 2010). The welfare state was built on a mutual arrangement between its citizens and the state, whereby the citizens would contribute with work and taxes according to their abilities (Kolstrup, 2015). Income taxes were regulated in relation to citizens' income and capital, and every citizen had a right to access various free services, including healthcare, prescription medication and education. Public services were the same for all citizens and were distributed by need rather than economic status. The state provided support for citizens who became unable to take care of themselves, such as home help, or income if they were unable to work (Ploug & Kvist, 1994). This meant that every citizen, on the basis of their civil registration number, had a caseworker employed by the state or municipality to facilitate this assistance, or give advice if needed.

Providing high-quality healthcare for every citizen is one of the primary aims of the welfare state. However, despite the provision of healthcare through the welfare state, the healthcare field is not just a national phenomenon with geographical boundaries. International institutions and companies significantly shape the structures of this field. As Collyer, Willis, and Lewis (2017, p.11) explain, the healthcare field is shaped by:

... powerful institutions of medicine; organizations such as hospitals, consumer advocacy associations, medical schools and Royal Societies; industries both small and large; a plethora of governance bodies; and occupational groups from specialist doctors and health educators to pharmaceutical salespeople and ward attendants.

Changes in the healthcare field

Over the last few decades, western welfare states, including Denmark, have transformed towards a market-oriented model of social welfare provision (Gilbert, 2002; Larsen & Harsløf, 2019). The

Danish healthcare field has experienced a transformation, in which a fully-fledged adoption of new public management strategies has been introduced, with a strong focus on efficiency and budget control (Larsen & Harsløf, 2019). This has mostly had consequences for healthcare practice; healthcare professionals have less focus on the comfort and care of patients and greater focus on goal-oriented and evidence-based work, including the documentation of work processes (Dahl & Rask Eriksen, 2005; Ryssel Bystrup et al., 2018).

New breakthroughs in treatment are also transforming the healthcare field (Bernhardt et al., 2017) and are increasing citizens' expectations regarding institutions, healthcare professionals, and the rehabilitation process as part of restoring health. This may create a mismatch, a hysteresis between the established dispositions of relatives, exemplified in their subjective expectations of treatment, care and support in institutions dealing with the rehabilitation of patients recovering from a stroke, and the circumstances defined by their new relative position in the transformed healthcare field. By being 'assigned to a position or a precise class of neighboring position' (Bourdieu, 1985, p. 724), relatives are expected to possess specific capitals that they may not (yet) have. In other words; they may not have the capacity to decipher homologies (similarities) between the previous context and the new one..

Methods

The empirical work for this study is based on a longitudinal qualitative study investigating the rehabilitation process of 12 patients, 2.5 years after their stroke. When admitted to hospital, six of the patients in this study had severe brain injury, resulting in a loss of verbal language, low consciousness, and absent or few voluntary functions. The relatives of these six patients were included in this study because they had a special role in the rehabilitation process, namely that of speaking for their next of kin.

Table 1: Participants included in this study

The data consist of 44 observations (each lasting 60-120 minutes) of formal meetings and clinical interactions between relatives and professionals. Twenty in-depth interviews (each lasting 45-60 minutes) with relatives and several informal discussions with relatives were also conducted. Data collection was conducted from May 2015 to January 2018.

The study was approved by the Danish Data Protection Agency. All participants were informed of the purpose of the study and the use of their data, both verbally and in writing, and they (or their closest relative) gave written consent to participation. All data were handled with full confidentiality.

The research interest was theoretically inspired and the semi-structured observation and interview guides drew mainly on Bourdieu's theoretical concepts of field, capital and habitus. These concepts provided a way to examine different practices in the interaction between healthcare professionals and patients and relatives, with a focus on how rehabilitation resources were produced, established and rewarded in the field. The guides were constructed as an overall framework, making it possible to follow and elaborate on what emerged during both the observations and the interviews. The first author (A1), who collected the data, made field notes during the observations and then made a full text draft as soon as possible after the observations. Interviews were recorded and transcribed by the first author (A1).

