

For Better or for Worse: Lifeworld, System and Family Caregiving for a Chronic Genetic Disease

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Abstract

Modernity has meant a cultural and social differentiation within the western society, which, according to Jürgen Habermas' theory on communication, can be seen as a division between different forms of actions that takes place in different realms of the society. By combining Habermas' notions of lifeworld and system with Arthur Frank's analysis of stories as a way to experience illness, the article performs a cultural analysis of the meeting between families involved in caregiving in relation to Huntington's disease and the Swedish welfare system. The ethnographic material shows how caregiving is given meaning through communicative action and illness stories, which are broken up by an instrumental legal discourse employed by the welfare system. This confrontation between communicative and instrumental action breeds alienation towards the state and the welfare system among the affected families. However, the families are able to empower themselves and confront the system through a hybrid form of action, which combines communicative and instrumental action. As such this hybridity, and the space that opens up on the basis of this hybridity, constitutes an important space within the modern society.

Keywords: Caregiving, lifeworld, system, illness stories, Huntington's disease, hybridity

Introduction

Elizabeth: I've struggled a lot with the National Insurance Agency, although they're the ones who have been the most correct in our case. We've had a really good administrator. She demanded millions of papers and sums back and forth. But when we were done with filling in the forms and when she'd been here and made her assessments... So I think she has been very correct. Then we have our local municipality: beneath all criticism. Oh, the welfare administrators in our municipality...we're not friends with each other at all. We're on our third administrator right now. The first one that took care of our case thought that Brian and I should get a divorce, so that the responsibility for Brian's caregiving should rest on them [the municipality and the welfare system]. On one occasion, she said that if we got a divorce, they could take over the caregiving, so that I could continue to live in our house. Yes! It is humiliating, and they don't have empathy!

These words are Elizabeth's, whose husband Brian is affected by Huntington's disease (HD), a rare genetic, chronic and eventually fatal disease that affects the brain.¹ In many ways, their whole life was turned upside down when the disease struck, causing implications, not only in the lives of Brian and Elizabeth, but also of their two children whom Brian and Elizabeth suddenly realized were at risk of inheriting the gene that causes Huntington's disease. The prospect of fighting and handling a chronic disease, for which no cure is available, and which inevitably ends in an early death, was suddenly a fight that might be fought all over again if the children had inherited the HD-gene from their father. Since the time of Brian's diagnosis, one of the children has taken the difficult step to find out, by going through a genetic test, if she, like her father, carries the HD-gene. The test showed that she is not a HD-gene carrier, that is, she will be spared from HD. As for her brother, the answer concerning his fate is still residing within his genetic make-up, as he has not undergone the genetic test that will show whether he is a HD-gene carrier or not.

The chronic and genetic nature of a disease like HD obviously leaves a strong mark on the everyday life of the family, which to a large extent is structured by the needs of the affected individual and the progression of the disease, as well as all the existential aspects that come up in relation to the genetic nature of HD. Yet, the everyday lives of Elizabeth and Brian and other families affected by HD is also very much conditioned by the various forms of assistance they can obtain through the institutions of the Swedish welfare state,² a situation in which their circumstances are being subjected to the decision-making of the welfare bureaucracy. Elizabeth's comment above is directed towards a statement made by an administrator working within the local municipality who, when individuals apply for assistance and support from the municipality, assess and make a means test of the caregiving situation. How can we understand the statement made by the administrator above, whose suggestion of a divorce between Elizabeth and Brian seems to be totally out of hand? And how can we understand Elizabeth's anger and feelings about what she perceived to be the administrator's lack of empathy?

To put it differently: What is at stake in the interactions between families who are in the same situation as Elizabeth's and the welfare system? And how can we understand these interactions from a cultural point of view?

The aim of this article is to perform, on the basis of contextually bound empirical material, a cultural analysis of what happens in the interaction between families involved in caregiving and the welfare system. As illustrated by the citation above, these meetings might take the form of a conflict between the family and the system in which different perspectives and actions are contested. More importantly, however, the following analysis aims to problematize the manner in which families confront the demands of the welfare system, and are at times able to develop a space between themselves and that system from which they can act and better confront the difficulties presented to them by Huntington's disease. As such, this analysis provides an account of caregiving for chronic diseases that interprets the interaction between the families and the welfare system in terms of crucial cultural tendencies within modernity and the late modern society. Consequently, this analysis constitutes an additional account in relation to other studies on caregiving, for example performed within nursing studies, which often do not include perspectives derived from the cultural and social sciences (e.g. Skirton et. al. 2010; Williams et. al. 2012).

In order to do this, and following a methodological discussion, the article shall begin by presenting the theoretical framework of the study. The text then proceeds to analyse the different manners in which the affected families and the Swedish welfare apparatus perceive, frame and address Huntington's disease. Next, the article will address the issue of how the affected families empower themselves by creating a space between themselves and the welfare system by adopting the language of the welfare system. This space, from which they act and confront the system, can be characterized as a hybrid form of action and communication that undermines the power of the welfare system. We will end the article with some concluding remarks.

Method

The ethnographic material, which this article is based upon, was obtained as part of a study conducted in southern Sweden 2009-2010 with individuals who are affected by Huntington's disease in various ways. In line with the aim of this article, HD functions as an illustrative case, as it represents a large group of devastating chronic diseases for which there are currently no cures available. The choice of HD as an illustrative case is a well-established research strategy where HD has taken the form of a 'model disease' in relation to social and ethical issues within genetics. This is particularly relevant with regard to predictive genetic testing, as HD was among the first genetic diseases where this form of genetic testing became available for individuals at risk (Brouwer-Dudokdewit et. al. 2002; Tibben

2007). Moreover, despite the relatively low number of affected individuals, HD has come to function as a 'model disease' also within the medical sciences. The reason for this is that it is caused by a mutation in a known gene, but shares clinical features with more common brain disorders such as Alzheimer's disease and Parkinson's disease for which there are no clear explanations as to what causes these diseases. Consequently, HD contains features that are unique; the prospect of both parents and children being affected due to the genetic basis of the disease, as well as the possibility to take a predictive genetic test where individuals who are at risk can find out whether they are carrying the mutated HD gene. HD also includes features that are shared with a number of other chronic diseases. In relation to those issues that are investigated in this text, HD affected individuals do require substantial help and assistance in the later stages of the disease. Because of this, the experiences of the HD affected individuals, in relation to the caregiving situation and their interaction with the welfare system, are seen as resembling the experiences made by other individuals who are affected by more common disorders such as Alzheimer's disease and Parkinson's disease. This resemblance is also acknowledged by Williams et al. who, from a perspective of nursing science, investigated family caregiving for HD (Williams et al. 2012:142).

HD has affected all those who have participated in this study in different ways. Participants were recruited through advertisements at various websites aimed for HD affected individuals, as well as through personal visits (made by Hagen who did not know any of the participants before the study took place) and through national and local meetings for HD affected individuals. As HD is both a sensitive and difficult topic for many of those who are affected, the decision was taken on behalf of the authors to let both the sample size and the determination of participants included in the study be based only upon those individuals who came forward as a result of these advertisements and meetings. All of those who came forward and expressed a wish for taking part in the study were sent additional information (including the form for informed consent) and were also given time to further reflect on their participation, as well as the informed consent. By relying upon this approach, the risk for adverse reactions on behalf of the participants due to the sensitive topic were seen as being minimized and all participants were given time to reflect upon their participation. The participants of the study represent *a cross-section* of the various ways individuals can be affected by HD, from individuals with motor symptoms to members of the family. This cross-section provides an opportunity to give a general overview of HD, as well as to provide an investigation that is not biased to a particular feature of HD, such as the issue of predictive genetic testing.

Semi-structured interviews were performed with eleven individuals in families that have been affected by the disease. Hagen performed these interviews. The interviews lasted between 1 hour and 30 minutes and 2 hours and 30 minutes. All interviews were conducted in Swedish and took place at a location of the inter-

viewees' choice. An interview-guide was employed for the interviews, but it was used in a flexible way so the interviewees could go into various aspects regarding their experiences of HD on their own terms. All interviews were recorded by the use of a digital voice recorder, and all interviews were subsequently transcribed *in verbatim* and analyzed by Hagen. The original format was kept in all the translated citations from the interviews used in this article; they have not been altered into grammatically correct English. Moreover, in order to protect the privacy of the participating individuals, the alteration of all names featured in the text was done solely to protect the anonymity of the participating individuals. The analysis took place as follows: First, each manuscript was read several times until a number of themes were identified. Next, the different manuscripts were compared with each other with respect to these themes, and in the third successive step of the analysis, a table of overarching themes was organized, which represented the results of the comparison made in the second stage of the analysis. In the last stage of the analysis, these overarching themes were related to more general cultural and social theoretical frameworks. The regional ethical committee at Lund University approved the study.

The following section provides a presentation of the theoretical framework employed in the article. In order to carry out the ethnographic focus of the article, we intend to use perspectives taken from Jürgen Habermas' account on communicative and instrumental action and combine them with anthropological approaches to understanding stories in relation to illness and disease. This strategy will permit us to situate the experiences made by the affected families within the general cultural and social frameworks of the late modern society.

Communicative Action through Illness Stories: Theoretical Pre-suppositions and Key Concepts

In his theory on communicative action, Jürgen Habermas represents modern society in terms of an analytical division between lifeworld and system that stand in a tension-like relationship towards each other (Habermas 1987). Both system and lifeworld perform essential functions for society, where the lifeworld acts as a source of legitimate norms and reproduces those cultural and social patterns on which society rests. The modernization of western society gave rise to an increasing societal differentiation that separated sections assigned for the production and distribution of material goods from the contexts of the lifeworld (Crossley 2005: 37-38). These designated sections – the economic system and the administrative system of the state – came to be organized on the basis of instrumental rationality and instrumental action as a way to achieve an increased efficiency in production and distribution of material goods, as well as entitlements provided by the welfare state.³