The data were analysed in an approach inspired by grounded theory and developed by Charmaz (2014). According to Charmaz, grounded theory can complement other approaches in qualitative studies, since it shares the epistemological position that the social reality is always constructed, multiple and processual, and also offers thorough guidelines regarding the steps in the qualitative research process that shed new insights into data. Transcriptions of observations and interviews were coded line by line and selected transcriptions were coded separately. The analysis focused on ensuring that codes were as multi-faceted and fitting as possible; thus, memos were

written while reading the data which were discussed by author A1 and A2 and then incorporated into the analysis. The many codes that emerged were assembled into more overall groupings by A1 and A2 to construct central empirical categories. NVivo was used to organise and analyse the data.

Findings

Relatives' expectations

The relatives in this study described how they expected the state (represented by the health professionals) not only to provide the appropriate rehabilitation for their relative, but also to take responsibility for meeting the person's individual needs. Judy (wife of Will) highlights these expectations. Judy was 69 years old and grew up after the Second World War, when Denmark's welfare state was expanding and the state had responsibilities in areas previously held by families. She described herself and her family as part of the system – she was a former secretary in a public institution and her husband was a schoolteacher. She defined them as an ordinary middle-class family, good citizens who always paid their taxes. Judy described a trust in the welfare state that manifested itself as incorporated knowledge. Judy had high expectations of the healthcare system and when it became obvious that Will would have to go to a nursing home, she and her daughter visited many nursing homes to find the best one. But as she explained, their desires were not considered:

I expected us to have a choice. But in the end, they just told us that it was this nursing home [the one Will had been assigned to] or none. If we did not want it, we could take him home. Which is not even possible...the decision was just forced upon us.

Judy expected the system not only to provide a nursing home, but also to consider the family's wishes, thereby supporting them in regaining the ability to live the best possible life. Since she had paid taxes all her working life, she expected more service than she received in return.

Expectations regarding the healthcare system also correlated with the relatives' previous experience of, and views on, the state system in general. Bill, Cindy's husband, described himself as a self-made man. He had no formal education and presented himself as a person who had rarely relied on the system. Nevertheless, he was frustrated due to his high expectations:

One doctor called me, and asked me why Cindy had been admitted to intensive care. Why did he ask me, shouldn't he know? I told them that Cindy would not want a male nurse. Nevertheless, they made a male nurse her primary nurse and contact person.

Bill was discouraged by being expected to have an overview of the rehabilitation process. Nonetheless, he found that when he asked for something specific, as in the example above, he was not heard. Realising that his expectations would not be met in the healthcare field, Bill decided to take action himself. He requested his wife's medical records, hired a lawyer to look through the rehabilitation process, and bought his wife various supplementary materials, (e.g., new braces for her hands, and provided a hairdresser) when the professionals did not supply these, or he found it took too long for them to take action. He described how this made it difficult for him to trust the healthcare professionals: 'I know these big systems. You just have to trust in yourself'.

Bill's positioning himself as being independent of the system along with his disappointment in the service he received disrupted his cognitive schemata of what the system should offer. His misplaced anticipations caused him to make a virtue of necessity by criticising the state for being ineffective and untrustworthy. Thus, as argued by Bourdieu (1990, p. 62): 'The presence of the past in this kind of false anticipation of the future performed by habitus is, paradoxically, most clearly seen when the sense of the probable future is belied and when dispositions ill-adjusted to the objective chances because of a hysteresis effect '.

In summary, some relatives – citizens of a welfare state – believed in a healthcare field with efficacy and room for individual choices, and that did not match what they experienced.

This meant that their matrix of perceptions was not able to 'make possible the achievement of infinitely diversified tasks, thanks to analogical transfers of schemes [acquired in prior practice]'. (Bourdieu, 1977, p. 82-83). Rather, the configuration of their capital resulted in less success within the new field structures. In the case of Bill, he was acting according to the new norms of his role as a relative and was able to build new schemes of action, such as taking over the job of the healthcare professionals by helping his wife by purchasing, e.g., dental braces and better braces for her hands.