The major difference that separates the lifeworld from the system resides in a disparity between the relation to rationality and the way actions are performed in the lifeworld and the system. Communicative action is founded on mutual understandings and meanings made on the basis of a shared everyday situation. This mutuality enables individuals to harmonize their plan of action in accordance with reaching a common understanding of a situation. The everyday lifeworld can then be regarded as the subjective world that we all experience through our everyday life, but also as a collective cultural and social background from which mutual understandings emerge through communicative action (Habermas 1987: 119-152). Instrumental action that is employed by the system is, on the other hand, oriented towards reaching success and societal goals rather than mutual understanding. The system is to be seen as operating on a *societal level*, detached from individuals who nevertheless make up the smallest units of the system. Money, power, as well as law became the most efficient ways to achieve coordination and integration of the activities within the system. Coordination of system activities through communicative action becomes impracticable as a consequence of an increased modernization and societal differentiation. The classic example of this kind of impersonal integration is of course the economic market where money and such notions as input and output measurements coordinate and steer the activities of the participants who in various ways operate in the economic system (Habermas 1987: 160, 164-166; Habermas 1996: 39-40). Another example of this impersonal integration within the modern society comes in the form of a formal legal discourse that, in a similar fashion to money, regulates and coordinates various forms of actions that hitherto were regulated through informal traditions and customs. The expansion of law in the modern society, the legal regulation of new previously informally regulated cultural and social matters, is defined as a trend towards a 'juridification' by Habermas (Habermas 1987: 357). Communicative and instrumental actions are then to be seen as operating on the basis of two distinct perspectives, as well as operating on two distinct levels of society.

In order to convert Habermas' theoretical insights into operational concepts that work on the micro-level of everyday life, his theory on communicative action needs to be matched with additional accounts taken from ethnology and anthropology. It is in relation to this elaboration that illness stories become relevant, and where the works of, among others, Arthur Frank become important. The concept of illness is employed in medical anthropology as a means of capturing and understanding the experiences of sickness and suffering amongst individuals, but also in conjunction with their families and wider social networks. Subsequently, the concept of illness has come to function as an alternative in relation to biomedical knowledge, which in various ways reconfigures the experience of illness in accordance with an alteration in biological structure and functioning (Kleinman 1988: 2-6). In conjunction to communication and the creation of meaning, Arthur Frank makes the remark that serious illness is, by its very nature, something that

disrupts the flow of everyday life and which prompts all those who are affected to redirect their lives and selves (Frank 1995: 56-59).

This redirection and the formation of new understandings of the self in relation to others occur in response to the disruptive force of illness, through the construction of illness stories. Moreover, Frank also makes a connection between the formation of illness stories and the body. As he argues, the disease-stricken body 'sets in motion the need for new stories when its disease disrupts the old stories'. According to Frank, human communication with the world, and the communion this communication rests on, can analytically be said to begin in the body itself (Frank 1995:1- 2, 50). The telling of these stories is an altogether social activity. Stories are told to others and create, in the process, meaning in relation to the illness. As such, these stories incorporate both the subjective world of the storyteller, as well as the cultural and social frameworks which constitute the lifeworld of all those who formulate the illness story, along with those who respond to it.

The meaning created through the illness story thereby includes aspects that are highly subjective and personal, but also aspects that are derived from cultural frameworks within the lifeworld. The formulation and construction of illness stories can then be understood as *a form of communicative action*, which is formulated on the basis of the diseased-stricken body and through which new meanings are formulated by all those affected in relation to the disruption caused by illness in everyday-life. Communicative action thereby organizes and gives meaning to our experiences of illness. The interaction between the caregiving families and the welfare system can then analytically be interpreted as an interaction between the lifeworld and the system, which incorporates a meeting, as well as movements back and forth, between communicative and instrumental action. Moreover, these theoretical assumptions lead up to a methodological step which, according to Habermas, means that system perspectives 'cannot be adequately dealt with by way of lifeworld analysis undertaken from an internal perspective; it only comes into view when the lifeworld is objectified' (Habermas 1987: 232-233). That is, in order to achieve a systems perspective on the caregiving situation, the analysis will have to operationalize, in the same way as communicative action is made operative through illness narratives, the instrumental rationality used by the welfare system.

The consequences of this methodological step for this analysis are two-fold: First, in order to operationalize a system perspective in our analysis, we will make use of Swedish social welfare laws. These laws constitute the primary medium of instrumental rationality that objectifies the caregiving situation of the HD affected families. The interaction between the HD affected families and the welfare system is essentially then an interaction between these families and the legal discourse that make up Swedish social welfare laws. Second, given this crucial importance of a legal discourse as a form of instrumental action, it follows that interactions between the affected families and various administrators, do not constitute the

actual interactions between the families and the system. These interactions both rely upon and are governed by the legal discourse that specifies what social welfare the affected families are entitled to.

In order to give a fuller understanding of all the aspects that have been outlined in this section, we need to make use of the ethnographic material. In the next section, we will probe more deeply into this dual character of the caregiving, based on the presuppositions and concepts presented in this section. The first part of the next section will investigate caregiving from the perspective of the affected families. Following this, we will turn to the question of what happens when this perspective meets with the perspective taken by the welfare system.