Practical tasks for relatives

Some of the relatives expressed surprise about their many responsibilities in the rehabilitation process. Judy explained: 'We have paid our taxes all our lives, and I expected there would be somebody to take care of things when we needed it'. It was therefore an unexpected and, to some, an overwhelming duty to be responsible for so many practicalities, and some expressed frustration over the lack of service in the healthcare system.

Judy described how she had much to deal with when her husband was discharged from hospital and was admitted to a local nursing home:

I have to keep track of so much all the time. I call and call and call. ... When I went to the doctor, I asked her why this was happening? She said things like that are very difficult to control. But that can't be right. It is their job to manage things concerning Will. She told me that many people just give up on how to get what is their right.... But that is so wrong.

Judy did not expect to have to manage the finances herself, and she found it complicated to navigate the healthcare field. She found it more difficult to ask for benefits that she believed were her right than she expected. Judy adopted a strategy of pushing the system. She consistently contacted managers and people in charge. She continued to complain and draw attention to mistakes or omissions because she thought this might help Will. She felt it was her obligation as a relative and

so, as has been pointed out by Karp and Watts-Roy (1999), she became a 'difficult' relative because she had false anticipations. These were due to insufficient 'capacities' to 'think, feel and act' in the appropriate way; that is, her dispositions were not guiding her to respond creatively to the new constraints of her 'extant milieu' (Wacquant 2016, p.65)

During an interview, Peter, the 55-year-old husband of Violet, described how he was struggling with the practical tasks after Violet had been admitted to a nursing home:

I find it hard to get an overview of what to do..... I have something to do all the time: medicine, documents, pension, finances, I have to pay all sort of things.....Even at the nursing home I have to take care of all sorts of things....But how was I to know this?

Peter, who had lived a challenging and obstacle-filled life, is an example of a relative surprised by what the professionals expected of him. He felt the heavy responsibility of being a relative, and he often asked for help:

I have been to the local authority administration so many times. I tell them they have to help me, but nothing ever happens.... It bloody well can't be right. I need a contact person who can help me with all these things. As if I weren't worried enough in the first place.

However, he described how he gave up when his requests were not met. He explained: 'I always thought there would be some kind of safety net to pick you up when you need it'. Peter expressed his frustration over what he found to be a changed 'system', and therefore his generative principles of 'distinct and distinctive practices' relating to what is right and wrong did not match those of the 'system'. As a result, his demands diminished and he waited for somebody in the healthcare field to take over, becoming a passive recipient in the process.

In contrast, Whasid and family had immigrated from a country with no welfare system and had lived in Denmark for over 25 years. Their habitus guided them to become caregivers when family members were ill. Whasid, the son of Ahmed, did not seem surprised when faced with the various responsibilities. At the first meeting at the hospital, he told the professionals that he (and his family) had already arranged who in their network would do what when the patient was discharged from hospital: 'We also did that when our mother was ill. We stayed with her in shifts. Our father preferred not to have too many strangers in the house, and if there were any extras she needed we could pay for them ourselves'. This example highlights how 'transposable dispositions' may make it possible to meet the expectations emanating from the field.

Compared to native Danes, this family displayed more resilience regarding the practical burden of being a relative. They were proud to take care of things, showing that they did not need assistance from strangers. However, the data also showed that they did not ask many questions, nor did they ask for support, which implied that they were unaware of their opportunities of asking for more help or having an impact on the rehabilitation process. In contrast, the habitus of native Danes led them to assume that help from the healthcare system and the opportunity to influence the rehabilitation process was their right as a citizen.

Overall, the relatives were assigned many more practical tasks in the communication and transition between different institutions in a complex healthcare field (Adler-Milstein et al, 2011; Lee & Garvin, 2003; Miller & Tucker, 2014). Most relatives experienced that their dispositions were not in alignment with the objective possibilities and demands of the field, and they responded differently to this mismatch: some relatives complained and struggled with the healthcare professionals, thus challenging their matrix of perceptions; some autonomously took action and did not trust 'the system', thus developing new schemes for action; and some relatives resigned and gave up, their dispositions ill-adjusted to the field, which led to negative sanctions on the part of the

rehabilitative services e.i. short meetings, less dialogue, more one-way information, quick decisions from professionals. The example of a non-native Dane exemplifies the case of relatives with different expectations of the healthcare field.

Relatives as 'informal case managers'

The transformation of the healthcare field has produced new positions for relatives, offering, and to some extent forcing, them to do certain jobs, such as caring for and helping their next of kin, as well as taking on coordination roles in the complex multidisciplinary rehabilitation process. Relatives described how they found themselves acting as 'informal case managers', becoming both coordinators and facilitators of the rehabilitation process.

Judy described how she had to 'keep an eye on things' and ensure that things were done because she found that mistakes were being made all the time.

At one time Will's leg was all swollen and warm, and when I asked about it, I was just told that it was nothing...After four days they sent him for a check-up, and then found he had a coronary thrombosis in his groin. That [kind of care] is simply not good enough.

Bill also described how he had to be a 'guard dog' watching over the system to prevent mistakes and make the system fulfil its obligations. In an interview a few weeks after his wife was admitted to hospital, he explained: 'I feel I have to be the guard dog all the time, a terrier keeping an eye on what they do and don't do. And I have to make sure that things are done'. Bill's role was one of taking action. He was not just a collaborator; he also kept an eye on what was done or not done. He had to have the strength to keep challenging the professionals, keeping them on their toes. Bill also stressed that the healthcare system is 'always concerned about costs' and how he thinks that the professionals 'are always looking for places to reduce costs, if you're not on your toes'.

The findings above demonstrate that the transformed healthcare field offers relatives various caring and helping roles – and indeed makes them necessary. Due to the transformation of the welfare state and its institutions, healthcare professionals are less available to be in charge of organising care. For some relatives, these roles were in stark contrast to their expectations, which meant that their ‘acquired system of generative schemes’ of ‘thoughts, perceptions and actions’ did not match what is needed in the transformed healthcare field. (Bourdieu 1990, p. 55).

Relatives negotiating

Some changes in the healthcare field have been verbalized as beneficial for relatives, such as the right to be informed and to participate in the rehabilitation process of their family member. This was recognised by some of our respondents. For example, Bill constantly struggled for participating in his wife’s rehabilitation, advocating for his knowledge and trying to influence decisions made by the professionals. He wanted the professionals to see Cindy’s progress and unique situation, arguing that she was a candidate for rehabilitation. Bill tried to negotiate and draw attention to the hope of progress and reasons for additional rehabilitation. He tried negotiating for more time, arguing that his wife had unique qualities and conditions:

Cindy probably needs one month longer than most people. She was very stressed at work the days before her operation. I believe in her. She is so sensitive. She would not be alive if there wasn’t a higher purpose... You don’t have to hurry that much – she just needs some time to come back.

Participants drew on their schemata of perception and appreciation, often pointing out positive signs of interaction, in order to negotiate with the healthcare professionals. Bill described what he saw at one meeting with a professional: ‘She sometimes tries to communicate; I am sure of that. That it is not just mumbling, but she actually tries to say something.... When I brought her flowers. she smiled’.

Many subjective observations by relatives were not always perceived by the professionals as relevant arguments, but rather as emotional and wishful thinking, that is, emotive layers of habitus (Wacquant, 2014, p.8) that did not match those acquired in, and required for action in, the transformed field. Healthcare professionals often felt they needed to 'be realistic' and 'be honest'. As the doctor said at a meeting between Bill and the healthcare professionals at the hospital: 'It is [Bill's] hope and wish to get her [his wife] home to live. But we have to be realistic.'

Peter also encountered staff talking about being honest and realistic:

This place is sometimes quite stressful if the brain can't handle it because there is so much training and treatment all the time. Then admission here is not realistic. So it is important that we talk about what needs to be done and where Violet is going in the future. We have to be totally honest, even though we know this is hard to hear.