Caregiving and the Affected Families

For the affected families, caregiving is understood and experienced as being tightly embedded in the dramatic and overall change that HD brings to affected families. Previous research on HD has shown that the impact of the disease is to a large degree situated in the family context (Forrest Keenan et. al. 2007; Tibben 2007: 169-170; Williams et. al. 2012, 2009). The disruptive force of HD is then obviously not limited to the sick individual alone, but it encloses the whole family. This aspect is illustrated by Thomas, who lives in a suburb to one of the major cities in the southern part of Sweden together with his wife Paula; she has been diagnosed with HD. At the time of the interview, it was not known whether their son, Jonathan, had inherited the gene (and thereby HD) or not. He has since then gone through genetic testing and learned that he is not a gene carrier for the disease. The adjustment forced upon Thomas and the family as a result of HD is experienced as a transition into an altogether different life trajectory, which started when Thomas noticed the first signs of HD in Paula. As her symptoms progressed, the disease also had a serious impact on their relationship as a married couple:

Thomas: Well, we don't have a married life together any longer...no.

One of these lacking dimensions is the inability for Thomas to communicate with Paula due to the motor symptoms and cognitive symptoms that are part of HD (Hartelius et. al. 2009):

Thomas: Yes...anyway, in a marriage, and that is important, you know. Then, communication is one of the most important things. I should have the possibility to communicate with my wife, and we haven't been able to do so in the same manner [since the onset of HD]. I haven't been able to get any feedback. And that has been a disadvantage for me, even when I had the company. I needed to have somebody...well, you sit at the kitchen-table and discuss. And I came home with a lot of problems, problems with alcohol at work or...eh... no money in the cash register or something like that, you know. I've been forced to take all decisions and I haven't had anybody to get feedback from. I couldn't go to our customers to get feedback, I couldn't go to my employees to get feedback.

HD also brought a number of significant changes for Thomas himself, who used to live a very active life as a self-employed entrepreneur, owning his own company with several employees. All this changed as Thomas started to notice the first signs of HD in Paula:

Thomas: I sold my company in the year 2000, that's 10 years ago, when I saw that things were starting to be bugged up, and then I stayed at home for a number of years and helped Jonathan with his schoolwork, and things like that.

It seems almost inevitable that the issue of loss and the question of what 'could have been' if the disease had not struck become important and difficult issues for people to come to terms with. In the interview, both Paula and Thomas keep coming back to the disruption caused by HD:

Paula: I think it's too early for me to get the disease. I could have been around 80 or something but 50...Jonathan hadn't moved out yet, hadn't left home when I got ill [...] And I sort of thought that our lives should start, that me and Thomas should have a good time together as we got older.

Thomas: This hasn't turned out as we expected, Paula? Buying a house in Thailand and...

Paula: No...nothing...

In very much a similar way, Carla's life has to a large extent been centred on HD as a result of her husband Steven's diagnosis twenty years ago. At the time of Steven's diagnosis, they were both in their early to mid thirties and they had two children who now were at risk for developing HD. Both of their children went through genetic testing to find out whether they carried the HD-gene. Both tests came out negative, which means HD will not return to their family. At the time of the interview, Steven had, a few months earlier, passed away from HD. Carla looked back on a life with HD, and what could have been had the disease not struck their family:

Carla: That's what you don't know? I remember one night a couple of years ago; I sat reading on the front porch because Steven had an assistant here. Those who lived across the street, they were the same age as us, and they sat there with a barbecue and a glass of wine. And I thought to myself: I wonder how that would have felt, really? Because those were things, I had never experienced, at that age in my life. We had the kids, and then it became...more to take care of...

As illustrated by Carla's and Thomas' recollections above, the lived experience of HD is laden with all those thoughts and emotions that arise when the disease disrupts your entire life and your family. Included within these thoughts and emotions are also feelings of responsibility which, according to Frank, guides people towards the moral commitments and responsibilities that illness calls them to (Frank 1995: 14-15).⁴ As studies of individuals suffering from other serious diseases have illustrated (Harding & Higginson 2001: 643; Lewinter 2003: 368; Champlin 2009: 1533), there is a great tendency for family members to feel a strong sense of obligation towards an ailing loved one. Similar senses of responsi-

bility and obligation are echoed in our informants' words. Thomas, for example, states that despite all the changes that Paula's disease has brought to his family and marriage, he feels a deep and enduring obligation towards Paula:

Thomas: The only thought I've been having is that all this should be for Paula's best, so she receives all the help that she can get.

Carolyn, whose husband is diagnosed with HD and who has three children who (at the time of writing) have not gone through predictive genetic testing for HD, points out the importance of being at hand if HD strikes yet another generation of her family:

Carolyn: I hope that I'll stay healthy. That's what I think, because there's a lot that rests on my shoulders then. I'm thinking if my children become ill as well, I hope that I'll be able to be at hand there then.

A similar account is given by Emma who carries a difficult burden, not only in relation to her own family, with her husband who is diagnosed with HD and her two children who have tested positive for the disease, but also in respect to the sister of her husband who has also been diagnosed with HD. For this family, the impact of the disease will repeat itself in one form or another, as Emma's children eventually will become ill. Being the only individual in the family who will not be afflicted by HD, her life is structured in an almost total way by HD. Nevertheless, she feels the responsibility to carry on despite these harsh conditions:

Emma: I'm there and I'm here, trying to stitch things together...a little bit there and a little bit here...so it isn't that strange that you sometimes feel like: Oh. I won't bother about all of this! But, then there is somebody who tells you that you can't do that. And that's really good, you know. That this inner voice tells you that you have to go on.