For the relatives, being 'realistic' seemed to be a change, moving away from a situation of hope, with everyone looking for signs of progress, to the decision that no further progress was expected. This shift was difficult to accept. The healthcare professionals' knowledge held the overall power in decision making, and the relatives' personal experiences were not considered to be valuable knowledge. However, if relatives were able to point to observations of a more biomedical nature, and asked relevant questions about possible treatments, this line of reasoning was considered relevant and was found to persuade healthcare professionals to discuss additional rehabilitation possibilities. As demonstrated in the case of Eric (56), the husband of Lilly, relatives attempted to match the power of the healthcare professionals, by involving friends and family. Eric was a self-employed craftsman and he used his networking ability to ensure his social capital gave credit in healthcare interactions. He described it like this:

We basically got things the way we wanted it, perhaps because we were quite tough in the beginning. Not everybody gets it like that. But at the very first meeting I allied

myself with our daughter-in-law, who is a physiotherapist working in neuro-rehabilitation, and a friend who is a social worker. This was to show the healthcare professionals that they could not do whatever they liked with us. It worked. After that, we didn't have any problems.

Relatives had matrices of perception and appreciation that related to information and knowledge that was important in the rehabilitation process. However, it seemed to be important how much different information the relatives could gather and where the information was obtained.

Information was considered conflicting and confusing when relatives talked to many agents both inside and outside the hospital. Judy described how she sought information from staff, private doctors, pharmacists, patient associations, the Internet, neighbours, friends, and other relatives. This made it difficult for her to know which knowledge was most valuable, but it also burdened the healthcare professionals when they were presented with the varying quality of her knowledge. One healthcare professional at the nursing home where Judy's husband lived commented:

Judy always brings up so many questions. She does not think things move fast enough. Then she calls everybody and sometimes she gets things moving, and that does not help at all.... She contacts everybody... "They do things like this or like that, why don't you do that? Why doesn't my husband get this and that?" The staff find her very troublesome.

The healthcare professionals explained that the patients must show progress to stay in rehabilitation, and therefore time was a limited resource. Instead of the expectations of a 'system' that will take care of them, the relatives described themselves in a 'battlefield' where they had to fight for their next of kin. Some relatives were able to transform their habitus, to build new schemes for perception, assessment and action. Other relatives became more incapable of taking action, and they therefore found themselves in the lowest position in terms of collaboration with the health professionals, not having the sense of how to play the game.

Discussion

The transformation of the Danish welfare state and the healthcare field is described as a shift from a social democratic state to a neoliberal state, in which economic functions take over more social functions, transferring the social and welfare-oriented functions to that of an economic and regulating function (Bourdieu & Wacquant, 1992). This is evident in the encounters between health professionals and relatives in neurorehabilitation, where the healthcare professionals refer to the time limitations in rehabilitation as due to costs, while the relatives also refer to cost reduction, but as an overall discourse. The state has transferred responsibility to the individual, and some of the relatives are frustrated over the lack of support from healthcare professionals.

These changes can produce inequality in healthcare. The focus on individual responsibility may seem liberating for relatives (and patients) who have the habitus and the capital to play this new game, while relatives who have not yet built sufficient schemata to act appropriately become 'difficult' relatives who do not succeed in collaborating with the healthcare professionals (Guldager, 2018, 2019). This seems to correlate with low social and economic capital, but inequality might also be produced in rehabilitation when relatives are not able to adjust to the mismatch between their expectations and the altered possibilities of the transformed healthcare field.

The findings of this study show that one way for the relatives to collaborate within this changed healthcare field is to seek support in their network, drawing on family and friends with relevant professional or personal knowledge and experience. In this context, social capital seems valuable when making their case to healthcare professionals and claiming their rights.

It is a limitation of this study that it does not contain empirical data that could demonstrate how the same relatives and healthcare professionals would have interacted in the healthcare field before its transformation. However, relating the data to the larger transforming field, hysteresis

emerges as a theoretical suggestion that illuminates new aspects of the encounter between healthcare professionals and relatives; relatives with a habitus that would previously have provided them with the ability to 'play the game' in the healthcare field now become 'problematic' relatives because their habitus and dispositions are no longer suited to reading the game in a transformed healthcare field. The relatives in this study do not themselves have earlier experiences of being a relative to a next of kin in stroke rehabilitation. In a manner similar to Crawford and McKee's description of a mismatch in the housing market (2018), their anticipations build on 'incorporated knowledge' and assumptions about how the healthcare field works constructed from their experiences as citizens of a welfare state. This is described by some of the relatives as almost a part of their DNA, having thought since childhood that the welfare state is supposed to take care of every citizen. And now some of the relatives are confronted with new norms and rules of how to be a relative in a stroke rehabilitation process.

Hypothetically, the mismatch between the relatives' habitus and the healthcare field might be expected manifest itself more in the older generation, because they grew up and established their expectations of the healthcare field when the welfare state was constituted in the 60s and 70s. However, according to Bourdieu, hysteresis cannot be explained by generational factors, but rather as a mismatch between habitus and field, in this case showing how relatives are being offered new positions that some are better suited to handle than others.

The theoretical notion of hysteresis does not explain the well-known complexity of, and tensions between, medical and lay knowledge, power relations in professional encounters, and the difficulties encountered by patients and relatives in accessing information (Chang, Dubbin, & Shim, 2015; Dubbin et al., 2013; Missinne, Neels, & Bracke, 2014; Pinxten & Lievens, 2014; Shim, 2010; Sointu, 2017). However, it does add further nuance to a situation in which some relatives' expectations and their trust in the healthcare field may have been appropriate only a few years ago,

but have now become a disadvantage in current reality. Inspired by the ideas of Crawford and McKee (2018), we argue that it is important to investigate how people adjust to the epochal changes in the welfare state, because this might illuminate how inequality is produced in the encounter between relatives and professionals, and this is as important as class differences or economic situations.

The examples presented above may resemble what relatives experience in other countries without a public welfare state and may, therefore, help to illuminate the common difficulties inherent to the position of being relative of someone recovering from a stroke. Nonetheless, these examples make useful the notion of hysteresis, specifically in the changing Danish healthcare field, which is part of a universal welfare state. Being raised as a citizen of a welfare state has become integrated into how relatives understand themselves as citizens and as potential patients or relatives of patients. When the expectations of how the state should act are not met, a conflict arises between how the relatives experience themselves and what they fundamentally believe in. This conflict is easily overlooked, however, because equality is taken for granted in a universal welfare state.

Furthermore, the concept of hysteresis highlights how this mismatch in expectations occurs among relatives who only a few years ago saw themselves as having a favoured position in the welfare system because they had the right amount and components of capital according to the welfare state's rules and values. Now, however, their habitus does not provide the ability to recognise and adjust to the changed game (Bourdieu, Chamboredon, & Passeron, 1991), and a new hierarchy of resources which can be converted into capital in the rehabilitation field is emerging (Guldager et al., 2018).

Conclusion

In this paper, we outline a theory concerning transformations that have taken place in the Danish welfare state which have meant that some relatives of patients in a stroke rehabilitation process sense that their dispositions are ill-adjusted to the objective opportunities. Relatives that take action themselves and do not wait to be helped by the healthcare professionals seem to have an advantage in terms of collaboration with the healthcare professionals.

Acknowledging the limits posed by of the small number of participants in this study, this article shows that when the mismatch between the relatives and the healthcare field, described as hysteresis, is invisible, it may mean that the health professionals perceive the relatives as frustrated and unreasonable and experience themselves as powerless. This might become a barrier to constructing positive collaboration between relatives and health professionals.

Furthermore, when hysteresis occurs, it opens up for matters concerning treatment and rehabilitation to be referred to official complaints boards by the relatives. In this article, two patients' cases ended as complaints, and several health professionals referred to their concerns about what they experience as the growing threat of complaints about their work. These concerns might make professionals more cautious, keeping strictly to their defined tasks simply for their own safety.