The important point to be made on the basis of the material presented above is the holistic nature of the illness story. Communicative action then organizes the experience and the meaning of caregiving in terms of this totality, as part of a much wider story that incorporates feelings of loss, love and moral responsibility towards the sick individual. The meaning of caregiving can then not be separated from all the other aspects that are part of the illness story.

This holistic nature of the communicative action is what constitutes the basis for the requests made by the affected families towards the system. Jimmy, who has a HD-affected mother to whom he acts as a primary caregiver, went through genetic testing that showed that he is not a gene carrier for HD. However, being out of danger himself, and relieved by the fact that he will not become ill, he now faces the difficult and emotional task of caring for his mother. A situation in which, and to Jimmy's sorrow, the roles between mother and son are reversed:

Jimmy: All I want to do is just to be with her, I want somebody else to take care of all that's related to the disease, like the National Insurance Agency or the municipality. I wish somebody else would come and take care of all that so I could come around and only be her son. I would like to just come around, to sit down and have a

chat. But there is always something that has to be cared for [...] I can never go over and just have a chat.

To receive assistance is thus a chance for Jimmy, not only to receive help with the concrete care of his mother, but also, once again – and before it is too late – to enter a relationship with his mother in which he has the chance to be her son and not only her caregiver. This is also an important part of the dilemma that Thomas faces when he asks the welfare system for help in the form of a personal assistant to help care for Paula. The holistic nature of this request is clearly reflected in how Thomas, who, as the primary attendant of Paula, feels the need to be available to her all the time. A personal assistant would allow Thomas to take more time off from an often difficult situation at home, giving him the opportunity to do something as simple as picking mushrooms in the local woods, which he views as his way of ‘recharging his batteries’. Caregivers often use strategies like these as a way of dealing with the difficult situation that they face (Shyu 2000). The possibility of a personal assistant, as he has requested, would provide him with a greater opportunity to take time off without being worried about Paula:

Thomas: It’s not so fun if I know that Paula is home alone, and if I’d go off I would have a hard time relaxing. I admit that, but there is no problem if there is someone with Paula. That’s why I believe a lot in this idea of getting personal assistance for her. Then she’ll be working every second weekend and I can go to the woods to pick mushrooms, you know.

As shown by the empirical material, the meaning of the requests made to the welfare system is encapsulated within an illness story that takes its point of departure in the life trajectory of the whole family. However, as we will show below, the welfare system applies an instrumental discourse that is grounded in legal terms rather than a holistic illness story.

The Meeting between the Families and the Welfare System

In their contacts with the welfare system, the affected families are confronted with an objectifying and technocratic legal discourse employed with a strategic meaning to achieve *goals that are motivated from the perspective of society as a whole*. This legal discourse substantiates the voice of the welfare system that defines the rights of the families and the measures that are provided by the welfare system.⁵ The legal act that covers the right for personal assistance exemplifies this instrumental and technical discourse that confronts the families as they seek help from the welfare state. The first section in the Act provides the legal definition of those who are entitled to personal assistance:

Section 1

This Act contains provisions relating to measures for special support and special service for those

1. who are mentally retarded, are autistic or have a condition resembling autism,
2. who have a considerable and permanent, intellectual functional impairment after brain damage when an adult, the impairment being caused by external force or a physical illness or,
3. who have some other lasting physical or mental functional impairments which are manifestly not due to normal ageing, if these impairments are major and cause considerable difficulties in daily life and, consequently, an extensive need for support or service (SFS 1993:387).

And section seven and nine contains a specification that defines the content of the assistance offered:

Section 7

Persons who are referred to in Section 1 are entitled to measures in the form of special support and special service pursuant to Section 9, subsections 1-9, if they need such assistance in their daily lives and if their needs are not satisfied in some other way. Persons who are referred to in Section 1, subsections 1 and 2, are also entitled, if the prerequisites are the same, to measures pursuant to Section 9, subsection 10 (SFS 1993:387).

Section 9a

Personal assistance pursuant to Section 9, subsection 2 refers to personally designed support that is provided by a limited number of persons for anyone who owing to major and lasting functional impairments needs assistance with her or his personal hygiene, meals, dressing and undressing, communicating with others or other help that requires extensive knowledge about the person with a functional impairment (basic needs) (SFS 1993:387).

Carla is very much aware of the importance of this legal discourse, and the necessity of transforming hers and Steven's illness story into this discourse in order to communicate with the welfare system. This awareness is also driven by the fact that she and Steven can not get by on their own any longer, the progression of the disease has come to the point that they both see no other alternative than to seek help from the system. This is a situation in which they are very much dependent on the assessment made by the system:

Carla: You end up in a position of dependence because you can't get by without this help that I really don't want. I would like to take care of my family by myself, but in the end, you feel that you really need the help. Then, you end up in a position of dependence [...]. You're dependent of the assistance, dependent of society.

There is a feeling of being powerless when Jimmy voices his frustration towards the assessment made by the welfare system when they applied for assistance. As a

way to evaluate their request, a welfare administrator from the Social Insurance Agency made a home visit in order to get a clear picture of their situation:

Jimmy: [...] It's a great frustration with the Social Insurance Agency. It...they're sitting on all the power and all you get is a letter in which there is... like a stamp that says: No! And that's when they've been around to look for themselves, they've been here with my mother for one hour, just sitting around a table, like we do, and talking. That's all they've seen. They don't want to see her doing anything, *to see how it is* [my emphasis] Around a kitchen table. Why can't they accompany me in every moment [of the caregiving] instead? So they can really see. If that were the case, I could accept a refusal [on our application].

A similar response comes from Carla in conjunction with the welfare administrators' visit to their home to evaluate their situation:

Carla: It's just this with being trusted...many times I've said to Steven: Don't pull yourself together just because they're here! Because they're here to see just how it really is. And don't say that everything is Ok [...] I've tried to get, and also got, consultations on my own with the Social Insurance Agency and the municipality, so that I don't need to offend Steven in front of them. Because it can feel like an insult when you're saying: He's doing this, and he's doing that.

Jimmy's and Carla's frustration can then be interpreted as a reaction against a misrepresentation of their illness story. Their perception of *how it is* in their everyday life disappears as the legal discourse decontextualizes and simplifies the holistic aspect of the illness story in order to mark out just those aspects that can be arranged in accordance with the overall goal or objective of the system (Feenberg 2010: 157-180). The anger directed by Elizabeth towards the welfare administrator who suggested a divorce illustrates the strain and the tensions that arise in the wake of this simplification made by the system. However, from the perspective of the administrator, who views Elizabeth's situation in the light of the framework of law and of the system, a divorce is of course one rational solution that would legally force the welfare system to take responsibility for Brian. The difference in perspectives is also part of Thomas' account:

Thomas: But the National Social Insurance Agency is giving us a hard time, of course. She doesn't need any help. Even though she sometimes chokes on her food, and is unable to take a shower, or rather, doesn't want to take a shower. So, she needs help all the time.

In relation to the lifeworld and communicative action, the use of a legal discourse constitutes the most rational way for society to deliver all those entitlements that are grounded in the rights that every individual can make a claim to as a citizen. This reduction can then be seen as a necessary step towards achieving the kind of transparent and effective large-scale redistribution of resources necessary of the welfare system in order for it to function in accordance with its overall goal. Zygmunt Bauman discusses modernity in terms of a 'quest for order' (Bauman 1991). Modernity, according to Bauman, is a fight of determination against ambiguity, of semantic precision against ambivalence, and fuzziness (Bauman 1991: 7). The entitlements provided by the welfare state can be seen in light of this very

modern 'quest for order', providing both social and political security in the form of legal rights as a safe-guard against an economic system that works according to the logics of free-market capitalism. However, this quest for social and political order comes with a price in the form of feelings of alienation towards society-at-large. These feelings of alienation on behalf of the families exemplify a dislocation in relation to how alienation is experienced within the welfare state and modern society. As alienation is experienced in conjunction with labour and processes of commodification, it 'recedes further and further into the background as the welfare state becomes established' and accordingly can be considered in terms of 'induced deformations of the lifeworld' (Habermas 1987: 349, 384). This is illustrated by Thomas' bitterness, not only towards the welfare system, but also towards society in general:

Thomas: They haven't even looked up what kind of disease she suffers from, even though there are only about 600-700 people in Sweden who...They haven't even...they just used a stamp: No! No, doctor's certificate, they didn't even wait for that [...] Yes, I feel bitterness towards them. Over what society can't do...that they can arrange everything else, but not when somebody becomes seriously ill.

However, these feelings of frustration and alienation are not the only reactions displayed by the families; these feelings are also a source of empowerment. This is something we shall investigate in what follows as we endeavour to break down the dichotomy between lifeworld and system. Instead, we shall open a 'Third space' within which the opportunity for empowerment presents itself.

Hybridization, 'Third Space' and Empowerment

The previous section points towards a tension-laden confrontation between the affected families and the welfare system, as the lifeworlds of the former meet the instrumental rationality of the latter. For Habermas, as well as for Frank, this tension-laden confrontation between lifeworld and system represents the dark side of modernity, which both Habermas and Frank represent in terms of a form of colonization upon the lifeworld on behalf of the system (Habermas 1987: 332-373, Frank 1995: 146). The Swedish state is, to be sure, a formidable opponent to run up against. And while the logics of the welfare system may seem highly rigid and insurmountable, some of the people we have spoken with have found ways of proceeding, to meet their own goals. Carla describes the difficulties, but also the importance, of expressing oneself in the legal discourse used by the system when trying to formulate an appeal against a decision made by the welfare system, in this case the local municipality:

Carla: If I had written those papers, I might have written them in about the same way as he [the attorney who helped her to compile the appeal] did, but I would have written them on the basis of my feelings as a close relative. He translated those feelings to a juridical language...and then it becomes this [Carla shows an appeal that she

and the lawyer were compiling in response to a rejection by the local municipality]. He was able to transmit our feelings with different words.