References

- Adler-Milstein, J., Desroches, C. M., & Jha, A. K. (2011). Health information exchange among US hospitals. *The American Journal of Managed Care*, 17, 761-768.
- Altin, S. V., & Stock, S. (2016). The impact of health literacy, patient-centered communication and shared decision-making on patients' satisfaction with care received in German primary care practices. *BMC Health Services Research*, 16(1).
- Bernhardt, J., Hayward, K. S., Kwakkel, G., Ward, N. S., Wolf, S. L., Borschmann, K., ... Cramer, S. C. (2017). Agreed definitions and a shared vision for new standards in stroke recovery research: The Stroke Recovery and Rehabilitation Roundtable taskforce. *International Journal of Stroke*, 12, 444-450.
- Bourdieu, P. (1977). Outline of a theory of practice. *Cambridge, UK: Cambridge University Press*.

- Bourdieu, P. (1990). *The logic of practice*. Stanford, CA: Stanford University Press.
- Bourdieu, P. (1986). *The forms of capital*. New York: Greenwood Press.
- Bourdieu, P. (1998). *Practical reason: On the theory of action*. Stanford, Calif: Stanford University Press.
- Bourdieu, P., Chamboredon, J.-C., Passeron, J.-C., & Krais, B. (1991). *The craft of sociology: Epistemological preliminaries*. Berlin and New York: de Gruyter.
- Bourdieu, P., & Wacquant, L. J. D. (1992). *An invitation to reflexive sociology*. Chicago, IL: University of Chicago Press.
- Charmaz, K. (2014). *Constructing Grounded Theory* (Second edition). USA: Sage.
- Chang, J., Dubbin, L., & Shim, J. (2015). Negotiating substance use stigma: The role of cultural health capital in provider–patient interactions. *Sociology of Health and Illness*, 38(1), 90-108.
- Collyer, F. (2018). Envisaging the healthcare sector as a field: Moving from Talcott Parsons to Pierre Bourdieu. *Social Theory & Health*, 16(2), 111-126.
- Collyer, F. M., Willis, K. F., & Lewis, S. (2017). Gatekeepers in the healthcare sector: Knowledge and Bourdieu's concept of field. *Social Science and Medicine*, 186, 96-103.
- Crawford, J., & McKee, K. (2018). Hysteresis: Understanding the housing aspirations gap. *Sociology*, 52, 182-197.
- Dahl, H. M., & Rask Eriksen, T. (2005). *Dilemmas of care in the Nordic welfare state: Continuity and change*. Aldershot, Hants, England; Burlington, VT: Ashgate.
- Dubbin, L. A., Chang, J. S., & Shim, J. K. (2013). Cultural health capital and the interactional dynamics of patient-centered care. *Social Science and Medicine*, 93, 113-120.
- Esping-Andersen, G. (1990). *The three worlds of welfare capitalism*. Cambridge, UK: Polity Press.
- Gabay, G. (2015). Perceived control over health, communication and patient-physician trust. *Patient Education and Counseling*, 98(12), 1550–1557.
- Gilbert, N. (2002). *Transformation of the welfare state: The silent surrender of public responsibility*. Oxford and New York: Oxford University Press.
- Guldager, R., Poulsen, I., Egerod, I., Mathiesen, L. L., & Larsen, K. (2018). Rehabilitation capital: a new form of capital to understand rehabilitation in a Nordic welfare state. *Health Sociology Review*, 27(2), 199-213.
- Guldager, R., Willis, K., Larsen, K., & Poulsen, I. (2019). Relatives' strategies in subacute brain injury rehabilitation: The warrior, the observer and the hesitant. *Journal of Clinical Nursing*, 28(1–2), 289-299.
- Hardy, C. (2014). Hysteresis. In M. Grenfell (Ed.), *Pierre Bourdieu: Key concepts*. Abingdon, Oxon; New York: Routledge.