Carla's experience, as described in the citation above, was one that recognized that the language of the welfare system operated along a different register than the emotional reality of her everyday life. She employed an attorney to help her communicate the experiences of her lifeworld in the formal and instrumental language of the system. The result was a hybrid of sorts, which mixed the emotionally laden information she wished to communicate with the instrumental language comprehensible to the state. As Mikhail Bakhtin points out, hybridity is 'a mixture of two social languages [...] separated from one another by an epoch, by *social differentiation* or by some other factor' (Bakhtin 1981:358; quote taken from Young 1995: 20, our emphasis). Caregiving in this case, must be understood as more than a medical practice, or more than a politically steered administrative function of the state. Regarding the argument in this way, we find that between the lifeworld of families affected by HD and the rationality of the system, there is a mixture of communicative and instrumental action that has the potential to lead to new hybrid modes of communication. Furthermore, as Homi Bhabha points out from a post-colonial perspective, 'forms of popular rebellion and mobilization are often most subversive and transgressive when they are created through *oppositional cultural practices*' (Bhabha 1994: 20, our emphasis). In the case of caregiving, these oppositional practices come forward, not only in the form of documents drafted by attorneys, but also in the form of patient organizations and support groups. These patient organizations and support groups work in a manner not entirely dissimilar to the practices of Carla's attorney, engaging in activities that open up what Bhabha terms as a 'Third Space' (Bhabha 1994: 36-39). This is a space of communication and action that is not based on the illness stories of the affected families, nor on the legal discourse employed by the system, but on a combination or amalgamation (Lundin & Åkesson 1999: 7-15) of both.

In the Southern part of Sweden, a local support group for family members exists as part of the national patient organization for people who are neurologically disabled. Within this support group, the participants come together regularly to discuss the various problems that they face as families affected by HD. The foundation for the collective strength offered by the support group resides in the mutuality and sharing of the same lifeworld. In this way, the support group reproduces the meanings within the illness stories through communicative action. Jimmy reports about the way the support group has helped him in his situation:

Jimmy: We're all in the same situation. We come to hear what kind of problems the others have had; what they have succeeded with and what they have not succeeded with. If there's a problem, you can discuss it because there's bound to be someone else who has faced the same kind of problem; somebody who can help me get around that problem.

Emma is also a member of the same support group, and for her the group has become the only place where she has been able to raise the different kinds of difficulties that she faces in her everyday situation:

Emma: Yes, it [the support group] has meant a lot. Mainly because it was sort of the only place you could turn to. And say, like: Oh, now he's doing this and this! [referring to her husband who is diagnosed with HD]. But, that's normal, said somebody who has been through the same kind of problem. So, because of this it has meant a lot to have the support group.

The support group provides a sort of 'breathing space' for the participants where they can meet and freely ventilate various aspects of the disease. This is something that has been observed in other contexts than HD, for example among individuals affected by burnout syndrome (Hammarlin 2008). Moreover, the support group gives the participants a chance to defend their illness stories and the meaning contained within these stories against the legal discourse endorsed by the system. It becomes their way to regain their own voices and their own meanings in relation to the definitions made by the welfare system.

Another crucial and important aspect of the establishment of this 'Third space' is facilitated by the national patient organization for people who are neurologically disabled, which offers in-depth knowledge of social welfare laws. Carla, who is active in the same local support group as Jimmy, indicates that these courses provide both strength and knowledge to the participants who take part in them. Important here is the degree to which it helps to define the extent of their legal rights in relation to the various parts of the welfare system:

Carla: We've got this strength through the courses at Valjeviken [the location on which the courses are held]. There we get to know what I have the right to claim, and what I don't have right to claim. We've been taught to never accept a decision by mouth. If the administrator says that it is no use trying to apply for some entitlement because you will not get the approval...Ok, no. I will have that in writing please, because that means you've just been given a decision in this matter.

The local support group plays an important role in opening a new space for potential action in which the families make use of both their illness stories and the legal discourse as a means of empowering themselves and reacting against the dependency they feel towards the system. Moreover, their response also reflects the organization of society and, in extension, the intrinsic aspect of modernity, which has given rise to those divisions that are the key-concepts within this article: life-world and system, communicative action and instrumental action. Consequently, as Habermas acknowledges, the 'language of law, unlike the moral communication restricted to the lifeworld, can function as a transformer in the society-wide communication circulating between system and lifeworld' (Habermas 1996: 81). Moreover, these new forms of empowerment, coming across through a 'Third space', break the dichotomy between the lifeworld and system, as patients, their families and patient groups work in hybrid manners to facilitate change, and meet the rigidity and dominant position of the Swedish welfare system. Modernity does

have its dark sides, which can be diagnosed as a colonization of the lifeworld, social pathologies and crises (Baxter 2011: 168); but, as we have shown in this section, those intrinsic aspects of modernity that give rise to these diagnoses also carry the potential for the establishment of a 'Third space' through hybridity. Here, Robert Young notes that the double logic that is encapsulated within this hybrid 'Third space' of communication and action 'could be said to be as characteristic of the twentieth century as oppositional dialectical thinking was of the nineteenth' (Young 1995: 27). Because of this hybridity, the act of regaining your voice in the twentieth century, which Arthur Frank depicts as a form of 'post-colonial construction of the self' (Frank 1995: 10), also contains the possibility to undermine the instrumental action of the system by attaining the language and practices employed by the opponent.

In this article, we have performed a cultural analysis of the meeting between families involved in caregiving in cases of Huntington's disease and the welfare system. Other studies performed upon the interaction between families affected by HD and healthcare services within the United Kingdom and USA have shown that caregiving families were concerned by such issues as access and affordability to health care services, as well as a lack of knowledge about HD on behalf of health and welfare services. In order to meet these challenges, Skirton et al. requests an alignment between the needs of the affected families and the services provided by the welfare system (Skirton et al. 2010: 508). This cultural analysis has however shown that the interaction between the affected families and the welfare system is concentrated around differences in communicative action and an instrumental legal discourse. Compared with other studies, performed for example within the medical sciences, this study exemplifies how intrinsic features of modernity form a crucial part in the shaping of how families involved in family caregiving experience the interaction with the welfare system. The importance of these intrinsic features of modernity implies that an alignment between the needs of the affected families and the welfare system must also encompass an alignment between communicative and instrumental action, as well as the dominance attained by the welfare system. However, our analysis has also shown how families involved in caregiving are able to overcome and undermine the dominance attained by the system. This occurs through a 'Third space' that we have characterised as a hybrid form of action, as an amalgamation of communicative and instrumental action. The last part of the article has exemplified this aspect in the context of a local patient support group, whose activities constitute a movement between their own illness stories and the legal discourse used by the system. In this context, an empowering 'Third space' gives them the opportunity to act, in a more instrumental manner, towards the system. We link the emergence of this hybrid with the cultural and social process of modernization and the separation between lifeworld and system. This shows how new forms of empowerment arise from these intrinsic aspects of modernity. Our investigation therefore points towards how the divi-

sion between communicative and instrumental action constitutes, not an end-point in regard to cultural processes within the late modern society, but rather a point of departure from which hybrid forms of communications and action arise. As such, these hybrid forms represent an important cultural phenomenon to consider in our attempts to understand cultural and social change within modernity.

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Notes

- ¹ Huntington's disease (HD) is caused by a mutation in the HD gene and the pattern of inheritance is autosomal dominant, which means that a child of an affected parent has a 50 % risk of inheriting the mutated gene (Huntington's Disease Collaborative Research Group, 1993). The mutation is fully penetrant, indicating that its presence always leads to disease. The disease is characterised by a combination of neurological, psychiatric and cognitive symptoms. In general, the onset of the neurological symptoms appear between 35 to 45 years of age, and the progression of the disease always leads to death within 15-20 years after the onset of the neurological symptoms (Ross & Tabrizi 2011). No disease-modifying treatment or cure is available. The formal clinical diagnosis is based on the presence of unequivocal signs of motor dysfunction (Huntington's disease Study group 1996). These neurological symptoms include disturbances of mainly involuntary movements, where the control of voluntary movements becomes more and more difficult as the disease progresses and finally being impossible to coordinate for the affected individual. The psychiatric symptoms of HD, which most often are present before the onset of the neurological symptoms, include personality changes, irritability and aggressive behaviour, as well as depression (Johnson et al. 2007; Julien et al. 2007). HD also includes cognitive disturbances involving deficits in attention that progress to dementia in the later stages of the disease (Stout et al. 2011).
- ² In Sweden, social insurance is individually based and compensates loss of income when a person is unable to support him/herself by working as a result of, for example, an illness or caring for a child at home. Social insurance is administered by the Swedish Social Insurance Agency, which is mainly financed through taxes. Social insurance includes universal benefits and means-tested benefits as well as income-related benefits. In the Swedish health-care system, responsibility for health and medical care is shared by the central government, county councils and municipalities. The role of the central government is to establish principles and guidelines for care and to set the political agenda for health and medical care. Responsibility for providing health care is decentralized to the county councils and, in some cases, municipal governments. Sweden's municipalities are responsible for care for elderly people in the home or in special accommodation. Their remit also includes care for people with physical disabilities or psychological disorders.
- ³ The integration of modern societies is not only, as discussed by Brännström (2009: 244) and others (Baxter 1987; Scambler 2001), achieved through language, culture and communicative action, but also through money and administrative power. This process of societal differentiation came to be established in subsequent waves, where the Western democratic welfare state constitutes the latest formation in this evolution towards a greater societal differentiation and complexity. The establishment of social welfare policies is meant to counteract those extreme disadvantages and insecurities that come with the functionality of the capitalist economic system. However, the establishment of various welfare policies, notwithstanding their capacity to provide social security, is not without negative effects, since these policies locate more and more decision power in the hands of experts and administrative structures whose decisions are removed from contexts of the lifeworld of those clients who interacts with these welfare systems (Buechler 1995: 445).
- ⁴ The source of this commitment and responsibility is traced by Arthur Frank, on the basis of the philosopher Emmanuel Levinas, to reside in the communicative body and the obligations imposed by the human face (Frank 1995: 14-15, 157). The human face opens, in Levinas highly tensed language, "the primordial discourse whose first word is obligation" (Levinas 1969: 201; Clifton-Soderstrom 2003). The emotions and feelings conveyed by the human face impose a feeling of responsibility through the face-to-face encounter with another human being, and these face-to-face encounters harbour an inherent ethical obligation towards another

human being, compelling an individual to be there for the individual in need of care and compassion (Lavoie et. al. 2006: 228).

- 5 According to Deflem (1996), the emergence of this legal discourse can be ascribed to modernity and the separation between lifeworld and system, a condition in which morality has become a personal and subjective matter of concern, whereas law has more and more attained the form of a functional and technical tool for erasing ambivalence and achieving transparency on behalf of the system (Deflem 1996: 6-7).

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