- Harsløf, I., Søbjerger Nielsen, U., & Feiring, M. (2017). Danish and Norwegian hospital social workers' cross-institutional work amidst inter-sectoral restructuring of health and social welfare. *European Journal of Social Work*, 20, 584–595.
- Karp, D. A., & Watts-Roy, D. (1999). Bearing Responsibility: How Caregivers to the Mentally Ill Assess Their Obligations. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 3, 469-491.
- Kolstrup, S. (2015). Den Danske velfærdsmodel 1891-2011: sporskifter, motiver, drivkræfter. [The Danish welfare model 1891-2011: Change over, motives and power] *Frederiksberg: Frydenlund*.
- Larsen, K., & Harsløf, I. (2019). Promoting health as a form of capital: The transformation of the Danish healthcare field as experienced by private healthcare professionals. In I F. Collyer & K. Willis (Eds.), *Navigating private and public healthcare: Experiences of patients, doctors and policy-makers*. London, England: Palgrave Macmillan.
- Lee, R. G., & Garvin, T. (2003). Moving from information transfer to information exchange in health and healthcare. *Social Science & Medicine*, 56, 449-464.
- Mcdonough, P., & Polzer, J. (2012). Habitus, hysteresis, and organizational change in the public sector. *Canadian Journal of Sociology*, 37, 357-379.
- Miller, A. R., & Tucker, C. (2014). Health information exchange, system size and information silos. *Journal of Health Economics*, 33, 28-42.
- Miller, E. T. (2015). family caregivers - a precious resource. *Rehabilitation Nursing*, 40, 131-132.
- Missinne, S., Neels, K., & Bracke, P. (2014). Reconsidering inequalities in preventive healthcare: An application of cultural health capital theory and the life-course perspective to the take-up of mammography screening. *Sociology of Health and Illness*, 36(8), 1259-1275.
- Nordhaug, M. (2013). Which patient's keeper? Partiality and justice in nursing care. *CC-BY-SA Høgskolen i Oslo og Akershus*.
- Padgett, D. (2017). Qualitative methods in social work research. *Los Angeles, CA: SAGE*.
- Petersen, J. H., Petersen, K., & Christiansen, N. F. (2010). Dansk Velfærdshistorie. [History of Danish welfare] *Odense: Syddansk Universitetsforlag*.
- Pinxten, W., & Lievens, J. (2014). The importance of economic, social and cultural capital in understanding health inequalities: Using a Bourdieu-based approach in research on physical and mental health perceptions. *Sociology of Health and Illness*, 36(7), 1095-1110.
- Ploug, N., & Kvist, J. (1994). Social tryghed i Europa: udvikling eller afvikling? [Social safety in EU: development or phasing out?] *København: Socialforskningsinstituttet*.
- Ryssel Bystrup, M.; Larsen, K; Hindhede, AL; Pallesen, H; Aadal, L; Feiring, M (2018). An outline of history of neurorehabilitation in Denmark - a sociological perspective. *Praktiske Grunde*, 3-4, 5-28.
- Shim, J. K. (2010). Cultural health capital: A theoretical approach to understanding healthcare interactions and the dynamics of unequal treatment. *Journal of Health & Social Behavior*, 51, 1-15.

Sointu, E. (2017). 'Good' patient/'bad' patient: clinical learning and the entrenching of inequality. *Sociology of Health and Illness*, 39, 63-77.

Vandenberghe, F. (1999). "The real is relational": An epistemological analysis of Pierre Bourdieu's generative structuralism. *Sociological Theory*, 17(1), 32-67.

Wacquant, L. (2004). Pointers on Pierre Bourdieu and democratic politics. *Constellations*, 11(1), 3-15.

Wacquant, L. (2014). Homines in extremis: What fighting scholars teach us about habitus. *Body & Society*, 20(2), 3-17.

Wacquant, L. (2016). A concise genealogy and anatomy of habitus. *The Sociological Review*, 64(1), 64-72.

Accepted author manuscript